



Understanding the impact of cancer diagnosis and
treatment on everyday life

Final Report

October 2022

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1. Introduction

Cancer presents a significant global problem. The number of people diagnosed and living long term with cancer is rising rapidly, placing a huge burden on families, communities and healthcare systems. Millions of people develop cancer, with half of those diagnosed in the UK living at least 10 years. Improvements in detection and treatment mean that more people are experiencing cancer as a long-term condition. However, cancer profoundly changes lives and creates lasting problems. New treatments bring new side effects and it is vital we know what these are and what impact they have so we can work out how people can be supported to live their best lives. As cancer incidence increases and treatment improves, many will enter old age as cancer survivors or on lifelong treatments. We must understand how cancer affects this generation and what should be in place to help them live independently and well.

Health care is adapting to growing numbers of people living with cancer, tailoring care and support following diagnosis according to need through personalised care rather than a 'one size fits all' approach where everyone has the same frequency of appointments or intensity of support. Patients need to understand what they might expect and how they can manage consequences. We need to know what extra supports should be in place, for whom and when these are most needed. Understanding the long-term impact of cancer and its treatment will enable cancer services to be better equipped to meet patient need, improving their long-term health and wellbeing and ability to tolerate treatments. This will benefit patients and family members, wider society, healthcare and health economy.

The experiences and needs of those whose lives are disrupted by cancer must drive decisions about the design and delivery of cancer care and support. This can only be achieved by asking people about the problems they face after a cancer diagnosis and long after treatment ends. We must ask enough people and ensure their views reflect those living with different cancers and geographical locations across the UK. This cannot be a one-off 'snap-shot', but over time, so we can track and understand how needs and experiences change in the same groups of people. This is a significant undertaking, requiring the collective efforts of patients, funders, the research team, clinical experts and cancer centres.

About HORIZONS

HORIZONS was established, co-ordinated and executed by the Macmillan Survivorship Research Group (MSRG) at the University of Southampton, directed by Prof Claire Foster. Thousands of people living with cancer across the UK were involved in HORIZONS (www.horizons-hub.org.uk). Our research is guided by people affected by cancer (HORIZONS User Reference Group), internationally renowned experts, charities and public bodies (through the HORIZONS Strategic Advisory Group and HORIZONS Tumour Specific Expert Panels), who ensure we deliver the findings healthcare and support services need.

HORIZONS is a powerful bank of health, social and wellbeing information for patients and clinical communities, telling us who, how and when to support people from diagnosis and over the years following treatment. Data from HORIZONS are being used to transform services, information and UK / international policy. Working with our established policy and practice partners (e.g. Macmillan, NICE, NHS England), HORIZONS will reshape healthcare services and support, improving the lives of people diagnosed with cancer.

Two distinctive strengths of HORIZONS are:

1. Involving **representative** groups of people with different cancer types, capturing data about health outcomes and experiences to uncover the complexity of cancer survivorship from a personal perspective.
2. The first survey was completed **before treatment begins** to enable us to assess the impact of treatment on people's lives in the months and years ahead.

The primary objective for HORIZONS is to understand the long-term experiences of living with cancer. Our earlier research with colorectal cancer patients (CREW) suggests that people have problems that last years after treatment and early identification and support of patient-identified needs may improve long-term health and wellbeing outcomes.

2. End of Grant Summary

Data collection

HORIZONS is an observational study which used a prospective, longitudinal cohort design to gather patient-reported outcomes and clinical details from three representative cohorts of recently diagnosed cancer patients over time. The three cohorts in HORIZONS are:

- women aged under 50 with breast cancer;
- women with a gynaecological cancer (endometrial, cervical, ovarian, primary peritoneal, fallopian tube and vulval);
- men and women with Diffuse Large B Cell non-Hodgkin Lymphoma (NHL).

The breast cancer cohort was selected to gain an understanding of younger breast cancer survivors' experiences. Many of these women were likely to have poorer prognoses, including higher risk of recurrence. The gynaecological cohort was selected as it included less common cancers as well as a range of ages and treatment types. The NHL cohort was selected as it was the most common high grade (faster growing) lymphoma, in contrast to solid tumour cohorts.

HORIZONS participants were recruited between September 2016 and May 2019, from 78 NHS treatment centres, or sites, in the UK (NHS Trusts in England, NHS Boards in Scotland and Wales, and Health and Social Care Trusts in Northern Ireland). This equates to 110 hospitals taking part in HORIZONS. Sites were located in Northern Ireland, Wales, Scotland and England: 22 were located in the Devolved Nations of the UK, while 13 were located in London. They served rural and urban, affluent and less affluent localities, including tertiary cancer centres, large teaching hospitals and smaller district general hospitals with under 200 beds. The majority of sites (50) recruited patients to all three HORIZONS cohorts, 62 recruited to the breast cohort, 57 to the gynae cohort and 72 to the NHL cohort. Nineteen sites had been involved in previous MSRG studies. A map of the HORIZONS sites is shown in figure 1.

Figure 1 HORIZONS recruiting sites showing the spread of geographical locations



Regulatory approvals

HORIZONS received ethical approval from the National Research Ethics Committee (Lancaster, North West, reference number 16/NW/0425) and was adopted onto the National Institute for Health Research (NIHR) Clinical Research Network (CRN) Portfolio.

The recruitment process

Eligible patients were identified from multi-disciplinary team lists and meetings, clinic lists and clinician referral, which were recorded on a Screening Log. Screened, eligible patients were approached by site staff and invited to take part in HORIZONS. Wherever possible, all patients were approached prior to the start of primary cancer treatment, however when primary treatment was also the patient's diagnostic procedure (most often in the gynaecological cancers cohort), patients could be recruited after diagnosis.

Baseline data collection

Patients who gave written, informed consent to take part in HORIZONS were asked to complete a baseline questionnaire in A4 booklet form, to send back later or complete at site. There were different questionnaires for each cancer cohort, comprising core questions common to all and cohort-specific questions (Appendix A).

Site staff completed Case Report Forms (CRFs) for each participant as soon as possible after consent. CRFs could be completed on paper or online via the HORIZONS study website. The purpose of the CRFs was to collect clinical information about HORIZONS participants from their medical records held at site.

Follow-up data collection

Follow-up questionnaires were sent from the HORIZONS Co-ordinating Centre at 3 months, 12 months, 18 months, 24 months and 36 months after consent. The content of the follow-up questionnaires was based on that of the baseline questionnaires (Appendix A). At each follow-up time point, additional measures appropriate to that time in the patient journey were added while other measures less relevant to the patient journey at that time were removed. Online follow-up HORIZONS questionnaires were made available so that participants could complete questionnaires electronically if they preferred. Follow-up CRFs were completed by site staff at 6 months, 12 months, 24 months and 36 months after consent.

Questionnaire and Case Report Form measures

HORIZONS questionnaires and Case Report Forms (CRFs) included a selection of validated and study-specific outcome measures, informed by the study's conceptual framework and expert and patient feedback. Key sociodemographic, socioeconomic and clinical information (e.g. age, gender, ethnicity, marital status, employment, cancer type, cancer stage) were collected at baseline, and characteristics that were likely to change were included on a regular basis in follow-ups. Postcode data collected at consent were used to calculate a measure of relative area deprivation: the Index of Multiple Deprivation.

A core set of questionnaire measures was administered to all participants at each assessment point. Additional measures and questions were included at different time points including burden of treatment, comorbidities, life events, lifestyle, social networks and the use of health and social care services. A selected measure (the SF-12v219) was incorporated to enable comparisons with the UK Understanding Society longitudinal household panel survey that captures social, economic and health data on the UK general population. All measures and questions assessed are described in appendix A.

Clinical information including cancer type, stage, treatment details, comorbid conditions, recurrence, relapse, survival, genetic tests, family history, route to diagnosis, follow-up care, height and weight, was abstracted from clinical records by staff at the HORIZONS participating sites. Changes in health and treatment were monitored through follow-up CRFs.

Data management

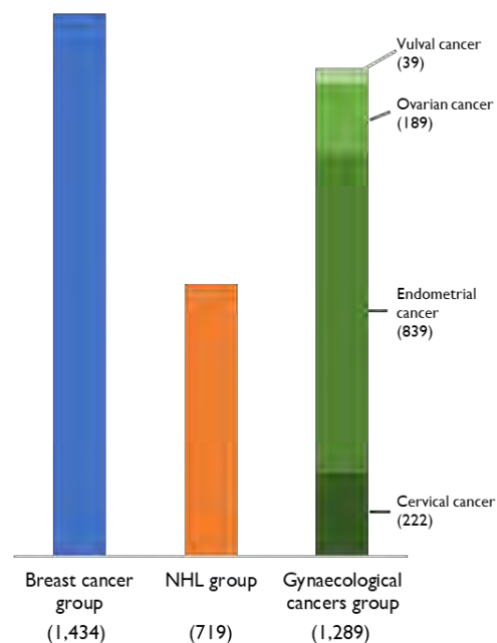
Data from HORIZONS CRFs and questionnaires were entered into a database by HORIZONS team members at the HORIZONS Co-ordinating Centre. Ten per cent of all entered data were re-entered and error rates monitored regularly. If the error rate exceeded 5% at any checkpoint, all data checked at that point would be re-entered. CRF data was monitored for completeness and accuracy regularly.

Recruitment

Between September 2016 and May 2019, 7,301 patients were identified as eligible to participate in HORIZONS at the recruiting hospitals. Of these, 5876 (82%) were approached and asked whether they would like to take part. 3442, 59% of those patients invited to take part in HORIZONS, gave their full consent to do so.

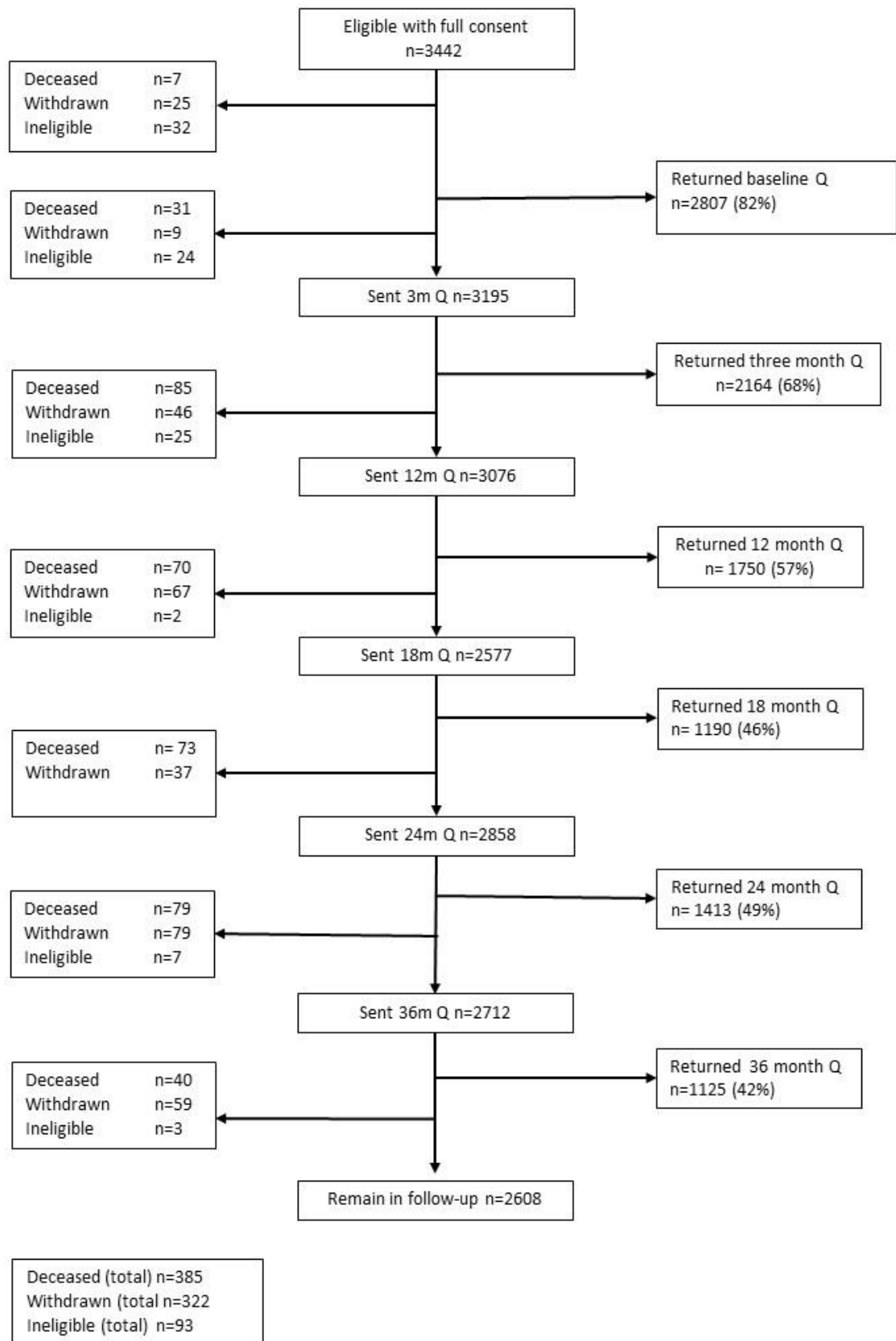
Most of the 3442 consenting patients were from England (82%), 9% from Wales, 6% from Scotland and 3% from Northern Ireland. The number of participants by cancer type is shown in figure 2.

Figure 2: Number of participants, by HORIZONS cohort



Of the 3442 participants who gave full consent to take part in HORIZONS, 2807 (85%) returned a baseline questionnaire. Follow-up questionnaire return rates for the three months, 12 months, 24 months and 36 months time-points are shown in figure 3. As can be seen, throughout the follow-up period, participants were lost to further follow-up either because they had died, had actively withdrawn from the study, or were found to be ineligible.

Figure 3: HORIZONS follow-up questionnaire return rates



Some questionnaires not sent if hospital site did not think it appropriate

Demographics

Table 1 shows the average age and ethnicity of study participants in the three HORIZONS cohorts. Participants' ages ranged from 22 to 93 years at recruitment. Most were white British, with women of other ethnicities making up 10% of all participants.

Table 1: Age and ethnicity of HORIZONS participants

	Mean age	Ethnicity (White British)
Breast	42.7	86%
NHL	65.3	90%
Gynaecological cancers	61.4	93%

The level of deprivation experienced in the postcode area in which each participant lived was calculated using the Indices of Multiple Deprivation: there were participants from each level of deprivation (table 2).

Table 2: Level of deprivation of HORIZONS participants

1 (Most deprived)	14%
2	18%
3	22%
4	22%
5 (Least deprived)	24%

Makeup of the breast cancer cohort (diagnosed <50 years)

The breast cancer cohort provides a unique insight into the experiences of younger women (<50 years) diagnosed with cancer. This cohort were the youngest HORIZONS participants on average, with a large number in employment (81%). Few women in this group lived alone at baseline (7%) and over half were caring for a child aged below 18 years (59%). Less than a quarter of the group were living in rented accommodation.

Makeup of the NHL cohort

NHL is more common in men, and this was reflected in our cohort: 57% were male. On average, they were the oldest cohort at recruitment to the study, which explains a high number being in retirement (59%). Around a fifth of the cohort were living alone. Just under 10% had caring responsibilities for a child (aged below 18). Most of the cohort also own their accommodation (79%).

Makeup of the gynaecological cancers cohort

The mixed gynaecological cancers cohort included women diagnosed with cervical, endometrial, ovarian or vulval cancer. Almost half of this group were in retirement (48%) when recruited to the study, with 39% in employment. A fifth of the gynaecological cancer cohort lived alone at baseline, with 12% having caring responsibilities for a child under 18. A large proportion of this group also owned their accommodation (77%).

Findings

To date, analysis of HORIZONS data has focussed on five core areas/themes:

1. Understanding the experiences of the COVID-19 pandemic for people living with and beyond cancer who were advised to shield
2. Determining which pre-treatment factors are associated with quality of life in women with gynaecological cancers
3. Social networks of younger women with breast cancer
4. Quality of Life, self-efficacy, anxiety and depression before treatment and 3 months follow up
5. Qualitative experiences of people accessing supportive services

Main findings from each area of analysis are outlined below. Future analyses will expand on these, including an exploration of Breast and Non-Hodgkin Lymphoma cohort specific data.

1. Understanding the Experiences of the COVID-19 Pandemic

The COVID-19 pandemic occurred when HORIZONS data collection had reached the 18-36 month data collection point. We added a mixed methods study in order to i) understand the experiences and needs of people being treated for and recovering from cancer during the pandemic; ii) understand any differences in responses to the main HORIZONS questionnaires completed before and since the pandemic.

A survey was developed to ask about experiences of COVID-19, of social distancing measures, of changes to treatment and care, and impact on quality of life and wellbeing. The survey was included with regular scheduled HORIZONS questionnaires (either the 24 month or the 36-month questionnaire) from September 2020, and could be completed online or on paper, depending on participant preference. A qualitative study was conducted to understand experiences in more detail. Telephone interviews were conducted with a sub-sample of the HORIZONS cohort who had given consent to be contacted about other studies. Interviews took place between April and June 2021, were audio recorded and were transcribed.

Brief Summary of Survey Data

- 80% agreed with their advice to shield/not shield
- Individuals were more likely to take additional shielding precautions (e.g. cleaning their incoming mail) if they agreed with their advice to shield or felt they should shield
- 49% needed other people to undertake daily tasks (e.g. food shopping)
- 75% did not have any financial concerns as a result of the pandemic
- Treatment was planned for 138 individuals, of whom 54 (39%) had changes made to their planned treatment
- Most individuals received a remote HCP consultation during the pandemic. 70% reported a preference for face-to-face appointments
- For half of individuals, the pandemic had little or no negative impact on their overall QoL
- A significantly greater proportion of individuals who agreed with their advice to shield or felt they should have been advised to shield, reported negative impact on QoL ($\geq 49\%$), compared to 38% of those who agreed they should not shield.

Brief Summary of Interview Data

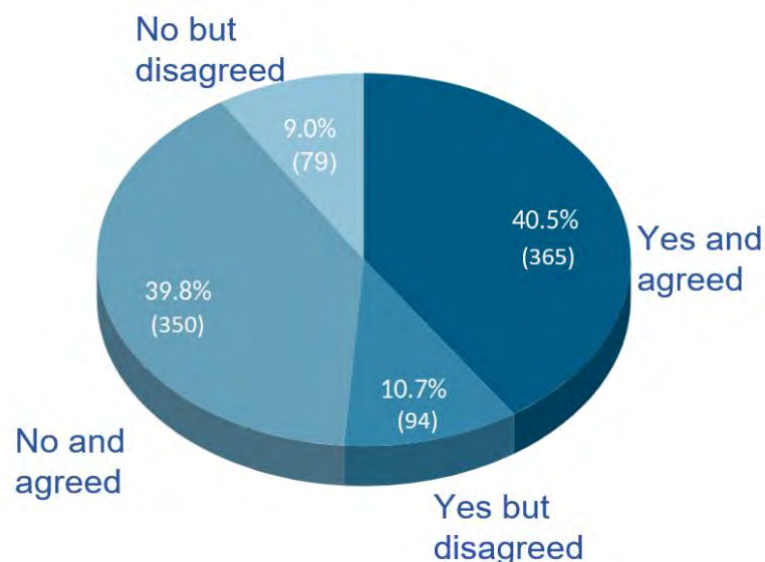
- Individuals' behaviours and responses to shielding advice were governed by a personal risk assessment
- Interview participants were very attentive to hygiene and social distancing precautions when outside of the house
- Some individuals expressed concern about easing of precautions and the behaviour of others

Findings in more detail

COVID-19 surveys were sent to 1846 HORIZONS participants. Of these, 662 were sent with a 24-month questionnaire and 1184 with a 36-month questionnaire. A total of 916 surveys were completed, a response rate of 50%. Only 51 (5.6%) participants, had tested positive for COVID-19, with an additional 46 (5.0%) reporting COVID-19 symptoms unconfirmed with a test. Four were hospitalised as a result of COVID-19.

51.2% (out of 879 who answered the question) received a shielding letter (97.9% of NHL, 46.7% of breast, and 24.8% of gynae cohort). Figure 4 shows that 40% of the sample agreed with their advice to shield (yes and agreed), 40% agreed they did not need to shield (no and agreed), 11% disagreed with advice to shield (yes but disagreed) and 9% felt they should have been advised to shield (no but disagreed). People who agreed with advice to shield were sicker at the start of the study (higher ECOG status), were older, and were more likely to be receiving treatment. Women in the breast cancer cohort were much more likely to disagree with advice to shield: 70% of those who disagreed with advice were within the breast cancer cohort, with 17% from NHL and 13% from gynae.

Figure 4: HORIZONS participants' responses to whether they had been advised to shield



We looked at the response to behavioural guidance of the different groups. There was no statistically significant difference between the groups in terms of the government's whole population measures: handwashing; face covering; keeping 2m apart when out; not visiting the homes of others. There were significant differences between the four groups in terms of actions shown in table 3. Only one of these actions – no visitors in own home – was mandated, the others being advisory to people shielding. Respondents were more likely to take the additional precautions if they agreed with their advice to shield (yes and agree), or if they did not receive advice to shield but felt they should have (no but disagreed). Those

who disagreed with their advice to shield were more likely to stay home than those who agreed they did not need to shield, but less likely to undertake the other precautions.

Table 3: HORIZONS participants' actions related to government measures

	Stay Home All the Time	Stay Home Nearly All the Time	Keep 2m Apart at Home	Cleaning Post/ Shopping	Wearing Gloves	No Visitors in Own Home
Yes and agreed	87.4% (N=283)	92.1% (N=303)	49.3% (N=164)	76.7% (N=264)	60.1% (N=190)	96.8% (N=337)
No but disagreed	68.1% (N=47)	88.5% (N=69)	47.4% (N=36)	69.2% (N=54)	57.1% (N=40)	93.5% (N=72)
No and agreed	43.9% (N=137)	77.6% (N=260)	30.7% (N=100)	57.4% (N=191)	52.8% (N=168)	93.0% (N=317)
Yes but disagreed	52.9% (N=45)	83.5% (N=76)	22.5% (N=20)	44.4% (N=40)	42.0% (N=34)	85.1% (N=80)

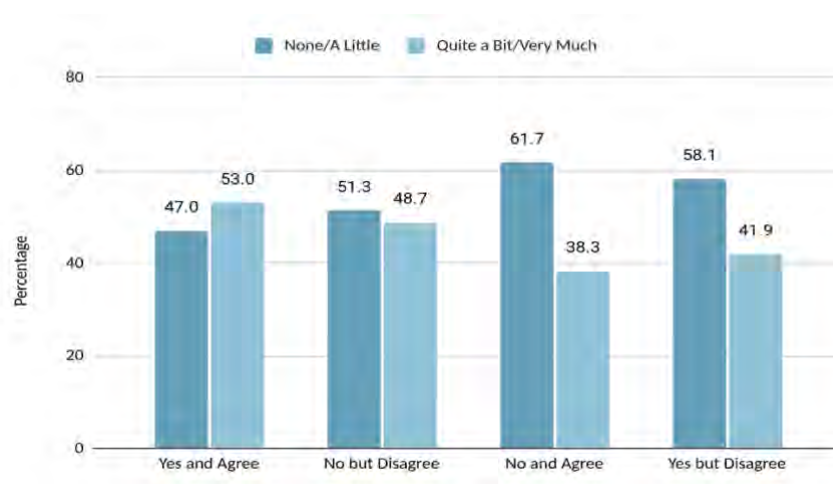
Half of respondents (449, 49.4%) needed other people to take on tasks, such as food shopping or collecting medicines during the pandemic, with only 10 (1.1%) reporting being unable to access such support. Most commonly, household members (246, 26.9%) or family/friends (219, 23.9%) carried out these tasks, with 152 (16.6%) making use of a food delivery service and 95 (10.4%) using a pharmacy service. Neighbours (77, 8.4%), NHS volunteers (18, 2.0%) and local community group (17, 1.9%) also took on these tasks. Most respondents (684, 75.1%) did not have any financial concerns as a result of the pandemic, 172 (18.9%) were a little concerned and (55, 6.0%) were either quite or very concerned.

The respondents were two to three years post diagnosis, and most (767; 84.7%) did not report any cancer treatment during the pandemic. In 60% of cases, treatment went ahead as planned. Changes included: cancelled treatment 14/55 (25.4%), change to treatment start date (12, 21.8%), change to how often the treatment was delivered (9, 16.4%), where treatment was delivered (9, 16.4%), the type of treatment given (5, 9.1%) and treatment mode (1, 1.8%). The survey free text comments described delays to reconstructive surgery, delays to hormone injections, delays to routine scans and changes to telephone instead of face-to-face appointments. About half of respondents were due to have scans or other tests related to their cancer during the pandemic and of these, 14% (119/882) had their planned tests or scans changed. Most people who needed to book a GP appointment during the pandemic (332/564, 59%) were able to do so, but a sizeable minority (232/564, 41%) could not.

Most (745) people reported a remote consultation (telephone or video) with a health care professional during the pandemic. Of those who did, the majority (518/70%) preferred face-to-face appointments very much or slightly.

For about half of respondents, the pandemic had either a little (46%) or no (6%) negative impact on their overall quality of life. There was a statistically significant difference between the shielding groups in terms of negative impact on quality of life (figure 5) of participants: 53% of those who agreed with their advice to shield and 49% of those who felt they should have been advised to shield reported quite a bit/very much impact. This compared to 38% of those who agreed they should not shield.

Figure 5: negative impact on the quality of life of HORIZONS participants by shielding advice



A total of 21 telephone interviews were completed. The sample comprised 16 women and 5 men (5 young women with breast cancer, 4 women with gynaecological cancer, 12 people with NHL). Eighteen interview participants had received advice to shield. It was apparent from the interviews that people's behaviours were governed by a personal risk assessment. Psychological and social factors influenced decisions about how to respond to shielding advice. While some followed shielding advice, others weighed up that advice against their own perception of their vulnerability, of what they considered was sensible for their circumstance and what they felt was an acceptable level of risk. For example, people who were living alone made decisions to continue to go out to work or to move in with family who could pose a risk through their own activities.

the thought of being locked inside the house for more than the couple of days I think it was just impossible, so I took the decision not to shield and carry on working, with precautions. (interview 1)

It would have had, you know, quite a catastrophic effect on my daughters as well as myself (interview 14)

Interview participants were very attentive to hygiene and social distancing precautions when outside of the house. While a few felt they did not have enough information about COVID-19, additional information requirements often related to understanding personal risk

I guess the point is, like more information on, kind of, how I made it onto their list initially. The criteria, where it might have been helpful just in terms of assessing my risk (Interview 13)

At the time of interviews, the first UK lockdown was easing and vaccination numbers increasing, but there remained concern among some participants about the easing of precautions and the behaviour of other people

I'm obviously sticking to the rules, I'm very careful, but I'm more worried about other people how they've start to behave. (4)

Six people taking part in interviews were receiving treatment (not including tamoxifen) at the start of the pandemic. Two continued to receive chemotherapy without delay, while others experienced some delay to maintenance/targeted therapies. There were two reports of a regular follow-up test being missed, and one delay to a mammogram. There were

concerns among participants regarding remote methods of follow-up, with some finding telephone consultation more difficult than face to face, and others concerned about missing a physical examination. There were also positive aspects of virtual appointments reported, in particular the time saved in attending hospitals for what are often brief appointments.

I think you worry a little bit because it's those actual examinations and tests that you're given while you're there that give you the peace of mind that nothing's come back and obviously just a few questions over the phone isn't going to give you that kind of reassurance (Interview 19)

2. Quality of Life in Women with Gynaecological Cancers

Our analysis aimed to determine which modifiable pre-treatment factors are associated with QOL at baseline (pre-treatment) and at three and 12-months follow-up. QOL was assessed using two measures: the QLACS-GSS¹ and the EORTC QLQ-C30 summary score.

Key Findings

- QOL significantly reduced between diagnosis and 3 months, followed by an improvement at 12 months.
- Having at least one limiting comorbidity was associated with worse QOL at baseline and 12 months
- Higher self-efficacy was associated with better QOL at baseline and 12 months
- Other factors associated with worse QOL at baseline included anxiety and depression
- Other factors associated with better QOL at baseline included obesity and better self-reported health status
- Other factors associated with worse QOL at 12 months included lower socio-economic status and depression
- Other factors associated with better QOL at 12 months included surgical treatment

Gynaecological Cohort

The gynaecological cohort included 1,222 women diagnosed with endometrial, ovarian, cervical or vulvar cancer from 82 UK NHS hospitals, for whom treatment was given with curative intent. The response rate for questionnaires was 80% at baseline and 59% at 12 months.

- Most participants had an ECOG performance status of either 0 or 1, indicating good functioning
- About half had at least one comorbidity which they reported limited the activities they did on a typical day
- Just under half of participants reported one or more indicators of lower socio-economic status (unemployed or on benefits - excluding child benefit, were renters, or lacked access to a car or the internet)
- The majority had a BMI of ≥ 25 indicating they were overweight or obese
- About half reported being physically active and most had never smoked
- Most participants lived with others, although less than 20% felt they were fully supported socially

¹ Avis N.E., Smith, K.W., McGraw, S., et al. (2005). Assessing quality of life in adult cancer survivors (QLACS). *Qual Life Res*, 14(4), 1007–23.

- About a third had caring responsibilities
- Most participants were treated with surgery (90%), 27% received chemotherapy and 21% radiotherapy.

QOL from Baseline to 12 months

There was a reduction in QOL between diagnosis and 3 months, followed by an improvement at 12 months (Figures 6a and 6b).

- On both measures, QOL was significantly worse at 3 months compared with baseline
- On the QLQ-C30 summary score, QOL was significantly better at 12 months compared to baseline
- On the QLACS-GSS, QOL improved between 3 and 12 months, but QOL did not return to baseline levels

Figure 6a: Quality of life in the first year (QLQ-C30 summary score*)

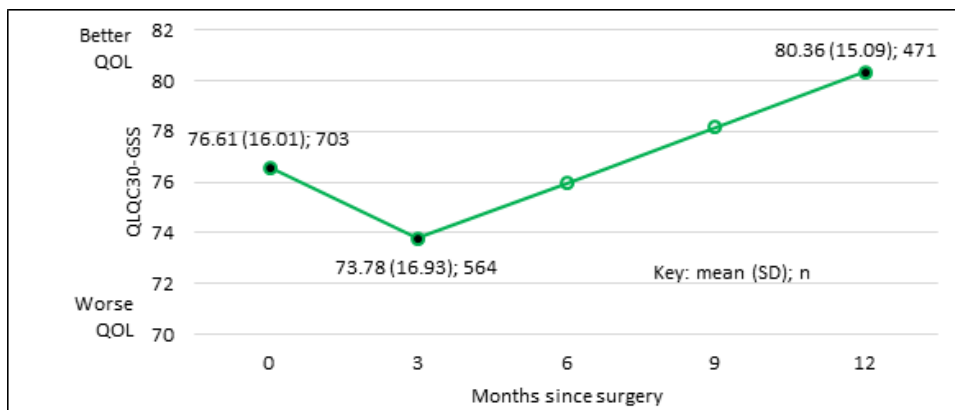
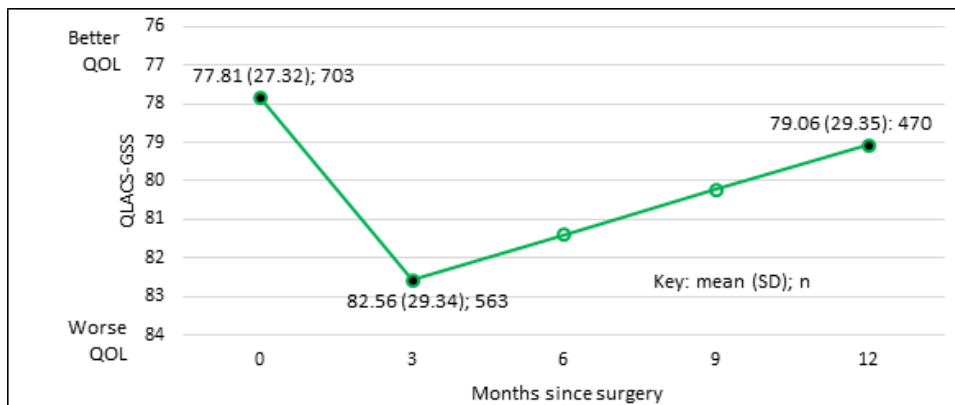


Figure 6b: Quality of life in the first year (QLACS-GSS summary score†)



* For the QLQ-C30 summary score, a higher score corresponds to better QOL

† For the QLACS-GSS, a lower score corresponds to better QOL

Association between baseline characteristics and QOL at baseline

Factors associated with worse QOL at baseline for both outcome measures were having at least one limiting comorbidity, anxiety and depression (as measured by HADS). In addition, having a cancer stage of ≥ 2 or living in the most deprived areas were associated with poorer QOL as measured by the QLQ-C30 summary score (Figure 7). Women with better self-reported health status (measured by EQ-5D) and greater self-efficacy had better QOL on both measures, as did women who were obese. For QLACS-GSS, better baseline QOL was

associated with being over the age of 50 and being physically active. Being single, separated or divorced were also associated with better QOL as measured by QLQ-C30 summary score.

Figure 7: Significant baseline characteristics associated with QOL at baseline on both measures (QLACS-GSS and QLQ-30 summary score)



*Green = associated with better QOL; red associated with poorer QOL

Association between baseline characteristics and QOL at 12 months

At 12 months, baseline factors associated with worse QOL on both measures were having either one or more limiting comorbidities, having a lower socio-economic status and depression (measured by HADS). Increased anxiety (measured by HADS) and a tumour grade of three were associated with worse QOL on the QLACS-GSS at 12 months. Obesity and living in the most deprived quintile at baseline were both associated with worse QOL at 12 months on the QLQ-C30 summary score (Figure 8). Higher self-efficacy at baseline was associated with better QOL on both measures at 12 months. We also found that having surgery was associated with better QOL at 12 months on both measures. Being over the age of 50 at diagnosis was associated with better QOL at 12 months as assessed by the QLACS-GSS.

Figure 8: Significant baseline characteristics associated with QOL at 12 months on both QOL measures (QLACS-GSS and QLQ-30 summary score)



*Green = associated with better QOL

Conclusion

Our findings highlight self-efficacy, mental health (most notably depression) and the presence of one or more limiting comorbidities as key modifiable risk factors that can impact QOL in women living with and beyond gynaecological cancers.

3. Social Networks

The importance of social networks in the self-management of long-term conditions is recognised but there is little understanding of the role of the social networks of people living with and beyond cancer. We have undertaken analysis of the breast cancer cohort baseline data to understand the mechanisms of network support for young women with breast cancer close to the time of diagnosis. Women were asked to list any network members who provided support and to rate the contribution of each network member (no help at all, some help, a lot of help) for three types of support: illness work (information about illness and illness management, e.g. helping understanding of health information, diet, medicines),

practical work (practical help with daily tasks, e.g. running the household), emotional work (emotional support, e.g. helping with wellbeing, feeling good, and comfort when worried).

Key Findings

- Social network members provide a substantial level of illness-related, practical and emotional support to young women with breast cancer around the time of diagnosis
- Friends and close family members were important sources of support
- Women who did not have a partner received higher levels of support from their wider social network than women who had a partner
- Women who had lower levels of education and who did not have a partner were least well supported.

Sample

The sample included 1202 women with breast cancer.

- Seventy percent of the sample were aged 41 to 50 years old
- Fifty eight percent were married and were caring for children
- A large number were of higher socio-economic status (SES) but 28% were on lower incomes and 27% were living in less affluent areas
- Only 7% were living alone.

Who were the network members of women with breast cancer?

- Just over 12,000 network members were reported
- Network members were more likely to be women (69%) and were in frequent contact with the woman with breast cancer (76%, at least once a month)
- 41% of network members were friends; partners/spouses and other close family members made up a third of network members
- A small proportion (2%) reported a pet in their network.

What support did network members provide?

- Network members provided more emotional support than illness or practical support
- Health care professionals provided most illness related support, followed by partners and close family members
- Partners provided the most practical and emotional support
- Close family and neighbours were important sources of practical support
- Friends, close family and pets provided emotional support.

Which women with breast cancer received more support?

- In multivariate analysis, controlling for network size, women of lower socioeconomic status (SES) received more of all types of support than those of higher SES
- In the multivariate analysis, and controlling for size of network, measures of socio-economic status remained significant
- Women with higher education received a lower amount of illness and emotional support
- Women with higher income was received a lower amount of illness and practical support
- Women living in deprived areas received more practical support than those living in affluent areas
- Women who were more involved with social activities received more of all types of support
- Those who were older and those not caring for children received less practical support

- Non-white women received more illness support than white women.

How do the personal circumstances of the woman with breast cancer affect network support?

- The sample was divided into four groups in terms of partner status and level of education (had a partner and higher education; had a partner and lower education; no partner and higher education; no partner and lower education)
- Women with higher education and no partner had the largest networks and those with lower education and no partner the smallest
- The support by network members tended to be higher in networks without a partner
- The absence of support from a partner was filled by friends in the group with higher education and by close family members as well as friends in the group with lower education.

Conclusion

There is a significant level of support provided to young women with breast cancer by their social network in terms of illness work, and practical and emotional support. However, it is important to understand and identify those who lack social network support across the cancer pathway and to develop network based interventions to support them.

4. Quality of Life, self-efficacy, anxiety and depression before treatment and three months follow up

Quality of Life (QOL) was assessed using our primary outcome measure: Quality of Life in Adult Cancer Survivors (QLACS). QLACS is patient-reported and measures 'generic' or non-cancer specific aspects such as pain, fatigue, positive and negative feelings, cognitive and sexual problems, and social avoidance. It also measures cancer-specific aspects including financial problems, family-related distress, distress about cancer coming back (recurrence) and benefit finding after cancer. Higher scores indicate poorer QOL. Comparisons of baseline (near diagnosis, pre-treatment) and the 3-month follow-up data revealed that, at 3 months, mean QLACS-GSS scores increased for all three cancer groups in HORIZONS suggesting that QOL declined (figure 9). Overall, all groups in HORIZONS reported poorer QOL across both timepoints compared to the CREW group (figure 9).

Self-efficacy (confidence to self-manage) was captured using the Self-Efficacy in Managing Chronic Disorders (SEMCD) scale.² Approximately 1 in 5 from each HORIZONS cohort reported low levels of self-efficacy before treatment (figure 10). The largest number of people reporting low confidence were from the NHL group (figure 10). At three months, a higher amount of the breast and NHL groups reported low confidence levels. However, there was a marginal reduction in the gynaecological cancers group. Overall, greater numbers of people in our HORIZONS group reported low confidence compared to our colorectal cancer group (CREW).

² Lorig, K.R., Ritter, P., Stewart, A. L., et al. (2001). Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Medical care*, 1217-1223.

Figure 9: Mean QLACS-GSS at baseline and 3 months follow-up (HORIZONS and CREW)

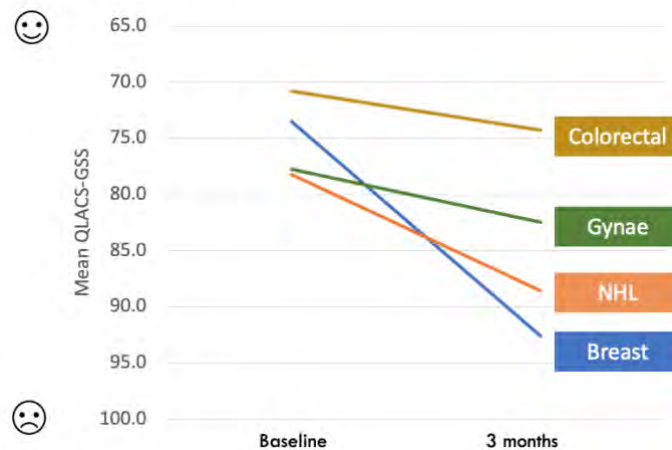
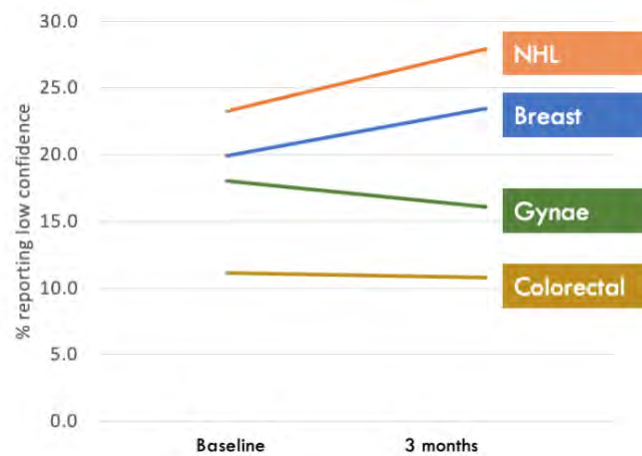


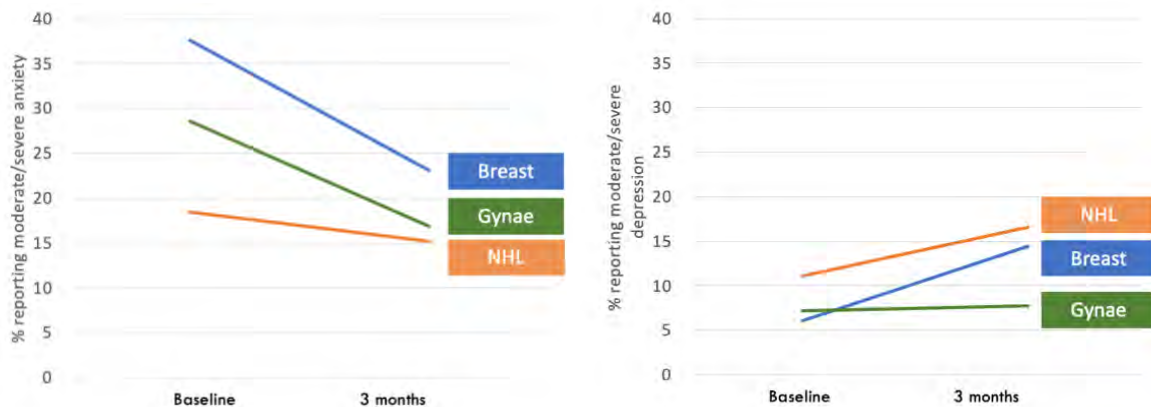
Figure 10: Percent of participants reporting 'low confidence' to manage health (mean SEMCD<4)



Depression and anxiety are assessed using the Hospital Anxiety and Depression Scale (HADS).³ Higher scores indicate more severe symptoms but these do not represent a clinical diagnosis. More HORIZONS participants reported high levels of anxiety before treatment compared to depression. More breast cancer participants reported high levels of anxiety compared to the other two groups, while more NHL participants reported high levels of depression (Figures 11a, 11b). At 3 months, the amount of people reporting high levels of depression increased in all groups, although there was a fall in the number of people reporting high levels of anxiety.

³ Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta psychiatrica scandinavica*, 67(6), 361-370.

Figures 11a and 11b: Proportion of participants reporting 'moderate-to-severe' anxiety (HADS-A>14) or depression (HADS-D>14)



5. HORIZONS qualitative study: Understanding, characterising and explaining how people connect with and mobilise supportive services and resources to help them to self-manage the consequences of cancer and its treatment and to promote recovery of health and wellbeing

Sample and method

- 30 face to face interviews were conducted, recruited from HORIZONS participants who consented to be contacted about further research.
- The sample comprised people who were between 12- and 18-months post treatment, a time when formal, scheduled support lessens and self-management is expected to increase.
- We purposively included people from rural and urban clusters, ensuring variation in cancer type, gender, socio-economic status, age, social network density, self-efficacy.
- To aid recall, participants were asked to map supportive services and resources they had used in relation to their cancer in advance of the interview.
- Interviewees were asked to describe for each service or resource: their experience of finding out about, making contact with and using the service or resource; any reasons for not seeking required support; and overall evaluation of support.
- Interviews were audio recorded and transcribed in full.
- Data are being analysed thematically, with the analysis involving people from different disciplines (sociology, psychology, nursing) and people living with and beyond cancer.

Key findings

Use of supportive services and resources was changing and diverse. The analysis identified three different groups, characterised by how they sought and used services and resources. The largest group is those for whom support was mainly from existing networks of relatives, friends and from health care professionals. They talked about how this was adequate for their support needs. This group also re-engaged with previous wellbeing activities they had used before their cancer diagnosis (such as yoga).

*Just used my own social group, you know, people that I know and trust
(interview 18)*

*there were other things I could have done, massage or reflexology but not---
not for me. There were just groups and people who wanted someone to sit and*

*chat to. I didn't feel the need to talk to people because, I was at work.
(interview 15)*

The second largest group is seekers of support and information from cancer services and resources, in addition to their existing network. These were people who actively sought out information, engaged with online forums and sought varied support from charities. This seeking often changed over time, with more during the earlier stages of their cancer journey.

I just thought rather than sort of ignore it, you know, I'd get as much as help as I possibly could (interview 30)

Even now if I sit--- sit on my 'phone and, you know, watching something on telly that hasn't got my interest and I'll, you know, go on Facebook. And when I've had enough of that, I'll google breast cancer something else but I may not have possibly ever googled before--- I just--- I don't know. It's like a bit of an obsessive thing but what--- there might be something new that I'm going to read or that's been missed or that I can do. (interview 6)

The smallest group had very limited social support, limited health skills and did not seek wider support and resources.

And then--- I don't know how to understand stuff (interview 22)

People discussed the different ways they found out about other resources and services, e.g. by referral, actively seeking help, through recommendations and by chance. People's personal social networks and healthcare professionals were also important not only for direct support, but also as a source of knowledge about services and resources that might help. Some also used existing relationships to deal with new needs (e.g. with therapists).

...I'd seen him on and off for a number of years anyway but when I got back on my feet, I was still getting problems with my neck and shoulder which, I think, was a lot to do with the stress of having cancer and the treatment. So, I went to him and he relieved the stress in my shoulders and neck and it was wonderful.

One important theme was the emotional challenges people experienced when seeking help. For instance, some people experienced nerves when going along to group settings, some found it difficult hearing from people who were not doing so well, and others did not want to have to think about how they felt in the past as they had 'moved on'.

The first time I went in, because I had known about this charity but it, I just didn't really know what to expect. So I was a bit nervous about going and it was just a spur of the moment thing because I think, I had been putting it off and off because I was thinking, 'I don't know what it will be like'.

Conclusion

The study has illustrated the importance of understanding diverse views of and need for supportive services and resources.

Lessons Learned

Running a longitudinal, observational study over several years provided many opportunities for reflecting on what processes and methods worked well and what not so well. Based on these reflections, a summary of important factors that facilitated study set-up, patient recruitment and data collection, is presented here.

Study Set-up

Site selection

As many Health Trusts and Health Boards in the UK as possible were informed about HORIZONS. The NIHR Clinical Research Network enabled wide dissemination of study details and provided financial support to treatment centres who recruited patients. We selected sites for HORIZONS based on perceived willingness and ability to recruit. We also chose a variety of Trusts and Health Boards (for example small and large sites, teaching hospitals and district hospitals) as well as sites in a range of geographical areas.

Site staff engagement

It was essential to engage staff working at our recruiting sites as soon as possible. We found personal contact was important and this was made possible by holding a HORIZONS Launch Day, HORIZONS Site Update Meetings and carrying out remote Site Initiation Visits. We provided HORIZONS information for site staff in a variety of formats to engage staff, including our HORIZONS website, 'how to' guides and Site Newsletters. We had regular teleconferences with site staff and we made available a Site Initiation recording to help new members of staff or as a refresher. We encouraged research nurses, Clinical Nurse Specialists and Clinical Trials Practitioners to become the Principal Investigator at their site.

Eligibility criteria

The HORIZONS team refined the study's eligibility criteria during the pilot phase of the study, based on site feedback and advice from clinical experts. This allowed us to clarify our eligibility requirements and enable recruitment of some patients after diagnostic surgery.

Recruitment

Recruitment of all eligible patients

We found that HORIZONS sites were not always familiar with the concept of inviting all eligible patients to take part. The study team therefore took time to explain to site staff why and how all eligible patients should be invited. The message was repeated in Site Initiation meetings, regular teleconferences with site staff, in newsletters and at our Site Update meetings. Where it was not possible for site staff to invite an eligible patient face-to-face, an option to contact the patient by phone and send the study documents to their home was made available.

We also found some clinical teams in our recruiting sites were reluctant to invite certain eligible patients whom they felt should not be approached, e.g. anxious, upset or frail patients. This was a particular problem for HORIZONS because patients were usually approached soon after diagnosis, potentially a difficult and sensitive time. We created a Best Practice Document to support site staff to approach patients sensitively in the short time available (following diagnosis but before the start of treatment). In addition, we tried to reduce 'gatekeeping' by emphasising the importance of patient choice in decisions about

taking part in research. We worked with individual sites to promote discussions around gatekeeping and enlisted the help of our Patient and Public Involvement (PPI) partners.

Data collection

Questionnaire design

Our questionnaires were designed with participants in mind, and we involved our PPI partners in decisions about questionnaire content, layout and length. As some questions were of a personal nature, we explained on the front page that questions could be skipped if they made the participant uncomfortable. We also suggested on the front page that a questionnaire be completed in a number of short sittings, rather than all in one go. An online completion option was also made available, which around 10% of participants used.

Case Report Form (CRF) design

Our CRFs were designed to be as easy as possible to complete. We involved pilot site staff members in the design, as well as our tumour specific expert panels. A popular, online option for completing CRFs was available and most clinical data were returned this way. If a HORIZONS participant's clinical data had not changed between annual updates, minimal data entry was required by site staff, reducing the time taken to complete many CRFs. HORIZONS Coordinating Centre staff were available to help with any CRF queries.

3. Our Impact 2016 – 2022

Impact strategy

Our impact strategy is informed by the Payback Model⁴, which seeks to affect change across academic, health-sector (including people living with and beyond cancer), and policy domains. It is also informed by Macmillan's Research Strategy⁵, delivering evidence that transforms health care through an understanding of what constitutes effective personalised care, and empowers individuals through an understanding of the long-term impact of cancer and the development of interventions to build confidence to self-manage.

Publications

Since 2016, the CentRIC⁺ team (previously the MSRG) have published 63 papers related to cancer survivorship, patient experience and personalised care (Appendix B). 17 papers have been published in high-profile peer-reviewed journals for projects specifically delivered under the MSRG Contracts (HORIZONS, CREW, RESTORE and ENABLE) in the period 2016 – 2020 (Appendix B). We have worked creatively to generate diverse knowledge products, including accessible reports of key findings (e.g. CREW at 5 years) and policy briefings.

Presentations

The CentRIC⁺ team / MSRG have sustained a strong presence at national and international conferences. During the HORIZONS contract, there have been 108 presentations on CREW, HORIZONS, RESTORE and ENABLE, including 22 invited presentations (Appendix C).

Grants

Grants (including HORIZONS programme funding) totalling in excess of £12 million have been awarded to members of CentRIC⁺ / MSRG as lead or co-applicants since the start of the HORIZONS programme in 2016 (Appendix D).

Influencing health policy

Since 2016, our research evidence has informed policy directed at supported self-management and integrated personalised care. Findings from CREW have contributed to an evidence base that has shifted policy to personalised care, including UK-wide prehabilitation guidance for people with cancer published by Macmillan, the National Institute for Health Research and the Royal College of Anaesthetists published in July 2019.⁶ CREW data have also shaped the Wessex Cancer Alliance's five year plan: *Our Cancer Plan for Wessex, 2019-*

⁴ Raftery, J., S. Hanley, T. Greenhalgh, M. Glover and A. Blatch-Jones (2016). "Models and applications for measuring the impact of health research: update of a systematic review for the Health Technology Assessment programme." *Health technology assessment* **20**(76).

⁵ Macmillan Research Impact Framework: Macmillan Cancer Support. https://www.macmillan.org.uk/_images/macmillan-research-impact-framework_tcm9-324278.pdf.

⁶ Prehabilitation for People With Cancer, Macmillan Cancer Support (2019). <https://www.macmillan.org.uk/assets/prehabilitation-guidance-for-people-with-cancer.pdf>

2024, and had informed quality standards for developing, implementing and measuring self-management support in Ontario, Canada.⁷

Between 2020 - 2021, data from HORIZONS, CREW and ENABLE (ENABLE led by Calman, delivered through MSRG and funded by Macmillan's grant scheme) have been used to understand and respond to the impact of the COVID-19 pandemic. In April 2020, data from CREW and HORIZONS were used by Macmillan's Leadership Group to understand the impact of the pandemic, including the proportion of people with comorbidities likely to be affected by COVID-19. Findings were submitted to Macmillan's Strategy and Development Team and the Macmillan Policy team.

In 2021, Lynn Calman was invited by Prof Peter Johnson to sit on the COVID Recovery Psychosocial Support Task and Finish Group for the NHS Cancer Programme, following publication of ENABLE COVID-19 report. The remit of the Task and Finish Group was to assess the effect of the COVID-19 pandemic on psychosocial support for cancer patients, their families and unpaid carers. Membership of this group ensured that ENABLE, HORIZONS and related MSRG activity influenced strategy and policy at a national level.

In September 2021, MSRG submitted evidence to the UK Parliament Health and Social Care Committee call on cancer outcomes in England. In March 2022, the House of Commons Health and Social Care Committee released their 'Evaluation of the Government's commitments in the area of cancer services in England', With notable citations of MSRG findings including:

- the importance of CNSs in delivering personalised care
- the variation in quality of personalised care, e.g. through completion of HNAs
- the comorbidity findings from CREW
- the importance of assessing comorbidities as part of Personalised Care
- the prevalence and determinants of depression findings from CREW

The Panel's report was featured in the BMJ (doi: <https://doi.org/10.1136/bmj.o862>) and the Daily Mail on the 31st March 2022.

Influencing health services and Health Care Professional training

CentRIC⁺ is well positioned to influence health services and health care professional training. HORIZONS builds on our CREW cohort of colorectal cancer patients. Findings from CREW have transformed the configuration and delivery of cancer services in the UK. For example, findings informed *Improving Access to Cancer Nurse Specialists and Key Workers*,⁸ funded by the NHS England Cancer Patient Experience Team, which evaluated the impact of Band 4 Cancer Support Workers in supporting patients from the time of diagnosis. This led to workforce redesign across Wessex.

CREW data have also informed the piloting of innovative models of integrated, personalised care, delivered within Wessex and nationally, including Cancer Nursing Across Boundaries (funded by Health Education England, which delivered supportive cancer care in primary care settings) and Right by You (Wessex) (funded by Macmillan, which is deploying

⁷ Self-Management in Cancer: Quality Standards, Ontario, Canada (2018).(<https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/57371>).

⁸ Improving Access to Cancer Nurse Specialists and Key Workers (2019): www.england.nhs.uk/south-east/cancer-alliances/wessex/resources/

boundary-spanning Cancer Nurse Specialists and Cancer Support Workers to provide integrated holistic support across primary, secondary and community care settings).

CREW and HORIZONS data have been presented in numerous national and regional alliance webinars since 2020, including a national showcase of the MSRG in January 2021, and presentations on prehabilitation and rehabilitation to regional alliances, including the Suffolk and North East Essex Integrated Care System in April 2021.

Since 2016, data from CREW have informed the content of educational resources for health care professionals. These include Macmillan's 'Consequences of Treatment' study days for health care professionals from July 2020, and PROsPer, a Health Education England-funded project providing learning resources for Allied Health Professionals and the wider health and care workforce on prehabilitation and rehabilitation.

We will continue to influence health services and health care professional training with HORIZONS data and findings through our established networks.

Empowering people living with and beyond cancer

A core part of our research programme has been to develop innovative digital resources directly informed by our CREW and HORIZONS data to build cancer survivors' self-efficacy to manage consequences of cancer and its treatment. RESTORE is a freely available, theory driven, evidence-based resource on managing cancer-related fatigue for patients and health professionals. When promoted on Macmillan's Facebook channel at its launch in October 2019, it attracted 1,300 reactions, 114 comments and 209 shares. In February 2020, the Wessex Cancer Alliance cited RESTORE in their five-year plan as an important resource for supported self-management. It was highlighted online by the Patient Information Forum, Tameside and Glossop NHS Trust, South Warwickshire NHS Trust, North Wales Cancer Patient Forum and Peter MacCallum Cancer Centre, Australia. There is interest in adapting RESTORE-types resources for other cancer related problems. There is also significant international interest from academic institutions and cancer centres in Canada, Hong Kong, Australia, Switzerland and Malaysia. In August 2022, RESTORE formed part of a trial run in France which provides further testing of the resource.

In 2022, we received funding from Boehringer Ingelheim via Macmillan to develop an online resource to support psychological problems associated with living with and beyond cancer.

Comms / Media

Living with and beyond cancer and supporting people to do this well has generated significant media interest, as evidenced by media attention resulting from CREW and related research and service evaluations, with numerous prominent articles including the national press (the Times, the Express, The I). Prof Claire Foster recorded a podcast with George Allagiah for Bowel Cancer UK discussing the psychological impact of bowel cancer: <https://podcasts.apple.com/us/podcast/in-conversation-george-alagiah-bowel-cancer-uk-podcast/id1459296636>. In July 2021, our COVID-19 HORIZONS data informed part of Macmillan's press release on the impact of the pandemic on people living with and beyond cancer. This resulted in media coverage in the Daily Mail and the Evening Standard. The British Psychological Society invited Prof Claire Foster to participate in a webinar hosted by Dr Sian Williams in 2021 focussed on the impact of cancer on cancer survivors.

4. Future Steps / Plans

The MSRG was established at the University of Southampton in 2002 and has remained at the forefront of psychosocial research in cancer. In that time, we have identified research into the impact of cancer and its treatment on everyday lives as a high priority for people living with and beyond cancer. Our Colorectal Well-being Study (CREW) and HORIZONS have explored in detail the impact cancer and its treatment have on people from before treatment begins and up to five years later, assessing the implications this has for long-term health and well-being.

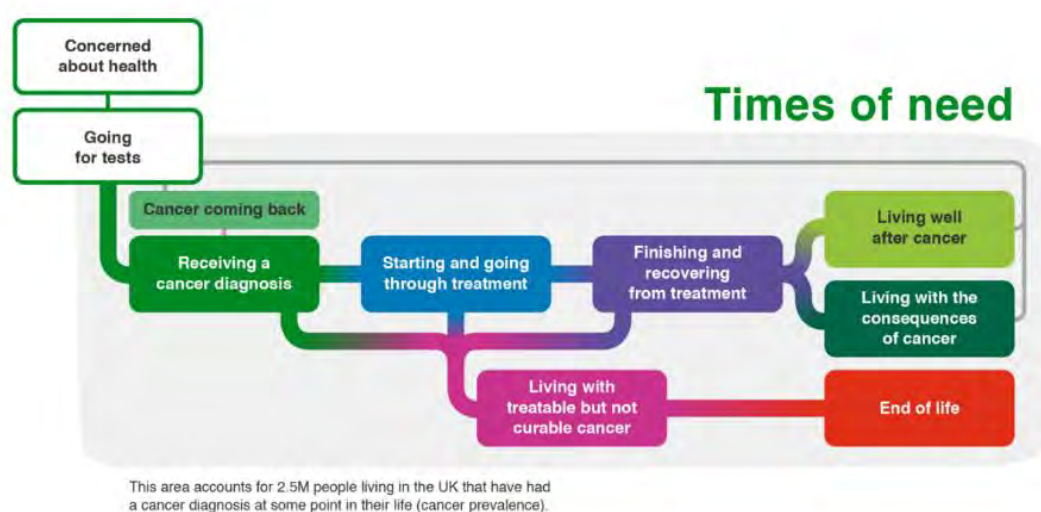
Our research focus has evolved to understand how the needs of people with cancer can be quickly identified and supported. We are co-creating and evaluating digital innovations to support cancer-related problems (including self-management and decision-making support) and evaluating how services can be configured to deliver integrated personalised care.

In March 2022, the MSRG was renamed Centre for Psychosocial Research in Cancer: CentRIC⁺. Renaming ourselves reflects the increasing range of our research and evaluation activities, the growing expertise of our team and our diverse funding streams. The CentRIC⁺ team will continue to collaborate with people living with cancer, health professionals, commissioners, policy makers, charities, cancer alliances, NHS England, Health Education England and others to provide the evidence needed to deliver patient-centred care.

Aligned with the Macmillan ‘times of need’ (figure 12), the work of CentRIC⁺ contributes to understanding and supporting people

- before they are diagnosed with cancer, when they are worried about their health or inherited cancer risk
- receiving a diagnosis and prehabilitation
- starting and going through treatment
- after treatment, and living well or living with consequences
- living with treatable but not curable cancer
- palliative/end of life

Figure 12: Macmillan’s Times of Need



Maximising the value of HORIZONS

HORIZONS data are an accessible resource and we are encouraging collaboration to ensure it is fully exploited. A growing number of teams are using HORIZONS information to explore important questions and we have agreement from the HORIZONS community to do this. The number of requests will increase significantly if we extend HORIZONS. The real value of HORIZONS is the capture of information over time and the potential to link to other datasets.

We are currently developing a costing model for analysis of the HORIZONS data. Potential clients include:

- Macmillan Cancer Support – undertaking discrete analyses and generating bespoke reports as required. (Analysis will require funding if is conducted by CentRIC⁺)
- Wessex Cancer Alliance / other UK Alliances – disseminating findings to affect change and potentially undertaking discrete analyses
- Developing resources informed by HORIZONS data – supporting people living with and beyond cancer to manage consequences e.g. RESTORE adaptations, mental health resource
- Developing resources in cancer genetics – patient facing decision support tools and integration into cancer care pathways (breast cancer, Lynch syndrome, template decision aid)

New governance structures will be created to support the delivery of CentRIC⁺ activities including a new User Reference Group and Strategic Advisory Group. These groups will be an important opportunity to ensure a diversity of representation and an international dimension to links.

Comms and data access post contract

Macmillan and CentRIC⁺ are recognised as partners in the development and publication of findings/outputs from HORIZONS research that has been funded by Macmillan Cancer Support. Both partners will agree to all publicity for Macmillan-funded research before release. Wherever possible, press releases will be developed in partnership and issued as a joint release. In the event of third-party involvement (e.g. in funding analyses conducted on Macmillan-funded research), publicity and press releases will be developed in partnership with Macmillan, CentRIC⁺ and the third party as appropriate.

Data held by CentRIC⁺ and collected through Macmillan-funded activity can be accessed by Macmillan via three routes:

1. Requesting remote access to data through CentRIC's Data Sharing policy (www.horizons-hub.org.uk/access_data.html)
2. Directly funding CentRIC⁺ to undertake analysis on behalf of Macmillan Cancer Support
3. Appropriately trained Macmillan staff can have access to data sets from Macmillan-funded research that have been cleaned and checked by CentRIC's statistician(s) or delegate, on an ongoing basis at the CentRIC⁺ site.

Intelligence from analyses will be categorised into:

- Tier 1: Highlights that will form the core of academic papers. This will be deemed sensitive until final academic publication. Intelligence from tier 1 will be deemed for 'in confidence

dissemination' and for internal use at Macmillan Cancer Support. Should Macmillan wish to make external use of data from Tier 1 intelligence, all material will be reviewed by CentRIC+ to ensure it is sufficiently different from any planned publication.

- Tier 2: All other information whose dissemination will not directly jeopardise a specific academic publication. This will be deemed suitable for proactive 'full dissemination'. CentRIC+ will ensure it is clear to staff, volunteers, users and the public when using research that Macmillan has funded that Macmillan was the funder of this research. Where activity involves a third party funding CentRIC+ to undertake analysis on data collected through Macmillan-funded research, it is agreed the acknowledgement will include Macmillan and the third party.

Acknowledgements

We thank all HORIZONS study participants and recruiting NHS trusts and boards; Faye Doyle, Amber Cole, Flavia Bellotto-Trigo, Helen Clegg, Hugh Hiscock, Laura Ingram, Ellysia Mason, Christine May, Joanna Oakley, Rebecca Petch, Bjoern Schukowsky, Nicola Scott, Nicole Tipler, Amber Wilson (study support); Sally Wheelwright, Victoria Bolton, Joshua Turner, Nicole Collaço, Amy Din, Chloe Grimmett, Joanne Haviland, Sebastian Stannard, Mubarak Patel, Natalia Permyakova, Samantha Sodergren, Sophia Taylor (researchers). Members of the Programme Management Group: Carl May, Alison Richardson, Anne Rogers and Peter Smith. Members of the Tumour Specific Expert Panel for the Gynaecological cancers cohort: Simon Crawford, Beryl Elledge, Alison Farmer, Emma Hudson, Raluca Nagy, Anne Lanceley, Eila Watson. Members of the Tumour Specific Expert Panel for the breast cancer cohort [NB some of them are already mentioned in the above]: Galina Velikova. Debbie Fenlon, Ramsey Cuttress, Diana Eccles, Ellen Copson, Diana Harcourt, Susan Stanway, Jill Noble, Angela McCullagh. Members of the Tumour Specific Expert Panel for the NHL cohort: Andy Davies, Gilly Howard-Jones, Simon Rule, Jemma Longley, Brooke Swash, Jackie Rafferty, Ian Danks, Charalampia Kyriakou. Members of the Study Advisory Board: Jo Armes, Dany Bell, Andy Davies, Anna Gavin, Rosie Loftus, Iain McNeish, Andy Ness, Alison Richardson, Lesley Smith, Peter Smith, Richard Stephens, Galina Velikova, David Weller and Jessica Corner. Members of the User Reference Group: Elspeth Banks, Beryl Elledge, Angela McCullagh, Tricia Moate, Raluca Nagy, Sue Natt, Jackie Rafferty, Janette Rawlinson, Susan Restorick-Banks, Stephen Scowcroft, Irene Soulsby, Richard Stephens, Lesley Turner. The Macmillan HORIZONS Programme was funded by Macmillan Cancer Support (ref: 3546834).

Appendix A: Matrix of Measures and questions in HORIZONS

(* denotes changes in measure – e.g. module(s)/items/questions/sub-scales added or removed; † denotes that questions/measures included are yet to be determined)

Measure / Question name <i>in alphabetical order</i>		Pilot Baseline	Pilot 3mo	Baseline	3mo	12mo	18mo	24mo	36mo	48mo†	60mo†
Quality of Life in Adult Cancer Survivors • <i>QLACS part 1</i> • <i>QLACS part 2</i>	QLACS	X	X	X	X	X*	X*	X*	X*	X*	X*
		X	X	X	X	X	X	X	X	X	X
						X	X	X	X	X	X
Body Image Scale <i>(see supplemental matrices, p.11, for more information)</i>	BIS	X	X	X	X	X		X	X		
Brief Illness Perception Questionnaire	B-IPQ; IPQ-B					X		X	X		
Caring responsibilities (for <18 y.o., others, yourself)		X		X			X				
Collective Efficacy of Networks Questionnaire	CENS								X		
Co-morbidities (List and impact on day-to-day tasks)		X		X				X	X		
Connor-Davidson Resilience Scale (2-item)	CD-RISC2	X	X	X	X	X		X	X		
European Organisation for Research and Treatment (EORTC) Quality of Life Questionnaire Core 30 items	QLQ-C30	X	X	X	X	X	X	X	X	X	X
Items from the EORTC QLQ Spiritual Well-being module: 22, 31 & 32	QLQ-SWB32	X		X							
EORTC-QLQ Breast cancer module	QLQ-BR23	X	X	X	X	X	X	X	X	X	X

Measure / Question name <i>in alphabetical order</i>		Pilot Baseline	Pilot 3mo	Baseline	3mo	12mo	18mo	24mo	36mo	48mo+	60mo+
EORTC-QLQ Breast Reconstruction module	QLQ-BRR24						X				
EORTC-QLQ Cervical cancer module	QLQ-CX24	X	X	X	X	X	X	X	X	X	X
EORTC-QLQ Endometrial cancer module	QLQ-EN24	X	X	X	X	X	X	X	X	X	X
EORTC-QLQ Non-Hodgkin's lymphoma high grade module	QLQ-NHL-HG29	X	X	X	X	X	X	X	X	X	X
EORTC-QLQ Ovarian cancer module	QLQ-OV28	X	X	X	X	X	X	X	X	X	X
EORTC-QLQ Vulval cancer module	EORTC-QLQ-VU34			X	X	X	X	X	X	X	X
EuroQoL 5 Dimensions 5 Levels & Visual Analogue Scale	EQ-5D-5L & VAS	X	X	X	X	X	X	X	X	X	X
Family history of cancer		X									
Family history of cardiac health							X				
Genetic testing for cancer		X									
Health literacy screening questions		X		X							
Health service use (Brief version)		X		X							
Health service use (Full version), travel costs & other expenses			X		X	X		X	X		
Hobbies, Interests & Supporting Others question [Social engagement]				X		X		X	X		
Hospital Anxiety and Depression Scale	HADS	X	X	X	X	X	X	X	X	X	X
Health Education Impact Questionnaire	heiQ™	X	X	X	X			X			

Measure / Question name <i>in alphabetical order</i>		Pilot Baseline	Pilot 3mo	Baseline	3mo	12mo	18mo	24mo	36mo	48mo+	60mo+
Medical Outcomes Study (MOS) – Social Support Survey	MOS-SSS	X	X	X	X	X	X	X	X	X	X
Menopause status				X			X				
Number of close friends & family		X	X	X	X	X		X	X		
Patient Activation Measure	PAM-13								X		
Patient Experience with Treatment & Self-Management	PETS		X		X	X	X	X*	X*		
Patient Roles and Responsibilities Scale	PRRS								X		
Personal Wellbeing Index (Adult)	PWI-A	X	X								
Posttraumatic Growth Inventory: Short Form	PTG-SF								X		
Program on Research for Integrating Services for the Maintenance of Autonomy	PRISMA-7						X				
Scale of Chemotherapy-Induced Neurotoxicity	SCIN						X		X		
Self-Efficacy for Managing Chronic Diseases & Cancer Survivors Self-Efficacy Scale	SEMCD	X	X	X	X	X	X	X	X	X	X
	CS-SES		X		X	X	X	X	X	X	X
The General Health Survey Questionnaire, Short Form 12 Ver 2.0	SF-12v2					X		X	X		
Supportive Care Needs Survey	SCNS-SF34					X		X	X		
Work and Social Adjustment Scale	WSAS		X		X	X	X		X		
Worry of Cancer Scale – Revised	WoC-R					X	X	X	X		

Measure / Question name <i>in alphabetical order</i>		Pilot Baseline	Pilot 3mo	Baseline	3mo	12mo	18mo	24mo	36mo	48mo+	60mo+
Social Network Mapping Tool (“Your Social Network” question)		X	X	X	X	X		X	X		
Lifestyle questions											
Alcohol intake self-assessment		X	X	X	X	X		X	X		
Body Mass Index	BMI	X	X*	X	X*	X*		X*	X*		
• Height (cm)		X		X							
• Weight (kg)		X	X	X	X	X		X	X		
Diet		X	X	X	X	X		X	X		
e-Cigarette use self-assessment		X	X	X	X	X		X	X		
Fruit & vegetable screening log		X	X	X	X	X		X	X		
Godin-Shephard Leisure-Time Exercise Questionnaire	LTEQ	X	X	X	X	X		X	X		
Information Needs Assessment (including lifestyle and other)			X		X	X		X	X		
Smoking self-assessment		X	X	X	X	X		X	X		
Strength & Resistance Exercise Measure		X	X	X	X	X		X	X		
Socio- demographic and-economic questions											
Accommodation type		X		X				X	X		
Age		X		X							
Car use/ownership		X		X							
Domestic/Marital Status		X		X			X		X		
Employment status		X		X		X		X	X		
Ethnicity		X		X							

Measure / Question name <i>in alphabetical order</i>		Pilot Baseline	Pilot 3mo	Baseline	3mo	12mo	18mo	24mo	36mo	48mo+	60mo+
Gender		X		X							
Highest level of education attained		X		X				X			
Household composition		X		X			X				
Internet / Online use		X		X							
Number of children (<18 years old) caring for				X			X				
Pre-tax (gross) salary / Income				X		X		X	X		
Receipt of benefits & pension				X		X		X	X		
Relationship status (supplement to Domestic status)							X		X		
Sexual orientation				X							
Sickness leave (number of days taken)				X		X		X	X		
Weekly hours worked				X		X		X	X		
Additional single EORTC items from EORTC item bank <i>(see supplemental matrices, p.8-10, for more information)</i>											
Aches & pains				X	X	X	X	X	X		
Burden of disease			X	X	X	X	X	X	X		
Burden of treatment					X	X	X				
Concern for fertility			X	X	X	X	X	X	X		
Changes in bowel habit (NHL specific)									X		
Changes in urinary habit: Frequency (NHL specific)									X		
Changes in urinary habit: urgency (NHL specific)									X		
Headaches				X	X	X	X	X	X		

Measure / Question name <i>in alphabetical order</i>		Pilot Baseline	Pilot 3mo	Baseline	3mo	12mo	18mo	24mo	36mo	48mo+	60mo+
Impact on work & education: Disruption			X	X	X	X	X	X	X		
Impact on work & education: Problems			X	X	X	X	X	X	X		
Leg lymphoedema (Ovarian specific)									X		
Peripheral Neuropathy				X	X	X	X	X	X		
Radiotherapy-specific adverse effects: Skin problems					X	X	X	X	X		
Symptoms of the menopause: Hot flushes				X	X	X	X	X	X		
Symptoms of the menopause: Night sweats				X	X	X	X	X	X		
Worry about future health			X	X	X	X	X	X	X		
Sexual function: Sexual activity				X	X	X	X	X	X		
Sexual function: Sexual enjoyment				X	X	X	X	X	X		
Sexual function: Sexual interest				X	X	X	X	X	X		
Sexual function: Sexual pain				X	X	X	X	X	X		
Sexual function: Vaginal dryness				X	X	X	X	X	X		
Sexual function: Vaginal shortening / stenosis				X	X	X	X	X	X		
Sexual function: Ejaculation problems				X	X	X	X	X	X		
Sexual function: Erectile dysfunction				X	X	X	X	X	X		
Sexual function: Ability to reach orgasm							X	X	X		
Open-ended questions											
Use of Complementary and Alternative Medicines (CAMs)			X		X	X		X	X		

Measure / Question name <i>in alphabetical order</i>		Pilot Baseline	Pilot 3mo	Baseline	3mo	12mo	18mo	24mo	36mo	48mo+	60mo+
Changes to lifestyle: alcohol intake, diet, smoking/e-Cigarettes, physical activity			X		X	X	X	X	X		
Experiences of self-management						X	X	X	X		
Changes to jobs and careers									X		
Life events		X	X	X	X	X	X	X	X	X	X
Anything else we ought to know?		X	X	X	X	X	X	X	X	X	X
Participant study feedback question		X	X					X			
Additional questions											
Follow-up mode of completion		X	X	X	X	X	X	X	X	X	X
Opinions on collection of saliva and blood samples		X									

Supplemental matrices of HORIZONS measures: EORTC additional items taken from the item bank/library

('+' denotes item included as part of cancer specific module, blank denotes equivalent item contained in the cancer specific module)

EORTC item	Question	Breast	Cervical	Endometrial	NHL	Ovarian	Vulval	Item Library Question Number
Aches & pains	Have you had aches or pains in your muscles or joints?	+	+				+	Q289 - aches pains muscles joints
Burden of disease	How much has your disease been a burden to you?	+	+	+	+		+	Q46 - burden disease patient
Burden of treatment	How much has your treatment been a burden to you?	+	+	+	+		+	Q47 - burden treatment patient
Changes in bowel habit (NHL specific)	Did you experience change in bowel habit as a result of your disease or treatment?	N/A	N/A	N/A	+		N/A	Q282 - change bowel habit
Changes in urinary habit: Frequency (NHL specific)	Have you passed urine frequently?	N/A			+	N/A		Q293 - urinate frequently
Changes in urinary habit: urgency (NHL specific)	When you felt the urge to pass urine, did you have to hurry to get to the toilet?	N/A	N/A		+	N/A		Q48 - hurry to toilet
Concern for fertility	If applicable: Have you been concerned about your ability to have children?	+	+	+		+	+	Q155 - worry fertility
Headaches	Did you have headaches?		+	+	+	+	+	Q127 - headaches
Impact on work & education: Problems	If applicable: Have you had problems at your work or place of study due to the disease?	+	+	+		+	+	Q369 - problem work/study
Impact on work & education: Disruption	If applicable: Have you worried about not being able to continue working or your education?	+	+	+		+	+	Q370 - worry continue work education

EORTC item	Question	Breast	Cervical	Endometrial	NHL	Ovarian	Vulval	Item Library Question Number
Leg lymphoedema (Ovarian specific)	Have you had swelling in one or both legs?	N/A			N/A	+		Q454 - swelling legs
Peripheral neuropathy	Have you had tingling or numbness in your hands or feet?	+					+	Q141 - tingling numbness fingers toes
Radiotherapy-specific adverse effects: Skin problems	Have you had skin problems (e.g. itchy, dry)?		+	+	N/A		+	Q142 - skin problems
Symptoms of the menopause: Hot flushes	Have you had hot flushes?			+	+		+	Q63 - hot flushes
Symptoms of the menopause: Night sweats	Did you have night sweats?	+		+	+		+	Q295 - night sweats
Worry about future health	Have you worried about your health in the future?		+	+			+	Q41 - worry health in future
Sexual function: Sexual activity	To what extent were you sexually active? (with or without intercourse)				+			Q74 – sexually active
Sexual function: Sexual enjoyment	To what extent was sex enjoyable for you?				+			Q84 – sexual activity enjoyable
Sexual function: Sexual interest / desire	To what extent were you interested in sex?				+		+	Q72 - interest in sex
Sexual function: Sexual pain	Have you had pain during sexual intercourse or other sexual activity?	+			+	+		Q89 – pain sexual activity

EORTC item	Question	Breast	Cervical	Endometrial	NHL	Ovarian	Vulval	Item Library Question Number
Sexual function: Vaginal dryness	Has your vagina felt dry during sexual activity?	+			+			Q472 – vagina dry sex
Sexual function: Vaginal shortening / stenosis	Has your vagina felt short and / or tight?	+			+	+		Q497 - vagina short tight
Sexual function: Ejaculation problems	Did you have ejaculation problems (e.g. dry ejaculation)	N/A	N/A	N/A	+	N/A	N/A	Q77 - problem erection
Sexual function: Erectile dysfunction	Did you have difficulty gaining or maintaining an erection?	N/A	N/A	N/A	+	N/A	N/A	Q78 - problem ejaculation
Sexual function: Ability to reach orgasm	Have you had a change in the ability to reach an orgasm since you received treatment for cancer?	+	+	+	+	+	+	Q85 - satisfaction reach orgasm

Body Image Scale (BIS) – Item appearance

('+' denotes BIS item included, blank denotes equivalent item contained in the cancer specific module)

Question	Breast	Cervical	Endometrial	NHL	Ovarian	Vulval	Equivalent EORTC item
Have you been feeling self-conscious about your appearance?	+	+	+	+	+	+	
Have you felt less physically attractive as a result of your disease or treatment?				+			BR23 item 9 CX24 item 15 EN24 item 17 OV28 item 20 VU34 item 18
Have you been dissatisfied with your appearance when dressed?	+	+	+	+	+	+	
Have you been feeling less feminine/masculine as a result of your disease or treatment?				+	+		BR23 item 10 CX24 item 16 EN24 item 18 VU34 item 19
Did you find it difficult to look at yourself naked?		+	+	+	+	+	BR23 item 11
Have you been feeling less sexually attractive as a result of your disease or treatment?	+	+	+	+	+	+	
Did you avoid people because of the way you felt about your appearance?	+	+	+	+	+	+	
Have you been feeling the treatment has left your body less whole?	+	+	+	+	+	+	
Have you felt dissatisfied with your body?			+	+			BR23 item 12 CX24 item 17 OV28 item 21 VU34 item 20
Have you been dissatisfied with the appearance of your scar?	+	+	+	N/A	+	+	

Appendix B: Publications (2016-Oct 2022)

Funded by the Macmillan programme

- 1 Vassilev I, Lin S, Calman L, et al. Sources of social network support for young women with breast cancer. PLoS One. (Accepted for publication)
- 2 Cummings A, Foster R, Calman L, Permyakova NV, Bridges J, Wiseman T, Corbett T, Smith PWF, Foster C. Quality of life and health status in older adults (≥ 65 years) up to five years following colorectal cancer treatment: Findings from the ColoREctal Wellbeing (CREW) cohort study. PLoS One. 2022 Jul 14;17(7):e0270033. doi: 10.1371/journal.pone.0270033.
- 3 Glasspool R, Wheelwright S, Bolton V, et al. Modifiable pre-treatment factors are associated with quality of life in women with gynaecological cancers at diagnosis and one year later: Results from the HORIZONS UK national cohort study. *Gynecologic Oncology*. 2022. Mar 26th. doi: 10.1016/j.ygyno.2022.03.012.
- 4 Calman L, Turner J, Fenlon D, et al. Prevalence and determinants of depression up to 5 years after colorectal cancer surgery: results from the ColoREctal Wellbeing (CREW) study. *Colorectal Disease*. 2021. doi: 10.1111/codi.15949.
- 5 Radcliffe E, Khan A, Wright D, et al. 'It feels it's wasting whatever time I've got left': A qualitative study of living with treatable but not curable cancer during the COVID-19 pandemic. *Palliat Med*. 202. doi: 10.1177/02692163211049497.
- 6 Invited blog for Bowel Cancer UK regarding psychosocial support during the pandemic for people with bowel cancer (published 10 May)
- 7 'I kept thinking that I will feel better soon', The Psychologist, invited article (published 8 Jun) <https://thepsychologist.bps.org.uk/i-kept-thinking-i-will-feel-better-soon>
- 8 Frankland J, Wheelwright S, Permyakova NV, et al. Prevalence and predictors of poor sexual well-being over 5 years following treatment for colorectal cancer: results from the ColoREctal Wellbeing (CREW) prospective longitudinal study. *BMJ Open* 2020;10:e038953.
- 9 Archer S, Holch P, Armes J, Calman L, Foster C, et al. "No turning back" Psycho-oncology in the time of COVID-19: Insights from a survey of UK professionals. *Psychooncology*. 2020 Sep;29(9):1430-1435. Wheelwright, S, Permyakova, NV, Calman, L, Din, A, Fenlon, D, Richardson, A, Sodergren, S, Smith, PWF, Winter, J, Foster, C, & Members of the Study Advisory Committee (2020). Does quality of life return to pre-treatment levels five years after curative intent surgery for colorectal cancer? Evidence from the ColoREctal Wellbeing (CREW) study. *PLOS ONE*, 15(4), e0231332. doi:10.1371/journal.pone.0231332
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- 11 Sodergren SC, Wheelwright S J, Permyakova NV, Patel M, Calman L, Smith PWF, Din A, Richardson A, Fenlon D, Foster C (2019). Supportive care needs of patients following treatment for colorectal cancer: risk factors for unmet needs and the association between unmet needs and health-related quality of life—results from the ColoREctal Wellbeing (CREW) study. *Journal of Cancer Survivorship*. pp1-11. DOI: 10.1007/s11764-019-00805-6
- 12 Cummings A, Grimmett C, Calman L, Patel M, Permyakova NV, Winter J, Corner J, Din A, Fenlon D, Richardson A, Smith PWF, Foster C (2018). Comorbidities are associated with poorer quality of life, functioning and worse symptoms in the 5 years following colorectal cancer surgery: Results from the ColoREctal Wellbeing (CREW) cohort study. *Psycho-Oncology*, 27(10):1-9. DOI: 10.1002/pon.4845
- 13 Foster C, Calman L, Richardson A, Pimperton H, Nash R (2018). Improving the lives of people living with and beyond cancer: Generating the evidence needed to inform policy and practice. *Journal of Cancer Policy*, 15(B): 92-95. DOI: 10.1016/j.jcpo.2018.02.004

- 14 Grimmett C, Haviland J, Winter J, Calman L, Din A, Richardson A, Smith PWF, Foster C (2017). Colorectal cancer patient's self-efficacy for managing illness-related problems in the first two years after diagnosis, results from the Colorectal Wellbeing (CREW) study. *Journal of Cancer Survivorship*, 11(5):634-642. DOI: 10.1007/s11764-017-0636-x
- 15 Haviland J, Sodergren S, Calman L, Corner J, Din A, Fenlon DR, Grimmett C, Richardson A, Smith PWF, Winter J, Foster C (2017). Social support following diagnosis and treatment for colorectal cancer and associations with health-related quality of life: results from the UK Colorectal Wellbeing (CREW) cohort study. *Psycho-Oncology*, 26:2276-2284. DOI: 10.1002/pon.4556
- 16 Foster C, Grimmett C, May CM, Ewings S, Myall M, Hulme C, Smith PWF, Powers C, Calman L, Armes J, Breckons, M, Corner J, Fenlon D, Batehup L, Lennan E, May C, Morris C, Neylon A, Ream E, Turner L, Yardley L, Richardson A (2016) A web-based intervention (RESTORE) to support self-management of cancer-related fatigue following primary cancer treatment: a multi-centre proof of concept randomised controlled trial. *Supportive Care in Cancer*, 24(6):2445-53 (published online first on 16 December 2015). DOI:10.1007/s00520-015-3044-7
- 17 Foster C, Haviland J, Winter J, Chivers-Seymour K, Batehup L, Calman L, Corner JL, Din A, Fenlon, DR, Ma, C, Richardson, A, Smith, PWF (2016) Pre-surgery depression and confidence to manage problems predict recovery trajectories of health and wellbeing in the first two years following colorectal cancer: results from the CREW cohort study. *PLOS ONE*, 11(5):e0155434. DOI: 10.1371/journal.pone.0155434

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1. Wright D, Gabbay J, Le May A. Determining the skills needed by frontline NHS staff to deliver quality improvement: findings from six case studies. *BMJ Qual Saf*. 2022 Jun;31(6):450-461. doi: 10.1136/bmjqs-2021-013065.
2. Corbett T, Cummings A, Lee K, Calman L, Fenerty V, Farrington N, Lewis L, Young A, Boddington H, Wiseman T, Richardson A, Foster C, Bridges J (2020). Planning and optimising CHAT&PLAN: a conversation-based intervention to promote person-centred care for older people living with multimorbidity *PLOS ONE* (in press)
3. Corbett T, Cummings A, Calman L, Farrington N, Fenerty V, Foster C, Richardson A, Wiseman T, Bridges J (2020). Self-management in older people living with cancer and multi-morbidity: A theory-led systematic review and synthesis of qualitative studies. *Psycho-Oncology* (in press)
4. Schmitz K, Stout N, Maitin-Shepard M, Campbell A, Schwartz A, Grimmett C, Meyerhardt J, Sokolof J (2020) Moving Through Cancer: Setting the agenda to make exercise standard in oncology practice. *Cancer*, 2020, DOI: 10.1002/cncr.33245 (in press)
5. Grimmett C, Foster C, Bradbury K., Lally P, May C, Myall M, Pinto B, Corbett T (2020) Exploring maintenance of physical activity behaviour change among people living with and beyond gastrointestinal cancer: A cross-sectional qualitative study and typology. *BMJ Open*, 2020, (in press)
6. Sodergren S, Wheelwright S, Fitzsimmons D, Efficace F, Sprangers MAG, Fayers PM, Harle A, Schmidt H, Bottomley A, Darlington A, Benson C, Bredart A, Hentschel L, Arraras JJ, Ioannidis G, Rohde G, Vassiliou V, Johnson C (2020) On behalf of the EORTC Quality of Life Group Developing symptom lists for people with cancer treated with targeted therapies. *Targeted Oncology* (in press).
7. Archer S, Holch P, Armes J, Calman L, Foster C, Gelcich S, MacLennan S, Absolom K. "No turning back" Psycho-oncology in the time of COVID-19: Insights from a survey of UK professionals. *PsychoOncology*. 2020; 29: 1430– 1435. <https://doi.org/10.1002/pon.5486>
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Cancer, Management of cancer and health after the clinic visit: A call to action for self-management in cancer care. Journal of the National Cancer Institute.
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11. Calman L, Radcliffe E, Berman R, Demain S, Restorick-Banks S, Richardson A, Wagland R, Foster C (2020). The ENABLE study protocol: Understanding and characterising the value and role of self-management support for people living with cancer that is treatable but not curable. *European Journal of Cancer Care*. 00:e13217. DOI:10.1111/ecc.13217
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Appendix C: Presentations

Invited presentations

1. Jun 2021: BPOS / BPS webinar. Psycho-Oncology during and beyond the COVID-19 pandemic: Where do we go from here?
2. IPOS, Christie Essentials in Palliative and End of Life Care Course, BPOS Webinar 2021 (ENABLE)
3. May 2021: BPS invited paper and participation in invited webinar on cancer survivorship
4. February 2021: IPOS. Webinar: e-health and cancer survivors,
5. Jan 2021: UKONS Sexual Health and Cancer Educational Event. Sexual Wellbeing among people living with and beyond cancer: findings from the Macmillan ColoRectal Wellbeing (CREW) cohort study.
6. Dec 2020: Seminar: Digital support in cancer survivorship (Hong Kong)
7. Nov 2020: Invited session chair. Harnessing Patient-Reported Outcomes (PROs) to optimise care for people living with and beyond cancer'. 2020 NCRI Cancer Conference. Belfast, UK
8. Feb 2020: Invited speaker. Psycho-Oncology and PROMs. Irish Association for Cancer Research 2020 Annual Cancer Conference, Galway, Ireland
9. Nov 2019: Invited keynote speaker. Advancing Comprehensive Cancer Care. 5th Victorian Comprehensive Cancer Centre (VCCC) Psycho-Oncology Conference, Melbourne, Australia
10. Apr 2019: Invited speaker and workshop host. 2019 NCRI and NHS England Living With and Beyond Cancer event, Manchester, UK
11. Mar 2019: Invited keynote speaker. 16th Annual Psychology, Health & Medicine Conference, Maynooth University, Maynooth, County Kildare, Ireland
12. Nov 2018: Invited session chair. E2 eHealth (free papers). 20th International Psycho- Oncology Society World Congress of Psycho-Oncology (IPOS 2018), Hong Kong
13. Mar 2018: Conference host. British Psychosocial Oncology Society – Annual Conference, Southampton, UK
14. Feb 2018: Invited symposium host. Promoting self-efficacy with digital tools. National Strategy against Cancer International Symposium, Bern, Switzerland
15. Jun 2017: Invited member of Delphi Group. To set international quality standards for care of men with prostate cancer. TruNTH/Prostate Cancer Outcomes International meeting, Vancouver, Canada
16. Feb 2017: Invited speaker. Challenges of surviving cancer. Royal College of Physicians of Edinburgh Medical Trainees' Conference, Newcastle Upon Tyne
17. Nov 2016: Invited symposium host. The changing face of cancer follow up – supported self-management. NCRI Cancer Conference, Liverpool
18. Oct 2016: Invited panel participant. Psychosocial support in practice: Who cares? EONS/IPOS Symposium, Dublin
19. Oct 2016: Invited symposium participant. Maximising the value of large scale surveys of cancer survivors. 18th International Psycho Oncology Society Congress, Dublin
20. Oct 2016: Invited speaker. The role of self-efficacy in recovering following a cancer diagnosis and treatment. European Oncology Nursing Society (EONS) 10, Dublin
21. June 2016: Invited participant. How can people with MS be best supported to self- manage their condition? – a roundtable discussion. MS Society
22. Mar 2016: Invited speaker. Meeting the challenges of survivorship by focusing on self-management. 2nd EORTC Cancer Survivorship Summit, Brussels

Proffered papers

- European Sociological Association Conference, August 2021. 'It feels it's wasting whatever time I've got left': Emotional work and living with treatable but not curable cancer during the COVID-19 pandemic. Radcliffe E, Khan A, Berman R, et al.
- IPOS 22nd Annual World Progress, 26 – 29 May 2021. [Three oral abstracts]
- NCRI Virtual Showcase, 2nd - 3rd November 2020 [two Oral Presentations, two posters]. Invited chair. Harnessing Patient-Reported Outcomes (PROs) to optimise care for people living with and beyond cancer'.
- UK Oncology Nursing Society Annual Conference November 2020 (One oral presentation)
- Virtual UK Oncology Forum Programme, Sept 2020 [one Oral Presentation].
- Irish Association for Cancer Research Annual Cancer Conference, Feb 2020, Galway, Ireland, Invited speaker. Psycho-Oncology and PROMs.
- British Thoracic Oncology Group (BTOG) January 2020 (One invited oral presentation)
- British Association of Sport and Exercise Science (BASES) Nov 2020 (one invited oral presentation)
- Evidence Based Perioperative Medicine (EBPOM) July 2020. (One invited oral presentation and discussant panel member)
- World Cancer Prehabilitation Conference. June 2019. (One invited oral presentation).
- European Congress on Obesity, Cancer Satellite Meeting. April 2019 (One invited oral presentation)
- International Society of Behaviour Nutrition and Physical Activity. June 2019. Accepted symposia and poster presentation
- Perioperative Exercise Testing and Training Society – Annual Scientific Meeting. (One invited oral presentation).
- UK Oncology Nursing Society Annual Conference November 2019 (One oral presentation)
- British Association of Surgical Oncology (BASO) November 2019 (One oral presentation – won best multi-disciplinary oral presentation prize)
- 12th Cachexia Conference, December 2019, Berlin, Germany [two Poster Presentations].
- 5th Victorian Comprehensive Cancer Centre (VCCC) Psycho-Oncology Conference, Melbourne, Australia, Nov 2019: Invited keynote speaker. Advancing Comprehensive Cancer Care
- EORTC Quality of Life in Clinical Trials Conference, Brussels, Belgium, May 2019: Invited speaker.
- NCRI and NHS England Living With and Beyond Cancer event, April 2019, Manchester, UK, Invited speaker and workshop host
- 16th Annual Psychology, Health & Medicine Conference, Mar 2019, County Kildare, Ireland Invited keynote speaker.
- Wessex Macmillan Conference, 20th March 2019, Southampton [two Oral Presentations]
- British Psycho-Oncology Society, 28th February 2019, [one Oral Presentation and two Poster Presentations].
- UKONS, 16th November 2018, Glasgow [one Poster Presentation].
- NCRI Cancer Conference, 4th November 2018, Glasgow [three Poster Presentations, one of which was HORIZONS]
- IPOS, 30th October 2018, Hong Kong [one Oral Presentation, one Poster Presentation. Poster presentation was on HORIZONS.]
- ECRS, 10th September 2018, Copenhagen [one Oral Presentation, one Poster Presentation. Poster presentation was on HORIZONS]
- Peri-operative Exercise Testing & Training Society, 6th July 2018, London [one invited Oral Presentation]

- Developing Effective Cancer Survivorship Services, 2nd July 2018, London [one Oral Presentation]
- MASCC, 28th June 2018, Vienna [three Poster Presentations]
- PHE Cancer Services, data and outcomes Conference, 20th June 2018, Manchester [one Oral Presentation, one Poster Presentation]
- Southampton Medical and Health Research Conference, 6th June 2018, Southampton [three Oral Presentations, four Poster Presentations. One Oral Presentation on HORIZONS.]
- British Psycho-Oncology Society, 8th March 2018, Southampton [two Oral Presentations and one Poster Presentation. One Oral Presentation was on HORIZONS. Southampton was the host.]
- Cancer Survivorship Summit- Improving outcomes for people living with and beyond cancer, 23rd February 2018, Birmingham [One Oral Presentation].
- Promoting Self-efficacy with digital tools, 8th February 2018, Bern, Switzerland [one Oral Presentation.]
- British Psychosocial Oncology Society (BPOS) Annual Conference, 16th-17th March 2017, Oxford [Poster Presentation]
- 2017 Annual Scientific Meeting of the BGCS, 15th-16th June 2017, Glasgow [Poster presentation]
- Scientific Conference 2017, 11th-13th July 2017, University of Essex
- NCRI Supportive and Palliative Care CSG Trials meeting, 25th September 2017, London [Presentation: Cancer survivorship and late consequences, Dr Lynn Calman]
- Lymphoma Association CNS Masterclass, 28th September 2017, Crewe [Masterclass: HORIZONS: a cohort study to explore recovery of health and well-being in adults diagnosed with cancer, Dr Josh Turner and Dr Becky Foster]
- The 10th Annual Royal Marsden Breast Cancer Meeting, 6th October 2017, London
- Haematology Nurse Forum, 3rd November 2017, London [Presentation HORIZONS: a cohort study to explore recovery of health and well-being in adults diagnosed with cancer, Dr Lynn Calman]
- NCRI Cancer Conference, 5-8th November 2017, Liverpool
- NCRI Non Hodgkin Lymphoma CSG Trials meeting, 6th November 2017, London
- The Royal Marsden Gynaecology Cancer Study Day, 22nd November 2017, London
- NCRI Gynaecological Oncology Clinical Studies Group Trials meeting, 30th November 2017, London [Presentation HORIZONS: a cohort study to explore recovery of health and well-being in adults diagnosed with cancer, Dr Lynn Calman]
- Royal College of Physicians of Edinburgh Medical Trainees' Conference, Feb 2017, Newcastle Upon Tyne, Invited speaker. Challenges of surviving cancer.
- Wessex Oncology Nurses Study day, 1st December 2017, Southampton
- NCRI Cancer Conference, Nov 2016, Liverpool, Invited symposium host. The changing face of cancer follow up – supported self-management.
- EONS/IPOS Symposium, Oct 2016, Dublin. Invited panel participant. Psychosocial support in practice: Who cares?
- European Oncology Nursing Society (EONS), Oct 2016, Dublin, Invited speaker. The role of self-efficacy in recovering following a cancer diagnosis and treatment.
- MS Society, June 2016, Invited participant. How can people with MS be best supported to self manage their condition? – a roundtable discussion.
- 2nd EORTC Cancer Survivorship Summit, Mar 2016, Brussels. Invited speaker. Meeting the challenges of survivorship by focusing on self-management.

- International Psycho Oncology Society (IPOS) Congress, 17-21 October 2016, Dublin: HORIZONS was presented at a symposium Chaired by Professor Claire Foster entitled 'Maximising the value of large scale surveys of cancer survivors'.

Appendix D: Grants

Bohringer Ingelheim / Macmillan Cancer Support, 2022-2023. Calman, Foster. <i>Content development for the Oncology Wellbeing Project: "Taking Cancer on" – the psychological challenges faced by cancer patients</i>	£326,000
NHS England, 2022-2023. Wright, Calman, Foster. <i>The Wessex Cancer Alliance Personalised Care and Support Assessment and Planning Project</i>	£89,642
Wessex Cancer Alliance, 2021-2023, Wright, Frankland, Calman, Foster. <i>Communities Against Cancer: A Qualitative Evaluation</i>	£50,000
NHS England, 2021-2023, Wright, Lippiett, Richardson, Calman, Foster. <i>Right by You Integrated (Wessex). As service evaluation</i>	£170,805
Macmillan Cancer Support, 2021-2022, Wright, Grimmett, Calman, Foster. <i>PROsPer (Pre/Rehabilitation and Personalised Care): Evaluation of an education intervention</i>	£20,000
NHS England, 2019-2020, Wright, Lippiett, Collaço, Calman, Foster, PAM evaluation	£70,000
Health Education England, 2019-2020, Foster, Richardson. <i>Evaluation of an outreach model from acute cancer nursing teams to support primary and community care</i>	£128,000
Cancer Research UK, 2019-2024, Eccles, Foster. <i>CANGENE-CANVAR: data resources, clinical and educational tools to leverage cancer susceptibility genetics for prevention and early detection of cancer</i>	£4,109,522
Marie Curie and the Motor Neurone Disease Association, 2018-2021, Wheelwright, Recio-Saucedo, McDermott, Foster, Hogden, Morrison, Hall. <i>Development and pilot testing of a web-based decision aid for people with motor neurone disease considering a gastrostomy</i>	£193,153
Tenovus Cancer Care, 2018-2019, Hopkinson, Elias, Morgan, Russell, Wheelwright. <i>eat-CIT: an investigation to inform the content of a web-based resource to help people with cancer self-manage eating difficulties during chemotherapy and/or immunotherapy (systemic anti-cancer) treatment</i>	£29,924
Macmillan Cancer Support, 2018-2021, Calman, Foster, Richardson, Restorick- Banks, Wagland, Demain. <i>Understanding and characterising supported self- management in the context of cancer which cannot be cured</i>	£246,863
Movember Foundation, 2017-2020, Foster, Moore, Brodie. <i>Movember TrueNTH Global Registry- Prostate Cancer Outcomes</i>	£509,547
Diamond Jubilee International Visiting Fellowship Award for Associate Professor Claire Wakefield, 2016-2019, Foster and Darlington	£15,000
Macmillan Cancer Support, 2016-2020, Foster, Calman, Corner, Haviland, May, Richardson, Rogers, Smith. <i>Macmillan HORIZONS Programme</i>	£2,407,003
Wessex Cancer Alliance, Recovery Package Transformation Funding, 2017-2020, Jack Grocott, Levett, Grimmett, Wotton, Hayes et al. <i>Wessex Fit-4-Cancer Surgery Trial (WesFit)</i>	£1,300,000
National Institute for Health Research, 2016-2021. Little, Geraghty, Stuart, Foster, Leydon, Yao, Rathod, Richardson, Wilkinson, Boehning, Eccles, Watson, Lewith, White, Neal, Yardley. <i>Life Affirming Survivorship support in Primary care (CLASP) Programme</i>	£2,499,011