Patient Reported Outcomes of Cancer Survivors in England 1 to 5 years after Diagnosis: a cross-sectional survey.

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2012-002317
Article Type:	Research
Date Submitted by the Author:	06-Nov-2012
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Primary Subject Heading:	Oncology
Secondary Subject Heading:	Health policy, Public health, Research methods
Keywords:	Adult oncology < ONCOLOGY, Breast tumours < ONCOLOGY, Gastrointestinal tumours < ONCOLOGY, Lymphoma < ONCOLOGY, Urological tumours < ONCOLOGY

Title:

Patient Reported Outcomes of Cancer Survivors in England 1 to 5 years after Diagnosis: a cross-sectional survey.

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Key Words:

Cancer, Survivorship, Quality of Life, Patient Reported Outcomes, EQ5D, FACT

Word Count:

abstract: 300 & main body of paper: 3994

Abstract

Objectives: To determine the feasibility and value of patient reported outcome measures (PROMS) in assessing quality of life (QoL) to inform the development of a national PROMS programme for cancer.

Design: Cross-sectional postal survey of cancer survivors using a population-based sampling approach.

Setting: English National Health Service.

Participants: 4,992 breast, colorectal, prostate and Non-Hodgkin's Lymphoma survivors one to five years from diagnosis.

Primary and Secondary Outcome Measures: Implementation issues, response rates and cancer-specific morbidities utilising items including the EQ5D QoL scale, tumour-specific sub-scales of the Functional Assessment of Cancer Therapy and Social Difficulties Inventory.

Results:

3,300 (66%) survivors invited to participate returned completed questionnaires. The majority aged 85+ years did not respond and there was an effect of deprivation on response rates. Response rates did not differ by gender, time since diagnosis or cancer type.

The presence of one or more long term conditions was associated with significantly lower QoL scores. Individuals from the most deprived areas reported lower QoL scores and poorer outcomes on other measures, as did those self-reporting recurrent disease or uncertainty about disease status. QoL scores were stable over time for all cancers except NHL. Overall QoL scores were lower than those from the general population in the Health Survey for England (2008) and General Practice Patient Survey.

47% of patients reported fear of recurrence whilst 20% reported moderate or severe difficulties with mobility or usual activities. Bowel and urinary problems were common among colorectal and prostate patients. Poor bowel and bladder control were significantly associated with lower QoL scores.

Conclusions: This method of assessing QoL of cancer survivors is feasible and acceptable to most survivors. Inclusion of PROMS as a routinely collected health dataset will enable identification of, and support for, the specific needs of survivors whilst allowing for comparison of outcome by service provider.

Funding

This survey was funded by the Department of Health, England.

Article Summary

Article Focus

To determine the feasibility of routinely collecting population-based patient reported outcomes (PROMS) of cancer survivors to gather information on quality of life and cancer related morbidities that can be used to inform the development of a national PROMS programme for cancer.

Key messages

- Collection of information on quality of life from cohorts of cancer patients who are 1 to 5 years post diagnosis through cancer registries is feasible.
- The best quality of life was reported by those in remission and with no other long term conditions.
- This information will enable health economies to compare outcome across provider organisations and facilitate provision of services to meet the needs of cancer survivors.

Strengths and Limitations

- Findings relate to the largest European survey of survivors of multiple cancer types at clearly defined time points from diagnosis.
- The study design eliminates many of the criticisms which have hindered the collection of population-based cancer patient reported outcome data in the past.
- English cancer registries provide a reliable denominator population from which to identify eligible participants.
- The questionnaires for the four cancer groups were identified as having face and content validity by a panel of health and social care professionals prior to use.
- Presence of multiple cancer groups, time points and some missing data may have resulted in a lack of power for certain analyses.
- Selection bias may have arisen through differences in-response rates according to cancer group, deprivation category and age.

- The study excluded those treated in the private sector.

Introduction

1.8 million people are living with and beyond a diagnosis of cancer in England and prevalence is predicted to increase by 3% per annum.[1] Cancer treatments are effectively reducing mortality and extending life, yet there is evidence that physical, psychological and social needs are not being addressed by the health and social care services, with individuals reporting significant unmet needs[2]. There is a lack of robust population-based information from which the prevalence, and impact, of disease and treatment associated morbidity burden can be ascertained and policy for appropriate interventions developed[3]. It has been equally difficult for health economies to compare the quality of health of those following treatment for cancer to those living with other long term conditions (LTC). These deficits have hampered the provision of comprehensive robust services for this growing population[4].

In the United States a number of significant initiatives have been launched to systematically measure health outcomes in cancer survivors using patient reported outcome measures (PROMS) through the National Cancer Institute and American Cancer Society[3 5-6]. In Europe, at least one regional cancer register has started to collect PROMS via approaches made through the treating clinical teams[7-8] . The focus of PROMS work to date has been on refining treatment decision making for individuals and determining methodological approaches to implementation and analysis[5-6 9-11]. These efforts have yet to feed through into major national health system service improvement initiatives. The evaluation of patients' experiences of cancer care in England, through the National Cancer Patient Experience Survey, has resulted in care provider organisations and commissioners being able to identify areas of strengths and weakness in acute cancer care provision[12].

Our objective was to determine the feasibility of routinely collecting population-based PROMS of cancer survivors to gather information on quality of life (QoL) and cancer related morbidities that can be used to inform the development of a national PROMS programme for cancer.

Methods

Study design

A cross-sectional postal survey was undertaken of individuals with a diagnosis of breast, colorectal, non-Hodgkin's lymphoma (NHL) or prostate cancer one, two, three and five years earlier. These four time-points were chosen to gain an understanding of whether PROMS varied over time. Patients attending private healthcare centres were excluded as the aims of the study focused on the assessment of PROMS within the National Health Service (NHS) in England.

Cohort Identification and Survey Process

Three cancer registries (Thames Cancer Registry, Eastern Cancer Registry and Information Centre, West Midlands Cancer Intelligence Unit) were chosen as representative examples of the eight cancer registries in England. They provided information on all relevant cancer diagnoses[12] (Supplementary File 1) between 01/02/2010-30/04/2010, 01/02/2009-30/04/2009, 01/02/2008-30/04/2008, and 01/02/2006-30/04/2006. The individual study cohorts for each cancer at time points one, two, three and five years from date of recorded diagnosis were compiled through identification of the 312 cases diagnosed most closely to a specified time-point (First of February for each year). Cases were excluded if: under the age of 16 years, deceased, or not known to have a UK address.

Identified participants were sent a questionnaire by post by the survey provider, *Quality Health*. This was sent under cover of a standard introductory letter with the letter-head of the cancer centre most recently recorded by the cancer registry as having provided treatment. The survey covered patients attending 70 of 160 (43%) acute NHS Trusts delivering cancer care in England during 2011. Patients consented to taking part in the survey by returning questionnaires and declined by not returning them, or by returning blank questionnaires. Two reminders were sent to non-responders. Checks for deceased patients were undertaken by the registries via the Demographic Batch Service at four separate time points in the survey process.

Details of a dedicated freephone telephone helpline, staffed 24 hours each day, were provided.

Questionnaire design and content (Supplementary files 2, 3, 4 and 5)

Questionnaires were developed for each cancer group. Content was identified through literature review, commissioned expert reviews[13-15], consultation with patient groups, cancer charities and expert advisory groups.

Generic content included:

- Demographic and treatment-related questions adapted from the National Cancer Patient Experience Survey.[12]
- Self-reported response to treatment and disease status
- Amount of physical activity performed each week quantified according to the Chief Medical Officer of England's recommendations[16].
- Presence or absence of long-term conditions (LTCs) other than cancer, using a list widely used in English Department of Health surveys.
- EQ5D: A 5 item generic health-related quality of life measure[17-18] chosen as it is a generic measure of health status widely used to evaluate population health in England[17].
- Social Difficulties Inventory (SDI): A cancer survivor specific measure covering wider QoL domains[19-20,21] including information on the social consequences of cancer.
- Experience of care.[22]
- Individual components on psychological issues and work status identified through the literature as being important to cancer survivors but not covered by other components of the survey[23], [24].

Tumour-specific content included

- Functional Assessment of Cancer Therapy (FACT) tumour specific components (FACT-B, FACT-C , FACT-Lym and FACT-P for breast, colorectal, NHL and prostate cancer respectively)[25].

A detailed description of the qualitative comments provided by respondents are reported in a parallel submission to the BMJ.

Cognitive testing was performed on the four site-specific versions of the questionnaire prior to their general use. This was done by sending questionnaires to volunteers (identified through cancer charities and the survey provider) prior to participating in a telephone interview. This style of testing was used to determine the population's ability to complete the questionnaire independently and to follow routing and other instructions in the questionnaire without prompting or help. Appropriate alterations were then made to the questionnaire. The two required changes were omission of a similar item from the FACT-B and FACT-P questionnaires *"I am able to feel like a woman"* and *"I am able to feel like a man".*

Data Handling/Analysis

Age (at time of survey) was categorised as <55, 55-64, 65-74, 75-84, and ≥85 years. Self-reported ethnicity was grouped into white, asian, mixed, black and other. Deprivation category was based on the complete index of multiple deprivation (IMD)[26]. This was derived from the lower super output area (small census area) associated with their place of residence at the time of completing the survey, and used because the survey did not include questions related to income or educational level.

Participants were asked if they had any LTC other than their cancer diagnosis and were asked to tick the appropriate LTCs. This variable was categorised into 'no other', 'one other' and 'two or more LTCs'.

A crosswalk algorithm was used to convert the 5L EQ5D to the 3L version, allowing a weighted health score to be assigned for each individual.[27] United Kingdom population data were used to calculate weighted scores (range -0.5 to 1 [perfect health]). Due to skewness, this outcome variable was categorised and ordered logistic regression undertaken. Three categories representing 'high', 'medium' and 'low' QoL scores were defined for ease of interpretation; these comprised scores equal to 1, less than 1 but greater than or equal to 0.5 and less than 0.5. Odds ratios should be interpreted either as the odds of being in group

2 (medium QoL scores) or group 3 (low QoL scores) compared to group 1 (high QoL scores) *or* the odds of being in group 3 (low QoL scores) compared to group 1 or group 2.

Cancer-specific questions from FACT[25] were used as explanatory variables in this analysis (FACT total score could not be calculated as only the cancer-specific subscale questions were included). Patient reported treatments were used in the analyses and treatment combinations were categorised for each cancer site with the most common used as the reference group.

Statistical methods

Chi-squared tests were used to compare categorical variables. Descriptive statistics were compared across cancer sites but the statistical models were stratified by cancer site. Variables were entered into the logistic regression model based on their *a priori* clinical and public health importance after agreement by the study investigators. Formal variable selection procedures were not invoked primarily due to statistical problems associated with these data-driven procedures[28] and, secondly, so that findings could be compared consistently across cancer sites and time points. Statistical significance was set at 1% to minimise the chances of false-positive associations. All analyses were undertaken using STATA v12.1.

Ethics and governance

Approval was given to approach patients without informed consent by the National Information Governance Board (Supplementary File 6) as the study was performed as service evaluation[29].

Results

Participants

Questionnaires were sent to 4992 individuals, 126 (2·5%) of these had moved or died prior to receiving the questionnaire resulting in a final sample size of 4866. 3300 completed questionnaires were received (66% of the study sample). Of the surveys received by participants, the response rate was 68% (3300/4866).

Response rates

Response rate varied significantly between cancer groups (Table 1a): 69·4% in the prostate group compared to 62·3% in the NHL group (p<0.001).

There was significant difference in the age structure of the non-responders vs. responders with a higher proportion of non-responders in the ≥85 years age group (p<0·001).

Response rates differed according to deprivation status (Table 1a) with a response rate of 71·4% in the least deprived category compared to 57·1% in the most deprived category (p<0·001).

No difference in response rates by time since diagnosis, sex or cancer type was found.

Demographics of respondents (Table 1b)

Overall there were more males than females. Median age was 69 years (range 36-102). There was significant variation in the distribution of ethnicity by cancer group with higher proportions of non-white ethnic groups with NHL. There was no significant difference by deprivation between cancer groups. Overall more than half of patients reported having a LTC. Breast cancer responders displayed a similar age profile to the overall UK incident population. There were fewer reported LTCs in the breast cohort than in other groups but this did not reach statistical significance.

Missing data

Missing data levels were extremely low, typically less than 5% for most fields. SDI had slightly higher levels of missing data with completeness ranging from 80-85%. For the regression modelling (Tables 3a-3d) which used complete case analysis approach, completeness levels were lower and ranged from 60% (colorectal, prostate) to 83% (breast). There was no evidence that the prevalence of missing data was related to the order of the questions.

Helpline calls and other contact from survey participants

64 calls were made to the helpline, whilst further information about patient status was received via letters from patients (11) and NHS Trusts (2). The total number of enquiries was 77, representing 0.02% of the study cohort.

Generic PROMS

Responses for the five EQ5D questions demonstrated that a higher percentage of NHL patients reported problems with self-care, mobility and usual activities. Two-thirds of breast cancer patients reported some degree of pain (Supplementary Table 1).

When detailed responses for the five EQ5D questions were summarised by time since diagnosis, there were no significant differences for pain, mobility, usual activities or self-care but the percentage reporting anxiety or depression symptoms decreased significantly (p=0·01) (Supplementary Table 2).

Skewed weighted health scores were obtained from the EQ5D by cancer group (Supplementary Figure 1). The prostate group had significantly higher median (0·88) scores than the other three groups (0·84) (p=0·001). The proportion of the populations reporting high QoL scores ranged from 24·4% for breast to 40·0% for prostate cancer (Table 2). Conversely, the proportion reporting low QoL scores ranged from 8.9% for breast to 13.1% for NHL. For all tumour groups, irrespective of remission status, the percentage of individuals reporting lower QoL scores increased as the number of other LTCs increased (Supplementary Tables 3-4).

Result by Tumour Type

Multivariable ordered logistic regression (Tables 3a-3d) identified three factors which were consistently associated with lower QoL scores irrespective of tumour type: presence of LTCs, undertaking little physical activity and self-reported disease status.

Breast Cancer (Table 3a)

Increasing number of LTCs, having recurrence of disease or being uncertain of disease status were associated with poorer outcomes across all three measures: The presence of one (OR 1·84, 95%CI 1·25,2·70) or two or more (Odds Ratio (OR) 7·30, 95%Confidence Interval (CI) 4·45,11·93) LTCs was significantly associated with lower QoL scores. Individuals self-reporting recurrent disease (OR 4·70, 95%CI 1·92,11·52) or those uncertain about their disease status (OR 2·51, 95%CI 1·27,4·96) were significantly more likely to report lower QoL scores compared to those self-reporting remission.

Increasing age and more days undertaking physical activity were significantly associated with better outcomes in EQ5D, SDI and FACT-B measures: Those aged 65-74 reported significantly higher QoL scores compared to under 55s (OR 0·36, 95%CI 0·22,0·58). Increasing physical activity was associated with higher QoL scores with each additional reported day per week of physical activity reducing the odds of a lower score by 12% (OR 0·88, 95%CI 0·82,0·95).

Individuals from the most deprived areas were significantly more likely to report lower EQ5D derived QoL scores than those from the most affluent areas (OR 3·00, 95%CI 1·64-5·50). Poorer outcomes in FACT-B items were associated with being in the most deprived category.

Colorectal Cancer (Table 3b)

The presence of one (OR 2·09, 95%CI 1·29,3·37) or two or more (OR 4·83, 95%CI 2·85,8·21) LTCs was significantly associated with lower QoL scores. Those who completed the questionnaire whilst undergoing treatment (OR 7·03, 95%CI 2·44,20·21), experiencing recurrent disease (OR 4·56, 95%CI 1·54,13·49) or who were uncertain about their disease status (OR 2·67, 95%CI 1·23,5·79) had significantly increased odds of reporting lower QoL scores compared to those reporting remission.

Increasing physical activity was significantly associated with a 17% decrease in the odds of a lower QoL score with each additional day per week of physical activity (OR 0·83, 95%CI 0·76,0·90).

23·5% reported urinary leakage, 19·0% difficulty controlling their bowels and 19·2% had a stoma. Individuals experiencing any difficulty controlling their bowels were more than twice as likely to report lower QoL scores (OR 2·30, 95%CI 1·43,3·72). The presence of a stoma or urinary leakage was not significantly associated with QoL.

Greater difficulties with holidays and travel were reported by those with colorectal cancer compared to other cancers. For example, only 51% of colorectal respondents reporting no difficulty compared to 64% with breast or prostate cancer.

Non-Hodgkin's Lymphoma (Table 3c)

The presence of one (OR 2·16, 95%CI 1·44,3·24) or two or more (OR 7·26, 95%CI 4·51,11·69) LTCs was significantly associated with lower QoL scores. Those currently being treated (OR 2·57, 95%CI 1·52,4·33), experiencing a recurrence (OR 3·73, 95%CI 1·68,8·29) or who were not sure about their disease status (OR 3·04, 95%CI 1·58,5·84) had increased odds of reporting lower QoL scores compared to those in remission. These same factors were associated with poorer outcomes on the SDI and FACT-Lym items.

A significant positive association between increasing physical activity and QoL was seen with each additional day of physical activity reducing the odds of lower QoL score by 9% (OR 0·91, 95%CI 0·84,0·98). QoL seemed to improve with time from diagnosis for NHL but the trend was not significant (p=0·100).

Prostate Cancer (Table 3d)

The presence of two or more LTCs (OR 4·28, 95%CI 2·62,7·01) or being in the most deprived category (OR 2·57, 95%CI 1·31,5·04) were significantly associated with lower QoL scores, as well as increased social distress and difficulties identified by FACT-P.

Patients who had surgery only (compared to radiotherapy and hormone treatment) had significantly higher QoL scores (OR 0·39, 95%CI 0·21,0·71) as did those reporting more days of physical activity (OR 0·82, 95%CI 0·75,0·88).

38·5% of prostate patients reported some degree of urinary leakage, 12·9% reported difficulty controlling their bowels and 58·4% reported being unable to have an erection with a further 11% reporting significant difficulty in having or maintaining an erection. The presence of urinary leakage was significantly associated with lower QoL scores (OR 3·52, 5%CI 2·32,5·35). Erectile dysfunction and difficulty controlling bowels were not significantly associated with QoL scores.

Prostate survivors had significantly lower overall social distress scores on the SDI as well as fewer problems in all three sub-scales (everyday living, money matters, self and others) compared to other cancer types.

Fear of recurrence and dying

Almost half (47·3%) of patients reported fear of recurrence and over a quarter (26·8%) reported fear of dying (Supplementary Table 5). Both of these fears decreased significantly with time since diagnosis.

Physical activity

Around one-fifth (21·4%) of participants reported taking 30 minutes or more of physical activity at least five days a week (in line with the Chief Medical Officer’s recommendations). This varied by cancer: 16·5% for NHL, 19·0% for breast, 20·2% for colorectal and 29·0% for prostate. Overall 29·8% of patients reported doing no physical activity; this varied by cancer

group with 33·5% of NHL, 31·5% of colorectal and 27·4% of both breast and prostate survivors doing no physical activity.

Discussion

This study represents the largest European survey of survivors of multiple cancer types at clearly defined time points from diagnosis and demonstrates the feasibility of this straightforward method of collecting informative self-reported PROMS data on population-based cohorts of individuals living with and beyond a diagnosis of cancer in England. The process eliminates many of the potential biases that have hindered the collection of population-based cancer PROMS data in the past originating from the use of clinical trial data or acute service provider units for recruitment[30]. English cancer registries, which capture approximately 98-99% of all cancers diagnosed in England[31], provide a reliable denominator population from which to identify eligible participants.

Acceptability and Validity

The relatively high response rate, low level of missing data and low number of calls to the dedicated 24 hour helpline suggest that the methodology is acceptable to the majority of participants. However, the finding of lower participation amongst the elderly or those residing in areas with the greatest socio-economic deprivation would suggest that individuals from these vulnerable groups may need to be assessed by alternative methods. Whilst the questionnaires were identified as having face and content validity by a panel of health and social care professionals prior to use this study does not permit us to comment on the responsiveness or reliability of the instruments. However, the core components of the questionnaires had been identified by independent review as being reliable and appropriate for use in this setting[13-15].

Key results

The QoL of survivors for all four cancers was significantly related to self-reported disease status (remission versus relapse/uncertain), age and presence of LTCs. QoL appeared to either remain constant or improve slightly as time from diagnosis increased. This suggests that some problems experienced by cancer patients persist for long periods.

We have quantified the community prevalence of previously known late morbidities and assessed their impact on QoL. Problems relating to urinary and bowel control have been

shown to be common, with nearly 40% of prostate survivors reporting urinary leakage and 13% difficulty controlling their bowels. Similarly, amongst colorectal survivors nearly a quarter reported urinary leakage and 19% reported difficulty controlling their bowels. These rates are comparable to other studies of cancer patients[32] but exceed those seen in non-cancer populations where the prevalence of urinary incontinence in adult men was 4·5% overall, rising to 16·0% for over 75 year olds[33]. In this study, the presence of "urinary leakage" in prostate survivors and "of difficulty controlling their bowels" in colorectal survivors were significantly associated with lower QoL scores making such symptoms important to address. Erectile dysfunction in prostate survivors, though common, did not significantly impact on QoL. The finding that QoL or physical problems such as difficulty controlling bowels or incontinence do not appear to be less prevalent five years following treatment may suggest individuals are not receiving adequate help or treatment for these conditions. Greater efforts should be made in prevention and early intervention for problems resulting from cancer treatment, and directed at those most at risk of the long–term problems identified from this study.

Comparison with the General Population Data

Most survivors in this study who were in remission and did not report a LTC were found to have a high QoL score. However, even the subgroup in remission with no LTC reported lower QoL scores than the data available from general population studies (Table 4). Some of this difference may be accounted for by age, as the Health Survey for England (2008)[34] and the General Practice Patient Survey (GPPS)[35] cohorts were substantially younger than the reported cancer study cohort. This assumption is supported from the HSE cohort aged over 45 years (median age 63, n=7672) which reported a reduction in QoL scores (good 45%, moderate 46%, poor 9%).

Long-term Conditions

The presence of one or more LTCs, other than their cancer diagnosis, was associated with lower QoL scores in all four cancer groups and mirrors findings from other studies[2 36]. The presence of multi-morbidity and LTCs identifies sub-sets of survivors who may require more active support than others. This needs to be factored into risk stratification models as

health services move away from hospital based cancer follow-up towards a greater focus on self-management.

Physical Activity

The extent to which cancer survivors take physical activity has not previously been reported in England. The findings agree with those from the USA[37], suggesting that prostate survivors are more likely than others to take moderate or vigorous physical activity. We observed an association between higher levels of activity and higher QoL scores, but it is not possible to assess from a cross-sectional survey whether there is a causal relationship.

A smaller percentage of study respondents (21·4%) met the Chief Medical Officer of England's recommendations for physical activity when compared with the HSE(2008) in which 34% of adults met these guidelines[34]. Restricting the HSE data to a similar age profile as the study participants (60-75 years) saw similar levels of physical activity (23%). The HSE data found a trend of decreased physical activity with increasing age, yet, in this study, prostate survivors (the oldest subgroup) reported higher physical activity levels.

Limitations

The presence of multiple cancer groups and time points, along with some missing data (typically <5%), may have resulted in a lack of power for certain analyses. The non-response rate varied significantly by cancer group, deprivation category and age, which could result in selection bias when generalising results. Our study excluded those treated in the private sector (estimated to be under 5% of cancer cases in England[38]). The highly skewed EQ5D outcome variable was categorised into three levels for multivariable modelling, which meant that information and perhaps discriminatory power was lost. However, our model parameterisation enabled a more natural interpretation of EQ5D QoL data and when comparisons were made with other alternative models, such as tobit regression, findings were very similar.

Where next for Cancer PROMS in England?

The use of cancer PROMS has generally been restricted to clinical research, especially clinical trials or small studies. Whilst important work has been undertaken to develop approaches for the measurement of PROMS, they have not been incorporated into routine measurement at a whole health system level. This study demonstrates that population-based survey approaches are feasible, yield acceptable response rates and are cost-effective. This approach could provide important insights into where improvement efforts should be targeted to reduce the long-term burden of cancer and its treatments on the growing number of cancer survivors.

Improving QoL in patients with LTC is one of the key goals of English government health policy (forming Domain 2 of the NHS Outcomes Framework)[39]. The approach we report should be scaled up and integrated within routine health outcome assessment on a national basis so that results can be distilled down to hospital/service provider level, as has been done in relation to the experience of acute care of cancer patients[12]. Improvements in quality of survivor care could then be driven by publishing hospital/provider level data.

Our findings support the on-going international efforts to identify risk factors for poor health-related QoL outcomes following a cancer diagnosis. These include the presence of other LTCs, deprivation and limited physical activity. These, along with the high prevalence of on-going condition-specific problems such as bowel, urinary and erectile dysfunction, warrant attention by cancer services.

Acknowledgements

Dr Nicola Davies, Professor Jane Maher, Dr Mick Peake, Professor Galina Velikova and Dr Penny Wright provided expert advice regarding questionnaire and study design. Thames Cancer Registry, Eastern Cancer Registry and Information Centre, and West Midlands Cancer Intelligence Unit provided information on all eligible cancer survivors. FACIT provided permission to use components of the FACT questionnaires and Penny Wright granted permission to use the Social Difficulties Inventory.

Funding

This survey was funded by the Department of Health, England.

Declaration of Competing Interests

All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: financial support for the submitted work from the Department of Health, England: AWG, GH and MR were employed by the Cancer Policy Team, Department of Health, England, whilst the research was carried out; AWG, LKF, RGF and EF, received financial support from Department of Health, England, to carry out the analysis of data reported; JC and MR co-chaired the Department of Health, England, Cancer Patient Experience Advisory Group.

Data Sharing Statement

Statistical code and dataset are available from the corresponding author at the University of Leeds, who will provide a permanent, citable and open access home for the dataset.

Author Contribution Statement

Adam Glaser contributed to the study design, data collection, data analysis, data interpretation and writing of this manuscript.

Lorna Fraser contributed to the data analysis, data interpretation and writing of this manuscript.

Jessica Corner contributed to the study design, data collection, data interpretation and writing of this manuscript.

Richard Feltbower contributed to the data analysis, data interpretation and writing of this manuscript.

Eva Morris contributed to the data analysis, data interpretation and writing of this manuscript.

Greg Hartwell contributed to the study design and data collection.

Mike Richards contributed to the study design, data interpretation, and writing of this manuscript.

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Table 1a Demographic data of responders and non-responders

Characteristic		Responders (n=3300)		Non Responders (n=1692)		Total number approached	Overall Percentage Responding
		n	%	n	%		
Cancer Group	**χ2=18.8, p<0·001**						
Breast		854	25.9	394	23.3	1248	68.4
Colorectal		802	24.3	446	26.4	1248	64.3
NHL		778	23.6	470	27.8	1248	62.3
Prostate		866	26.2	382	22.5	1248	69.4
Age	**χ2=108, p<0·001**						
under 55		467	14·2	282	16.7	749	62.3
55 to 64		692	21·0	335	19.8	1027	67.4
65 to 74		1,108	33·6	414	24.5	1522	72.8
75 to 84		835	25·3	434	25.6	1269	65.8
85+		198	6·0	227	13.4	425	46.6
IMD Category	**χ2=55.9, p<0.001**						
1 least deprived		826	25·0	331	19.6	1157	71.4
2		812	24·6	357	21.1	1169	69.5
3		703	21·3	349	20.7	1052	66.8
4		554	16·8	352	20.7	906	61.1
5 most deprived		399	12·1	300	17.7	699	57.1
Missing		6	0·2	3	0.2	9	66.7
Time since Diagnosis	**χ2=4.1, p=0·25**						
1 year		848	25·7	400	23.6	1248	67.9
2 years		834	25·3	414	24.5	1248	66.8
3 years		806	24·4	442	26.1	1248	64.6
5 years		812	24·6	436	25.8	1248	65.1

Table 1b. Demographic Data by Cancer Group

Characteristic		Breast (n=854)		Colorectal (n=802)		Non Hodgkin's Lymphoma (n=778)		Prostate (n=866)		Total (n=3300)	
		n	%	n	%	n	%	n	%	n	%
Sex	**χ2=1700, p<0·001**										
Male		10	*1·2*	435	*54·2*	419	*53·9*	848	*97·9*	1712	*51·9*
Female		829	*97·0*	348	*43·4*	352	*45·2*	0	*0*	1529	*46·3*
Missing		15	*1·8*	19	*2·4*	7	*0·9*	18	*2·1*	59	*1·8*
Age	**χ2=401, p<0·001**										
under 55		231	*27·0*	57	*7·1*	157	*20·2*	157	*18·1*	467	*14·2*
55 to 64		237	*27·8*	136	*17·0*	173	*22·2*	173	*20·0*	692	*21·0*
65 to 74		224	*26·2*	280	*34·9*	238	*30·6*	238	*27·5*	1,108	*33·6*
75 to 84		122	*14·3*	246	*30·7*	175	*22·5*	175	*20·2*	835	*25·3*
85+		40	*4·7*	83	*10·3*	35	*4·5*	35	*4·0*	198	*6·0*
Ethnicity	**χ2=74·6, p<0·001**										
White		768	*89·9*	740	*92·3*	688	*88·4*	786	*90·8*	2982	*90·4*
Asian		35	*4·1*	19	*2·3*	30	*3·9*	15	*1·7*	99	*3·0*
Black		14	*1·6*	11	*1·4*	21	*2·7*	36	*4·2*	82	*2·5*
Mixed		4	*0·5*	5	*0·6*	6	*0·8*	1	*0·1*	16	*0·5*
Other		4	*0·5*	0	*0*	4	*0·5*	3	*0·3*	11	*0·3*
Missing		29	*3·4*	27	*3·4*	29	*3·7*	25	*2·9*	110	*3·3*
IMD Category	**χ2=4·3, p0·97**										
1 least deprived		211	*24·7*	198	*24·7*	202	*26·0*	215	*24·8*	826	*25·0*
2		210	*24·6*	199	*24·8*	183	*23·5*	220	*25·4*	812	*24·6*
3		184	*21·5*	159	*19·8*	177	*22·7*	183	*21·1*	703	*21·3*
4		141	*16·5*	147	*18·3*	125	*16·1*	141	*16·3*	554	*16·8*
5 most deprived		104	*12·2*	98	*12·2*	91	*11·7*	106	*12·2*	399	*12·1*
Missing		4	*0·5*	1	*0·1*	0	*0*	1	*0·1*	6	*0·2*
Time since Diagnosis	**χ2=5·5, p=0·78**										
1 year		215	*25·2*	202	*25·2*	197	*25·3*	234	*27·0*	848	*25·7*
2 years		212	*24·8*	215	*26·8*	187	*24·0*	220	*25·4*	834	*25·3*
3 years		204	*23·9*	195	*24·3*	207	*26·6*	200	*23·1*	806	*24·4*
5 years		223	*26·1*	190	*23·7*	187	*24·0*	212	*24·5*	812	*24·6*
Other Long Term Health Condition	**χ2=12·1, p=0·06**										
Yes		435	*50·9*	432	*53·9*	435	*55·9*	501	*57·9*	1803	*54·6*
No		353	*41·3*	309	*38·5*	287	*36·9*	299	*34·5*	1248	*37·8*
Don't Know		30	*6·9*	23	*2·9*	33	*4·2*	27	*3·1*	113	*3·4*
Missing		36	*4·2*	38	*4·7*	23	*3·0*	39	*4·5*	136	*4·1*
Disease Status	**χ2=390·0, p<0·001**										
Remission		677	*79·3*	625	*77·9*	526	*67·6*	399	*46·1*	2227	*67·5*
Rx but present		26	*3·0*	32	*4·0*	81	*10·4*	144	*16·6*	283	*8·6*
Not treated		4	*0·5*	6	*0·7*	43	*5·5*	78	*9·0*	131	*4·0*

Recurrence		30	*3·5*	20	*2·5*	30	*3·9*	8	*0.9*	88	*2.6*
Not sure		58	*6·8*	69	*8·6*	53	*6·8*	140	*16·2*	320	*9·7*
Missing		59	*6·9*	50	*6·2*	45	*5·8*	97	*11·2*	251	*7·6*

Table 2. EQ5D outcome category by cancer sub-group

EQ5D Categories	'High' QoL (Scores=1)		Medium QoL (0.5≤Scores<1)		Low QoL (Scores<0.5)		Missing	
	n	*%*	n	*%*	n	*%*	n	*%*
Breast	208	*24·4*	514	*60·2*	76	*8·9*	56	*6·6*
Colorectal	255	*31·2*	434	*54·1*	87	*10·8*	26	*3·2*
Non Hodgkins Lymphoma	247	*31·7*	398	*51·2*	102	*13·1*	31	*4·0*
Prostate	347	*40·0*	390	*45·0*	81	*9·4*	48	*5·5*
Total	1057	*32·0*	1736	*52·6*	346	*10·5*	161	*4·9*

Table 3a. Ordered Logistic Regression Model EQ5D in Breast Cancer Patients [n=709, pseudoR^2=0·16 p<0·001]

Characteristic	Odds Ratio*	95% CI		P value
Age (years)				
<55 years	REF			
55-64	0·69	0·45	1·06	0·09
65-74	0·36	0·22	0·58	<0·001
75-84	0·59	0·32	1·08	0·09
85+	1·61	0·57	4·52	0·36
Deprivation				
1 least deprived	REF			
2	1·03	0·66	1·62	0·88
3	1·10	0·68	1·77	0·71
4	0·93	0·55	1·56	0·78
5 most deprived	3·00	1·64	5·50	<0·001
Physical Activity	0·88	0·82	0·95	<0·001
Number of other LTC (excl BP)				
0	REF			
1	1·84	1·25	2·70	0·002
2+	7·30	4·45	11·93	<0·001
Treatment*				
Radio+Chemo+Surgery+Hormone	REF			
Radio +Chemo+Surgery	0·67	0·38	1·20	0·18
Radio+Surgery	0·51	0·29	0·90	0·02
Radio+Surgery+Hormone	0·56	0·33	0·96	0·04
Surgery only	1·00	0·55	1·84	0·99
Other	0·92	0·53	1·58	0·76
Ethnicity				
White	REF			
Mixed	0·50	0·06	4·29	0·53
Asian	1·96	0·77	5·01	0·16
Black	0·29	0·08	0·98	0·05
Other	2·20	0·17	29·32	0·55
Disease Status				
Remission	REF			
Rx but present	1·49	0·56	3·93	0·43
Not treated	.	.	.	.
Recurrence	4·70	1·92	11·52	0·001
Not sure	2·51	1·27	4·96	0·008
Time since Diagnosis				
1 year	REF			
2 years	1·02	0·64	1·62	0·95
3 years	0·88	0·55	1·41	0·60
5 years	0·93	0·59	1·47	0·76

*Odds of reporting ‘medium’ or ‘low’ QoL EQ5D scores compared to ‘high’ QoL scores where ‘high’, ‘medium’ and ‘low’ QoL was defined as scores=1, 0.5≤scores<1 and scores<0.5 respectively.

Table 3b. Ordered Logistic Regression Model EQ5D in Colorectal Patients [n=485, pseudoR2=0·18, p<0·001]

Characteristic	**Odds Ratio**	**95% CI**		**P value**
Age (years)				
<55 years	REF			
55-64	1·28	0·59	2·75	0·53
65-74	1·16	0·57	2·35	0·69
75-84	1·23	0·57	2·64	0·59
85+	2·45	0·93	6·41	0·07
Sex				
Male	REF			
Female	1·22	0·81	1·82	0·34
Deprivation				
1 least deprived	REF			
2	0·83	0·48	1·43	0·50
3	0·57	0·33	1·00	0·05
4	0·62	0·34	1·13	0·12
5 most deprived	1·17	0·58	2·34	0·66
Physical Activity	0·83	0·76	0·90	<0·001
Number of other LTC(excl BP)				
0	REF			
1	2·09	1·29	3·37	<0·001
2+	4·83	2·85	8·21	<0·001
Treatment*				
Surgery only	REF			
Radio+Chemo+Surgery	1·15	0·60	2·21	0·67
Chemo+Surgery	1·35	0·85	2·17	0·21
Other	1·58	0·77	3·22	0·21
Ethnicity				
White	REF			
Mixed	1·72	0·24	12·42	0·59
Asian	1·99	0·46	8·54	0·36
Black	1·14	0·26	4·92	0·86
Other	1·72	0·24	12·42	0·59
Disease Status				
Remission	REF			
Rx but present	7·03	2·44	20·21	<0·001
Not treated	0·16	0·01	2·63	0·20
Recurrence	4·56	1·54	13·49	0·01
Not sure	2·67	1·23	5·79	0·01
Stoma				
No	REF			
Yes	1·32	0·80	2·19	0·27
Difficulty Controlling Bowels				
No	REF			
Yes	2·30	1·43	3·72	<0·001
Leak Urine				
No	REF			
Yes	1·41	0·87	2·30	0·16
Time since Diagnosis				
1 year	REF			
2 years	0·72	0·42	1·22	0·22
3 years	1·03	0·59	1·81	0·92
5 years	0·85	0·49	1·48	0·56

*Odds of reporting ‘medium’ or ‘low’ QoL EQ5D scores compared to ‘high’ QoL scores where ‘high’, ‘medium’ and ‘low’ QoL was defined as scores=1, 0.5≤scores<1 and scores<0.5 respectively.

Table 3c. Ordered Logistic Regression Model EQ5D in NHL Patients [n=614, pseudoR2=0·15 p<0·001]

Characteristic	Odds Ratio	95% CI		P value
Age (years)				
<55 years	REF			
55-64	0·89	0·55	1·45	0·65
65-74	1·23	0·75	1·99	0·41
75-84	1·60	0·94	2·73	0·08
85+	2·13	0·84	5·39	0·11
Sex				
Male	REF			
Female	1·25	0·89	1·74	0·19
Deprivation				
1 least deprived	REF			
2	1·06	0·67	1·69	0·80
3	1·21	0·75	1·95	0·43
4	1·64	0·97	2·76	0·07
5 most deprived	1·19	0·65	2·21	0·57
Physical Activity	0·91	0·84	0·98	0·01
Number of other LTC (excluding BP)				
0	REF			
1	2·16	1·44	3·24	<0·001
2+	7·26	4·51	11·69	<0·001
Treatment*				
Chemo only	REF			
Radio+Chemo	0·81	0·47	1·41	0·46
Chemo + Antibody	0·93	0·55	1·59	0·80
Radio+Chemo+Other	1·55	0·87	2·77	0·14
Other	0·96	0·63	1·46	0·86
Ethnicity				
White	REF			
Mixed	2·78	0·28	27·7	0·38
Asian	0·68	0·29	1·59	0·38
Black	0·91	0·33	2·49	0·85
Other	0·61	0·09	4·39	0·62
Disease Status				
Remission	REF			
Rx but present	2·57	1·52	4·33	<0·001
Not treated	0·83	0·17	3·96	0·82
Recurrence	3·73	1·68	8·29	0·001
Not sure	3·04	1·58	5·84	0·001
Time since Diagnosis				
1 year	REF			
2 years	0·62	0·38	0·99	0·05
3 years	0·60	0·38	0·96	0·03
5 years	0·57	0·36	0·90	0·02

*Odds of reporting ‘medium’ or ‘low’ QoL EQ5D scores compared to ‘high’ QoL scores where ‘high’, ‘medium’ and ‘low’ QoL was defined as scores=1, 0.5≤scores<1 and scores<0.5 respectively.

Table 3d. Ordered Logistic Regression Model EQ5D in Prostate Patients [n=524, pseudoR2=0·22 p<0·001]

Characteristic	Odds Ratio	95% CI		P value
Age (years)				
<55 years	REF			
55-64	1·32	0·41	4·30	0·64
65-74	1·72	0·55	5·38	0·36
75-84	1·32	0·41	4·30	0·64
85+	1·92	0·42	8·78	0·40
Deprivation				
1 least deprived	REF			
2	1·09	0·64	1·85	0·74
3	1·19	0·68	2·08	0·55
4	1·61	0·88	2·95	0·13
5 most deprived	2·57	1·31	5·04	0·01
Physical Activity	0·82	0·75	0·88	<0·001
Number of other LTC(excl BP)				
0	REF			
1	1·55	0·94	2·54	0·09
2+	4·28	2·62	7·01	<0·001
Treatment*				
Radio+Hormone	REF			
Surgery only	0·39	0·21	0·71	<0·001
Hormone only	1·68	0·85	3·33	0·14
Radio only	0·94	0·53	1·66	0·83
Active surveillance only	1·16	0·47	2·88	0·75
Other	·	·	·	·
Ethnicity				
White	REF			
Mixed	3·82	0·07	203·44	0·51
Asian	3·21	0·56	18·49	0·19
Black	2·54	0·96	6·73	0·06
Other	0·00	0·00	·	0·98
Disease Status				
Remission	REF			
Rx but present	1·75	0·94	3·26	0·08
Not treated	1·06	0·37	3·05	0·91
Recurrence	1·71	0·17	16·91	0·65
Not sure	1·48	0·85	2·58	0·17
Urinary Leakage				
No	REF			
Yes	3·52	2·32	5·35	<0·001
Erectile Dysfunction				
No	REF			
Yes	1·46	0·96	2·23	0·08
Difficulty Controlling Bowels				
No	REF			
Yes	1·62	0·90	2·92	0·10
Time since Diagnosis				
1 year	REF			
2 years	0·83	0·50	1·40	0·49
3 years	0·80	0·47	1·36	0·41
5 years	0·77	0·45	1·33	0·36

*Odds of reporting ‘medium’ or ‘low’ QoL EQ5D scores compared to ‘high’ QoL scores where ‘high’, ‘medium’ and ‘low’ QoL was defined as scores=1, 0.5≤scores<1 and scores<0.5 respectively.

Table 4. Comparison of Quality of Life scores with other population data

	Health Survey for England (HSE 2008)[34]		GP Population Survey (GPPS)[35]	GP Population Survey (GPPS)[35]	This survey	
	All ages	Ages≥ 45 years	All	No LTC	All	In remission with no LTC
Number of respondents	14116	7672	426933	193285	3300	848
Median age	48	63	48	39	69·3	63·2
'High' QOL (Scores=1)	56.0%	45·4%	50·6%	73·8%	32·0%	51·4%
'Medium' QOL (0.5≤Scores <1)	37.7%	45·6%	41·6%	25·2%	52·6%	44·3%
'Low' QOL (Scores <0·5)	6.3%	9·0%	7·8%	0·9%	10·5%	2·1%

Supplementary Table 1. Quality of Life Dimension Results (EQ5D) by Cancer Sub group

EQ5D dimension		**Breast (n=854)**		**Colorectal (n=802)**		**Non Hodgkin's Lymphoma (n=778)**		**Prostate (n=866)**		**Total (n=3300)**	
		n	***%***	**n**	***%***	**n**	***%***	**n**	***%***	**n**	***%***
Mobility χ2=51·3, p<0·001	No Problems	567	*66·4*	442	*55·1*	427	*54·9*	535	*61·8*	1971	*59·7*
	Slight Problems	105	*12·3*	159	*19·8*	140	*18·0*	131	*15·1*	535	*16·2*
	Moderate Problems	107	*12·5*	120	*15·0*	120	*15·4*	97	*11·2*	444	*13·5*
	Severe Problems	46	*5·4*	57	*7·1*	71	*9·1*	69	*8·0*	243	*7·4*
	Cannot walk	8	*0·9*	13	*1·6*	6	*0·8*	4	*0·4*	31	*0·9*
	Missing	21	*2·5*	11	*1·4*	14	*1·8*	30	*3·5*	76	*2·3*
Self Care χ2=30·4, p=0·002	No Problems	716	*83·8*	651	*81·2*	611	*78·5*	704	*81·3*	2682	*81·3*
	Slight Problems	47	*5·5*	67	*8·4*	66	*8·5*	78	*9·0*	258	*7·8*
	Moderate Problems	45	*5·3*	46	*5·7*	71	*9·1*	44	*5·1*	206	*6·2*
	Severe Problems	12	*1·4*	18	*2·2*	12	*1·5*	9	*1·0*	51	*1·5*
	Cannot wash/dress	6	*0·7*	9	*1·1*	4	*0·5*	4	*0·5*	23	*0·7*
	Missing	28	*3·3*	11	*1·4*	14	*1·8*	27	*3·1*	80	*2·4*
Usual Activities χ2=34·5, p<0·001	No Problems	513	*60·1*	429	*53·5*	411	*52·8*	533	*61·5*	1886	*57·2*
	Slight Problems	162	*19·0*	173	*21·6*	156	*20·1*	145	*16·7*	636	*19·3*
	Moderate Problems	111	*13·0*	113	*14·1*	127	*16·3*	104	*12·1*	455	*13·7*
	Severe Problems	31	*3·6*	48	*6·0*	49	*6·3*	43	*5·0*	171	*5·2*
	Cannot do usual activities	14	*1·6*	24	*3·0*	26	*3·3*	15	*1·7*	79	*2·4*
	Missing	23	*2·7*	15	*1·8*	9	*1·2*	26	*3·0*	73	*2·2*
Pain χ2=134·3, p<0·001	No Pain	329	*38·5*	429	*53·5*	408	*52·4*	526	*60·7*	1692	*51·3*
	Slight Pain	341	*39·9*	220	*27·4*	180	*23·1*	169	*19·5*	910	*27·6*
	Moderate Pain	113	*13·2*	92	*11·5*	120	*15·4*	101	*11·7*	426	*12·9*
	Severe Pain	39	*4·6*	35	*4·4*	51	*6·6*	38	*4·4*	163	*4·9*
	Extreme Pain	5	*0·6*	9	*1·1*	10	*1·3*	3	*0·3*	27	*0·8*
	Missing	27	*3·2*	17	*2·1*	9	*1·2*	29	*3·3*	82	*2·5*
Anxiety/ depression χ2=37·1, p<0·001	No anxiety/depression	475	*55·6*	504	*62·8*	464	*59·6*	566	*65·4*	2009	*60·9*
	Slight anxiety/depression	241	*28·2*	196	*24·4*	186	*23·9*	183	*21·1*	806	*24·4*
	Moderate anxiety/depression	78	*9·1*	78	*9·7*	83	*10·7*	76	*8·8*	315	*9·5*
	Severe anxiety/depression	21	*2·5*	6	*0·8*	21	*2·7*	8	*0·9*	56	*1·7*
	Extreme anxiety/depression	10	*1·2*	4	*0·5*	8	*1·0*	4	*0·5*	26	*0·8*
	Missing	29	*3·4*	14	*1·8*	16	*2·1*	29	*3·3*	88	*2·7*

Supplementary Table 2 Quality of Life Dimension Results (EQ5D) by time since diagnosis of cancer

		1 year (n=848)		2 years (n=834)		3 years (n=806)		5 years (n=812)		Total (n=3300)	
		N	%	N	%	N	%	N	%	N	%
Mobility	No Problems	521	*61.4*	501	*60.1*	486	*60.3*	463	*57.0*	1971	*59.7*
χ2=21.1, p=0.05	Slight Problems	150	*17.7*	123	*14.7*	127	*15.8*	135	*16.6*	535	*16.2*
	Moderate Problems	93	*11.0*	116	*13.9*	104	*12.9*	131	*13.1*	444	*13.5*
	Severe Problems	62	*7.3*	62	*7.4*	56	*6.9*	63	*7.8*	243	*7.4*
	Cannot walk	2	*0.2*	8	*9.6*	13	*1.6*	8	*1.0*	31	*0.9*
	Missing	20	*2.4*	24	*2.9*	20	*2.5*	12	*1.5*	76	*2.3*
Self Care	No Problems	696	*82.1*	674	*80.8*	659	*81.8*	653	*80.4*	2682	*81.3*
χ2=10.2, p=0.59	Slight Problems	59	*6.9*	65	*7.8*	61	*7.6*	73	*9.0*	258	*7.8*
	Moderate Problems	57	*6.7*	56	*6.7*	42	*5.2*	51	*6.3*	206	*6.2*
	Severe Problems	12	*1.4*	12	*1.4*	14	*1.7*	13	*1.6*	51	*1.5*
	Cannot wash/dress	3	*0.4*	4	*0.5*	10	*1.2*	6	*0.7*	23	*0.7*
	Missing	21	*2.5*	23	*2.8*	20	*2.5*	16	*2.0*	80	*2.4*
Usual Activities	No Problems	465	*54.8*	474	*56.8*	465	*57.7*	482	*59.4*	1886	*57.2*
χ2=13.9, p=0.31	Slight Problems	181	*21.3*	157	*18.8*	161	*20.0*	137	*16.9*	636	*19.3*
	Moderate Problems	131	*15.4*	112	*13.4*	95	*11.8*	117	*14.4*	455	*13.7*
	Severe Problems	35	*4.1*	45	*5.4*	44	*5.5*	47	*5.8*	171	*5.2*
	Cannot do usual activities	18	*2.1*	19	*2.3*	23	*2.8*	19	*2.3*	79	*2.4*
	Missing	18	*2.1*	27	*3.2*	18	*2.2*	10	*1.2*	73	*2.2*
Pain	No Pain	421	*49.6*	412	*49.4*	435	*54.0*	424	*52.2*	1692	*51.3*
χ2=18.0, p=0.12	Slight Pain	262	*30.9*	237	*28.4*	198	*24.6*	213	*26.2*	910	*27.6*
	Moderate Pain	101	*11.9*	112	*13.4*	105	*13.0*	108	*13.3*	426	*12.9*
	Severe Pain	34	*4.0*	44	*5.3*	38	*4.7*	47	*5.8*	163	*4.9*
	Extreme Pain	7	*0.8*	6	*0.7*	11	*1.4*	3	*0.4*	27	*0.8*
	Missing	23	*2.7*	23	*2.8*	19	*2.4*	17	*2.1*	82	*2.5*
Anxiety/depression	No anxiety/depression	466	*55.0*	505	*60.6*	499	*61.9*	539	*66.4*	2009	*60.9*
χ2=25.8, p=0.01	Slight anxiety/depression	244	*28.8*	195	*23.4*	196	*24.3*	171	*21.1*	806	*24.4*
	Moderate anxiety/depression	88	*10.4*	86	*10.3*	68	*8.4*	73	*9.0*	315	*9.5*
	Severe anxiety/depression	20	*2.4*	13	*1.5*	13	*1.6*	10	*1.2*	56	*1.7*
	Extreme anxiety/depression	6	*0.7*	8	*1.0*	6	*0.7*	6	*0.7*	26	*0.8*
	Missing	24	*2.8*	27	*3.2*	24	*3.0*	13	*1.6*	88	*2.7*

Supplementary Table 3. EQ5D outcome category by the number of Long Term Conditions (LTC) in patients in remission

EQ5D Categories	**High QoL (Scores=1)**		**Medium QoL (0.5≤Scores<1)**		**Low QoL (Scores<0.5)**		**Missing**		**Total**
	n	*%*	n	*%*	n	*%*	n	*%*	
No LTC	436	51·4	376	44·3	18	2·1	18	2·1	848
1 LTC	250	36·2	378	54·7	40	5·8	23	3·3	691
≥2 LTC	129	18·8	419	60·9	119	17·3	21	3·1	688
Total	815	36·6	1,173	52·7	177	7·9	62	2·8	2,227

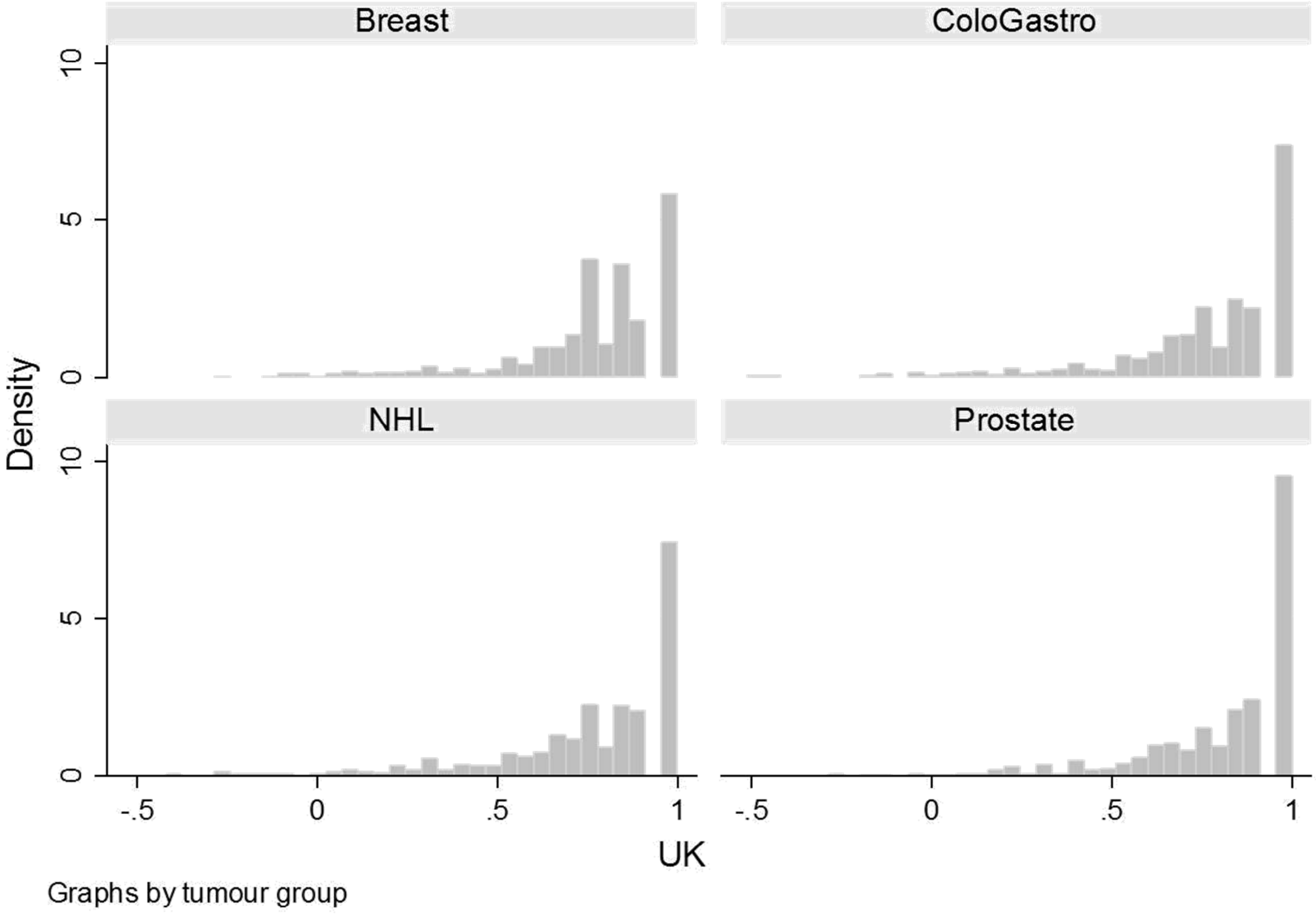
Supplementary Table 4. EQ5D outcome category by the number of Long Term Conditions (LTC) in patients not in remission

EQ5D Categories	**High QoL (Scores=1)**		**Medium QoL (0.5≤Scores<1)**		**Low QoL (Scores<0.5)**		**Missing**		**Total**
	n	*%*	n	*%*	n	*%*	n	*%*	
No LTC	79	33·9	130	55·8	15	6·4	9	3·9	233
1 LTC	64	23·1	175	63·2	25	9·0	13	4·7	277
≥2 LTC	37	11·9	166	53·2	94	30·1	15	4·8	312
Total	180	21·9	471	57·3	134	16·3	37	4·5	822

Supplementary Table 5. Fear of Dying and Recurrence of Disease by Time since Diagnosis

Fear of Dying	Yes%		No		Missing		Total
	n	%	n	%	n	%	
1 year ago	256	*30·2*	542	*63·9*	50	*5·9*	848
2 years ago	233	*27·9*	543	*65·1*	58	*7·0*	834
3 years ago	214	*26·6*	531	*65·9*	61	*7·6*	806
5 years ago	180	*22·2*	583	*71·8*	49	*6·0*	812
Total	883	*26·8*	2,199	*66·6*	218	*6·6*	3,300
Fear of Recurrence	n	%	n	%	n	%	
1 year ago	437	*51·5*	369	*43·5*	42	*5·0*	848
2 years ago	403	*48·3*	398	*47·7*	33	*4·0*	834
3 years ago	376	*46·7*	384	*47·6*	46	*5·7*	806
5 years ago	345	*42·5*	427	*52·6*	40	*4·9*	812
Total	1,561	*47·3*	1,578	*47·8*	161	*4·9*	3,300

Supplementary Figure 1. Distribution of EQ5D summary scores by cancer sub-type



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Supplementary File 1	**ICD10 Codes included in the Study**
Breast Cancer	ICD10 Codes C50 & D05
Colorectal/Lower G.I.	ICD10 Codes C18, C19, C20, and C21
Non-Hodgkin’s Lymphoma	ICD10 Codes C82, C83, C84 & C85
Prostate	ICD10 Code C61

Living with and beyond Breast Cancer

This questionnaire is about your health and quality of life since being diagnosed with your cancer. Its purpose is to provide information which can help the NHS monitor and improve the quality of health services for future patients.

Who should complete the questionnaire?
The questions should be answered by the person named in the letter enclosed with this questionnaire. If that person needs help to complete the questionnaire, the answers should be given from their point of view – not the point of view of the person who is helping.

Completing the questionnaire
For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don’t worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please **do not** write your name or address anywhere on the questionnaire.

IMPORTANT INFORMATION

To make sure the information we collect is useful, we need to collect some personal details from you and to access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the quality of life for people who are living with and beyond cancer. These statistics will be used to compare the differences in quality of life for people treated for different types of cancer by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:

- Your personal details and relevant health information can be held and used by an organisation contracted to the Department of Health to analyse the data
- Other information about you held by the Patient Demographics Service, the Secondary Users Service, Cancer Registries and other NHS databases can be held and used by an organisation contracted to the Department of Health to analyse the data
- Your personal details can be used to send you related follow-up questionnaires in the future

Your personal information will be handled securely and anonymised after analysis and before any publication.

Your personal information will not be released by the Department of Health or third party organisations working on its behalf unless required by law or where there is a clear overriding public interest.

You can withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

If you have any queries about the questionnaire,
please call the FREEPHONE helpline number **on 0800 783 1775**

Taking part in this survey is voluntary
Published reports will not contain any personal details

YOUR HEALTH TODAY

The questions in this section are all about your health and how you feel on the day you complete this questionnaire.

1. What treatments have you received for your breast cancer? **(Tick all that apply)**

1 ☐ Radiotherapy
2 ☐ Chemotherapy (excluding hormone treatment)
3 ☐ Hormone treatment
4 ☐ Surgery

2. How long is it since you completed your **initial treatment** for breast cancer? *Treatment includes any chemotherapy, radiotherapy, or surgery for your breast cancer. When answering this question please do not include hormone treatments such as Tamoxifen.*

1 ☐ I am still having my initial treatment
2 ☐ It is less than 3 months since my initial treatment
3 ☐ It is between 3 and 12 months since my initial treatment
4 ☐ It is between 1 and 5 years since my initial treatment
5 ☐ It is more than 5 years since my initial treatment
6 ☐ Don’t know / can’t remember

3. How has your breast cancer responded to treatment?

1 ☐ My breast cancer has responded fully to treatment (I am in remission)
2 ☐ My breast cancer has been treated but is still present
3 ☐ My breast cancer has not been treated at all
4 ☐ My breast cancer has come back after it was originally treated
5 ☐ I am not certain what is happening with my breast cancer

4. If you have had breast surgery, do any of the following apply to you? **(Tick all that apply)**

1 ☐ I have had a lumpectomy
2 ☐ I have had a mastectomy
3 ☐ I have had breast reconstruction
4 ☐ I am awaiting or considering breast reconstruction
5 ☐ None of these apply to me

YOUR HEALTH TODAY

Under each heading, please tick the ONE box that best describes your health TODAY.

5. MOBILITY	
I have no problems in walking about	☐ 1
I have slight problems in walking about	☐ 2
I have moderate problems in walking about	☐ 3
I have severe problems in walking about	☐ 4
I am unable to walk about	☐ 5
6. SELF CARE	
I have no problems washing or dressing myself	☐ 1
I have slight problems washing or dressing myself	☐ 2
I have moderate problems washing or dressing myself	☐ 3
I have severe problems washing or dressing myself	☐ 4
I am unable to wash or dress myself	☐ 5
7. USUAL ACTIVITIES *(work, study, housework, family or leisure activities)*	
I have no problems doing my usual activities	☐ 1
I have slight problems doing my usual activities	☐ 2
I have moderate problems doing my usual activities	☐ 3
I have severe problems doing my usual activities	☐ 4
I am unable to do my usual activities	☐ 5
8. PAIN / DISCOMFORT	
I have no pain or discomfort	☐ 1
I have slight pain or discomfort	☐ 2
I have moderate pain or discomfort	☐ 3
I have severe pain or discomfort	☐ 4
I have extreme pain or discomfort	☐ 5
9. ANXIETY / DEPRESSION	
I am not anxious or depressed	☐ 1
I am slightly anxious or depressed	☐ 2
I am moderately anxious or depressed	☐ 3
I am severely anxious or depressed	☐ 4
I am extremely anxious or depressed	☐ 5

YOUR HEALTH AND WELLBEING IN THE LAST 7 DAYS

The questions in this section are about your health and how you have felt in the past 7 days.

Please mark one box per line to give your response.

	During the past 7 days:	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
10.	I have been short of breath	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
11.	I am self conscious about the way I dress	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
12.	One or both of my arms are swollen or tender	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
13.	I feel sexually attractive	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
14.	I am bothered by hair loss	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
15.	I worry that other members of my family might someday get the same illness I have	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
16.	I worry about the effect of stress on my illness	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
17.	I am bothered by a change in weight	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
18.	I have certain parts of my body where I experience pain	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

19. In the **past week**, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your heart rate? *This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that is part of your job.*

None	**I day**	**2 days**	**3 days**	**4 days**	**5 days**	**6 days**	**7 days**
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past <u>month</u>.

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These might be to do with things like their family life, social activities, finances and work.

Please tick the response that best describes your answer.

	During the past month:	**No difficulty**	**A little**	**Quite a bit**	**Very much**	**Does not apply**
20.	Have you had any difficulty in maintaining your independence?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
21.	Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
22.	Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
23.	Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
24.	Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
25.	Have you had any difficulty with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
26.	Have you had any financial difficulties?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
27.	Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
28.	Have you had any difficulty concerning your work? (or education if you are a student)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
29.	Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

During the past month:	No difficulty	A little	Quite a bit	Very much	Does not apply
30. Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
31. Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
32. Have you had any difficulty concerning sexual matters?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
33. Have you had any difficulty concerning plans to have a family?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
34. Have you had any difficulty concerning your appearance or body image?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
35. Have you felt isolated?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
36. Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
37. Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
38. Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
39. Have you had any difficulty with your plans to travel or take a holiday?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
40. Have you had any difficulty with any other area of your everyday life?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Please tick the response that best describes your answer.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply to me
41. I have fears about my cancer spreading	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	6 ☐
42. I have fears about my cancer coming back	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	6 ☐
43. I have fears about death and dying	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
44. I experience memory loss	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
45. I have trouble sleeping	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
46. I have trouble concentrating	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
47. I always feel tired	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
48. I experience mood swings	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
49. I am often irritable	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	

OVERALL SUPPORT AND CARE

50. Do you have an up-to-date written care plan? *A care plan is a document that sets out your needs and goals for caring for your cancer.*

1 ☐ Yes, definitely
2 ☐ Yes, I think so
3 ☐ No
4 ☐ I do not need a care plan
5 ☐ Don't know

51. Do you have a named nurse who you can contact if you have a worry about your cancer care? *A named nurse is sometimes known as a Clinical Nurse Specialist or Specialist Cancer Nurse.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know

52. Do you know who to contact if you have a concern about any aspect of living with or after cancer?

1 ☐ Yes, definitely
2 ☐ Yes, I think so
3 ☐ No

53. Do you think that hospital staff did everything they could to support you following your cancer treatment?

1 ☐ Yes, all of the time
2 ☐ Only some of the time
3 ☐ Never
4 ☐ I did not need any support

54. Do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?

1 ☐ Yes, all of the time
2 ☐ Only some of the time
3 ☐ Never
4 ☐ My general practice is not involved
5 ☐ I do not need any support

55. Following your initial cancer treatment have you been given enough care and help from health and social services (for example, district nurses, home helps or occupational therapists)?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not need help from health or social services
5 ☐ Don't know / can't remember

56. Would it have been helpful to have had more advice or information on any of the following issues: **(Tick all that apply)**

1 ☐ Diet and lifestyle
2 ☐ Physical activity and exercise
3 ☐ Financial help or benefits
4 ☐ Free prescriptions
5 ☐ Returning to or staying in work
6 ☐ Information / advice for family / friends / carer
7 ☐ The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)
8 ☐ The psychological or emotional aspects of living with and after cancer
9 ☐ I have all the information and advice I need

ABOUT YOU

If you are helping someone to complete this questionnaire, please make sure this information is the patient's and not your own.

57. What **year** were you born?

(Please write in) e.g. | 1 | 9 | 4 | 4 |

| Y | Y | Y | Y |

58. Are you male or female?

1 ☐ Male
2 ☐ Female

59. Which of the following best describes your sexual orientation?

1 ☐ Heterosexual / straight (opposite sex)
2 ☐ Bisexual (both sexes)
3 ☐ Lesbian (same sex)
4 ☐ Other
5 ☐ Prefer not to answer

60. Which statement best describes your living arrangements?

1 ☐ I live with partner/spouse/family/friends
2 ☐ I live alone
3 ☐ I live in a nursing home, hospital or other long term care home
4 ☐ Other

61. Do you have a long standing health condition? *Please include anything* ***other than your cancer*** *that has troubled you over a period of time or that could affect you over a period of time.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know / can't say

62. Which, if any, of the following conditions do you have? **(Tick all that apply)**

1 ☐ Alzheimer's disease or dementia
2 ☐ Angina
3 ☐ Arthritis
4 ☐ Asthma or other chronic chest problem
5 ☐ Blindness or visual impairment
6 ☐ Deafness or hearing impairment
7 ☐ Diabetes
8 ☐ Epilepsy
9 ☐ Heart condition
10 ☐ High blood pressure
11 ☐ Kidney disease
12 ☐ Learning difficulty
13 ☐ Liver disease
14 ☐ Long term back problems
15 ☐ Long-standing mental health problem
16 ☐ Long-standing neurological problem
17 ☐ Another long-standing condition
18 ☐ I do not have any of these conditions

63. What was your employment status ***before you were diagnosed with cancer***?

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

64. What is your employment status currently? *If on maternity or sick leave answer in relation to your* ***usual*** *employment status*

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

65. If you are currently employed at the moment, are you:

1 ☐ Not working at all
2 ☐ Working less hours than usual
3 ☐ Working your usual hours
4 ☐ Working more hours than usual
5 ☐ This question does not apply to me

66. To which of these ethnic groups would you say you belong? **(Tick ONE only)**

a. WHITE

1 ☐ British
2 ☐ Irish
3 ☐ Any other White background (Please write in box)

b. MIXED

4 ☐ White and Black Caribbean
5 ☐ White and Black African
6 ☐ White and Asian
7 ☐ Any other Mixed background (Please write in box)

c. ASIAN OR ASIAN BRITISH

8 ☐ Indian
9 ☐ Pakistani
10 ☐ Bangladeshi
11 ☐ Any other Asian background (Please write in box)

d. BLACK OR BLACK BRITISH

12 ☐ Caribbean
13 ☐ African
14 ☐ Any other Black background (Please write in box)

e. CHINESE OR OTHER ETHNIC GROUP

15 ☐ Chinese
16 ☐ Any other ethnic group (Please write in box)

COMMENTS

If you have anything else you would like to tell us about living with and beyond cancer, please do so here:

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Questions 10 – 18 are from FACIT copyright 1987, 1997 by David Cella, PhD

Questions 20 – 40 are from the Social Difficulties Inventory. Originators of the Social Difficulties Inventory: Wright, E.P., Cull, A. and Selby, P.

Living with and beyond Colorectal / Gastro Intestinal Cancer

This questionnaire is about your health and quality of life since being diagnosed with your cancer. Its purpose is to provide information which can help the NHS monitor and improve the quality of health services for future patients.

Who should complete the questionnaire?
The questions should be answered by the person named in the letter enclosed with this questionnaire. If that person needs help to complete the questionnaire, the answers should be given from their point of view – not the point of view of the person who is helping.

Completing the questionnaire
For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please **do not** write your name or address anywhere on the questionnaire.

IMPORTANT INFORMATION

To make sure the information we collect is useful, we need to collect some personal details from you and to access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the quality of life for people who are living with and beyond cancer. These statistics will be used to compare the differences in quality of life for people treated for different types of cancer by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:

- Your personal details and relevant health information can be held and used by an organisation contracted to the Department of Health to analyse the data
- Other information about you held by the Patient Demographics Service, the Secondary Users Service, Cancer Registries and other NHS databases can be held and used by an organisation contracted to the Department of Health to analyse the data
- Your personal details can be used to send you related follow-up questionnaires in the future

Your personal information will be handled securely and anonymised after analysis and before any publication.

Your personal information will not be released by the Department of Health or third party organisations working on its behalf unless required by law or where there is a clear overriding public interest.

You can withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

If you have any queries about the questionnaire,
please call the FREEPHONE helpline number **on 0800 783 1775**

Taking part in this survey is voluntary
Published reports will not contain any personal details

YOUR HEALTH TODAY

The questions in this section are all about your health and how you feel on the day you complete this questionnaire.

1. What treatments have you received for your colorectal / GI cancer? **(Tick all that apply)**

1 ☐ Radiotherapy

2 ☐ Chemotherapy

3 ☐ Surgery

2. How long is it since you completed your **initial treatment** for colorectal / GI cancer? *Treatment includes any chemotherapy, radiotherapy, or surgery for your colorectal / GI cancer.*

1 ☐ I am still having my initial treatment

2 ☐ It is less than 3 months since my initial treatment

3 ☐ It is between 3 and 12 months since my initial treatment

4 ☐ It is between 1 and 5 years since my initial treatment

5 ☐ It is more than 5 years since my initial treatment

6 ☐ Don't know / can't remember

3. How has your colorectal / GI cancer responded to treatment?

1 ☐ My colorectal / GI cancer has responded fully to treatment (I am in remission)

2 ☐ My colorectal / GI cancer has been treated but is still present

3 ☐ My colorectal / GI cancer has not been treated at all

4 ☐ My colorectal / GI cancer has come back after it was originally treated

5 ☐ I am not certain what is happening with my colorectal / GI cancer

4. If you have a stoma (e.g. colostomy) is it:

1 ☐ Still present

2 ☐ Reversed

3 ☐ This does not apply to me

YOUR HEALTH TODAY

Under each heading, please tick the ONE box that best describes your health TODAY.

5. MOBILITY

I have no problems in walking about ☐1
I have slight problems in walking about ☐2
I have moderate problems in walking about ☐3
I have severe problems in walking about ☐4
I am unable to walk about ☐5

6. SELF CARE

I have no problems washing or dressing myself ☐1
I have slight problems washing or dressing myself ☐2
I have moderate problems washing or dressing myself ☐3
I have severe problems washing or dressing myself ☐4
I am unable to wash or dress myself ☐5

7. USUAL ACTIVITIES *(work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ☐1
I have slight problems doing my usual activities ☐2
I have moderate problems doing my usual activities ☐3
I have severe problems doing my usual activities ☐4
I am unable to do my usual activities ☐5

8. PAIN / DISCOMFORT

I have no pain or discomfort ☐1
I have slight pain or discomfort ☐2
I have moderate pain or discomfort ☐3
I have severe pain or discomfort ☐4
I have extreme pain or discomfort ☐5

9. ANXIETY / DEPRESSION

I am not anxious or depressed ☐1
I am slightly anxious or depressed ☐2
I am moderately anxious or depressed ☐3
I am severely anxious or depressed ☐4
I am extremely anxious or depressed ☐5

YOUR HEALTH AND WELL BEING IN THE LAST 7 DAYS

The questions in this section are about your health and how you have felt in the past 7 days.

Please mark one box per line to give your response.

	During the past 7 days:	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
10.	I have swelling or cramps in my stomach area	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
11.	I am losing weight	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
12.	I have control of my bowels	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
13.	I can digest my food well	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
14.	I have diarrhoea	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
15.	I have a good appetite	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
16.	I like the appearance of my body	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
17.	I have difficulty urinating	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
18.	I urinate more frequently than usual	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
19.	I leak urine	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

20. Do you have an ostomy appliance / stoma? 1 ☐ No 2 ☐ Yes

	If yes, please answer the next two items:	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
21.	I am embarrassed by my ostomy appliance / stoma	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
22.	Caring for my ostomy appliance / stoma is difficult	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

23. Do you have any difficulty in controlling your bowels (e.g. any accidents)? 1 ☐ No 2 ☐ Yes

		Monthly	**Weekly**	**Daily**	**Constantly**	**It varies**
24.	If yes, how often do you have difficulties?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

25. In the **past week**, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your heart rate? *This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that is part of your job.*

None	**I day**	**2 days**	**3 days**	**4 days**	**5 days**	**6 days**	**7 days**
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past <u>month</u>.

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These might be to do with things like their family life, social activities, finances and work.

Please tick the response that best describes your answer.

During the past month:	**No difficulty**	**A little**	**Quite a bit**	**Very much**	**Does not apply**
26. Have you had any difficulty in maintaining your independence?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
27. Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
28. Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
29. Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
30. Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
31. Have you had any difficulty with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
32. Have you had any financial difficulties?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
33. Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
34. Have you had any difficulty concerning your work? (or education if you are a student)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
35. Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

	During the past month:	No difficulty	A little	Quite a bit	Very much	Does not apply
36.	Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
37.	Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
38.	Have you had any difficulty concerning sexual matters?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
39.	Have you had any difficulty concerning plans to have a family?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
40.	Have you had any difficulty concerning your appearance or body image?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
41.	Have you felt isolated?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
42.	Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
43.	Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
44.	Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
45.	Have you had any difficulty with your plans to travel or take a holiday?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
46.	Have you had any difficulty with any other area of your everyday life?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Please tick the response that best describes your answer.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply to me
47. I have fears about my cancer spreading	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
48. I have fears about my cancer coming back	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
49. I have fears about death and dying	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
50. I experience memory loss	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
51. I have trouble sleeping	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
52. I have trouble concentrating	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
53. I always feel tired	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
54. I experience mood swings	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
55. I am often irritable	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	

OVERALL SUPPORT AND CARE

56. Do you have an up-to-date written care plan? *A care plan is a document that sets out your needs and goals for caring for your cancer.*

1 ☐ Yes, definitely
2 ☐ Yes, I think so
3 ☐ No
4 ☐ I do not need a care plan
5 ☐ Don't know

57. Do you have a named nurse who you can contact if you have a worry about your cancer care? *A named nurse is sometimes known as a Clinical Nurse Specialist or Specialist Cancer Nurse.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know

58. Do you know who to contact if you have a concern about any aspect of living with or after cancer?

1 ☐ Yes, definitely
2 ☐ Yes, I think so
3 ☐ No

59. Do you think that hospital staff did everything they could to support you following your cancer treatment?

1 ☐ Yes, all of the time
2 ☐ Only some of the time
3 ☐ Never
4 ☐ I did not need any support

60. Do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?

1 ☐ Yes, all of the time
2 ☐ Only some of the time
3 ☐ Never
4 ☐ My general practice is not involved
5 ☐ I do not need any support

61. Following your initial cancer treatment have you been given enough care and help from health and social services (for example, district nurses, home helps or occupational therapists)?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not need help from health or social services
5 ☐ Don't know / can't remember

62. Would it have been helpful to have had more advice or information on any of the following issues: **(Tick all that apply)**

1 ☐ Diet and lifestyle
2 ☐ Physical activity and exercise
3 ☐ Financial help or benefits
4 ☐ Free prescriptions
5 ☐ Returning to or staying in work
6 ☐ Information / advice for family / friends / carer
7 ☐ The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)
8 ☐ The psychological or emotional aspects of living with and after cancer
9 ☐ I have all the information and advice I need

ABOUT YOU

If you are helping someone to complete this questionnaire, please make sure this information is the patient's and not your own.

63. What **year** were you born?

(Please write in) e.g. 1 9 4 4

Y	Y	Y	Y

64. Are you male or female?

1 ☐ Male
2 ☐ Female

65. Which of the following best describes your sexual orientation?

1 ☐ Heterosexual / straight (opposite sex)
2 ☐ Bisexual (both sexes)
3 ☐ Gay or lesbian (same sex)
4 ☐ Other
5 ☐ Prefer not to answer

66. Which statement best describes your living arrangements?

1 ☐ I live with partner/spouse/family/friends
2 ☐ I live alone
3 ☐ I live in a nursing home, hospital or other long term care home
4 ☐ Other

67. Do you have a long standing health condition? *Please include anything **other than your cancer** that has troubled you over a period of time or that could affect you over a period of time.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know / can't say

68. Which, if any, of the following conditions do you have? **(Tick all that apply)**

1 ☐ Alzheimer's disease or dementia
2 ☐ Angina
3 ☐ Arthritis
4 ☐ Asthma or other chronic chest problem
5 ☐ Blindness or visual impairment
6 ☐ Deafness or hearing impairment
7 ☐ Diabetes
8 ☐ Epilepsy
9 ☐ Heart condition
10 ☐ High blood pressure
11 ☐ Kidney disease
12 ☐ Learning difficulty
13 ☐ Liver disease
14 ☐ Long term back problems
15 ☐ Long-standing mental health problem
16 ☐ Long-standing neurological problem
17 ☐ Another long-standing condition
18 ☐ I do not have any of these conditions

69. What was your employment status ***before you were diagnosed with cancer***?

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

70. What is your employment status currently? *If on maternity or sick leave answer in relation to your **usual** employment status.*

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

71. If you are currently employed at the moment, are you:

1 ☐ Not working at all
2 ☐ Working less hours than usual
3 ☐ Working your usual hours
4 ☐ Working more hours than usual
5 ☐ This question does not apply to me

72. To which of these ethnic groups would you say you belong? **(Tick ONE only)**

a. WHITE

1 ☐ British
2 ☐ Irish
3 ☐ Any other White background (Please write in box)

☐

b. MIXED

4 ☐ White and Black Caribbean
5 ☐ White and Black African
6 ☐ White and Asian
7 ☐ Any other Mixed background (Please write in box)

☐

c. ASIAN OR ASIAN BRITISH

8 ☐ Indian
9 ☐ Pakistani
10 ☐ Bangladeshi
11 ☐ Any other Asian background (Please write in box)

☐

d. BLACK OR BLACK BRITISH

12 ☐ Caribbean
13 ☐ African
14 ☐ Any other Black background (Please write in box)

☐

e. CHINESE OR OTHER ETHNIC GROUP

15 ☐ Chinese
16 ☐ Any other ethnic group (Please write in box)

☐

COMMENTS

If you have anything else you would like to tell us about living with and beyond cancer, please do so here:

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Living with and beyond Non Hodgkin's Lymphoma

This questionnaire is about your health and quality of life since being diagnosed with your cancer. Its purpose is to provide information which can help the NHS monitor and improve the quality of health services for future patients.

Who should complete the questionnaire?

The questions should be answered by the person named in the letter enclosed with this questionnaire. If that person needs help to complete the questionnaire, the answers should be given from their point of view – not the point of view of the person who is helping.

Completing the questionnaire

For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please **do not** write your name or address anywhere on the questionnaire.

IMPORTANT INFORMATION

To make sure the information we collect is useful, we need to collect some personal details from you and to access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the quality of life for people who are living with and beyond cancer. These statistics will be used to compare the differences in quality of life for people treated for different types of cancer by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:

- Your personal details and relevant health information can be held and used by an organisation contracted to the Department of Health to analyse the data
- Other information about you held by the Patient Demographics Service, the Secondary Users Service, Cancer Registries and other NHS databases can be held and used by an organisation contracted to the Department of Health to analyse the data
- Your personal details can be used to send you related follow-up questionnaires in the future

Your personal information will be handled securely and anonymised after analysis and before any publication.

Your personal information will not be released by the Department of Health or third party organisations working on its behalf unless required by law or where there is a clear overriding public interest.

You can withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

If you have any queries about the questionnaire,
please call the FREEPHONE helpline number **on 0800 783 1775**

Taking part in this survey is voluntary
Published reports will not contain any personal details

YOUR HEALTH TODAY

The questions in this section are all about your health and how you feel on the day you complete this questionnaire.

1. What treatments have you received for your Non Hodgkin's Lymphoma (NHL)? **(Tick all that apply)**

1 ☐ Radiotherapy
2 ☐ Chemotherapy
3 ☐ Surgery
4 ☐ Antibody therapy (including Rituximab)
5 ☐ Stem cell transplant

2. How long is it since you completed your **initial treatment** for NHL? *Treatment includes any chemotherapy, radiotherapy, or surgery for your NHL. When answering this question please do not include antibody (Rituximab) treatment which you may have been given as a maintenance treatment following chemotherapy.*

1 ☐ I am still having my initial treatment
2 ☐ It is less than 3 months since my initial treatment
3 ☐ It is between 3 and 12 months since my initial treatment
4 ☐ It is between 1 and 5 years since my initial treatment
5 ☐ It is more than 5 years since my initial treatment
6 ☐ Don't know / can't remember

3. How has your NHL responded to treatment?

1 ☐ My NHL has responded fully to treatment (I am in remission)
2 ☐ My NHL has been treated but is still present
3 ☐ My NHL has not been treated at all
4 ☐ My NHL has come back after it was originally treated
5 ☐ I am not certain what is happening with my NHL

YOUR HEALTH TODAY

Under each heading, please tick the ONE box that best describes your health TODAY.

4. MOBILITY

I have no problems in walking about	☐1
I have slight problems in walking about	☐2
I have moderate problems in walking about	☐3
I have severe problems in walking about	☐4
I am unable to walk about	☐5

5. SELF CARE

I have no problems washing or dressing myself	☐1
I have slight problems washing or dressing myself	☐2
I have moderate problems washing or dressing myself	☐3
I have severe problems washing or dressing myself	☐4
I am unable to wash or dress myself	☐5

6. USUAL ACTIVITIES *(work, study, housework, family or leisure activities)*

I have no problems doing my usual activities	☐1
I have slight problems doing my usual activities	☐2
I have moderate problems doing my usual activities	☐3
I have severe problems doing my usual activities	☐4
I am unable to do my usual activities	☐5

7. PAIN / DISCOMFORT

I have no pain or discomfort	☐1
I have slight pain or discomfort	☐2
I have moderate pain or discomfort	☐3
I have severe pain or discomfort	☐4
I have extreme pain or discomfort	☐5

8. ANXIETY / DEPRESSION

I am not anxious or depressed	☐1
I am slightly anxious or depressed	☐2
I am moderately anxious or depressed	☐3
I am severely anxious or depressed	☐4
I am extremely anxious or depressed	☐5

YOUR HEALTH AND WELL BEING IN THE LAST 7 DAYS

The questions in this section are about your health and how you have felt in the past 7 days.

Please mark one box per line to give your response.

	During the past 7 days:	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
9.	I have certain parts of my body where I experience pain	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
10.	I am bothered by lumps or swelling in certain parts of my body (e.g. neck, armpits, or groin)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
11.	I am bothered by fevers (episodes of high body temperature)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
12.	I have night sweats	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
13.	I am bothered by itching	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
14.	I have trouble sleeping at night	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
15.	I get tired easily	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
16.	I am losing weight	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
17.	I have a loss of appetite	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
18.	I have trouble concentrating	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
19.	I worry about getting infections	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
20.	I worry that I might get new symptoms of my illness	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
21.	I feel isolated from others because of my illness or treatment	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
22.	I have emotional ups and downs	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
23.	Because of my illness, I have difficulty planning for the future	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

24. In the **past week**, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your heart rate? *This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that is part of your job.*

None	**I day**	**2 days**	**3 days**	**4 days**	**5 days**	**6 days**	**7 days**
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These might be to do with things like their family life, social activities, finances and work.

Please tick the response that best describes your answer.

	During the past month:	**No difficulty**	**A little**	**Quite a bit**	**Very much**	**Does not apply**
25.	Have you had any difficulty in maintaining your independence?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
26.	Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
27.	Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
28.	Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
29.	Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
30.	Have you had any difficulty with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
31.	Have you had any financial difficulties?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
32.	Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
33.	Have you had any difficulty concerning your work? (or education if you are a student)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
34.	Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

During the past month:	**No difficulty**	**A little**	**Quite a bit**	**Very much**	**Does not apply**
35. Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
36. Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
37. Have you had any difficulty concerning sexual matters?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
38. Have you had any difficulty concerning plans to have a family?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
39. Have you had any difficulty concerning your appearance or body image?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
40. Have you felt isolated?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
41. Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
42. Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
43. Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
44. Have you had any difficulty with your plans to travel or take a holiday?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
45. Have you had any difficulty with any other area of your everyday life?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Please tick the response that best describes your answer.

		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply to me
46.	I have fears about my cancer spreading	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
47.	I have fears about my cancer coming back	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
48.	I have fears about death and dying	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
49.	I experience memory loss	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
50.	I have trouble sleeping	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
51.	I have trouble concentrating	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
52.	I always feel tired	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
53.	I experience mood swings	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
54.	I am often irritable	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	

OVERALL SUPPORT AND CARE

55. Do you have an up-to-date written care plan? *A care plan is a document that sets out your needs and goals for caring for your cancer.*

1 ☐ Yes, definitely
2 ☐ Yes, I think so
3 ☐ No
4 ☐ I do not need a care plan
5 ☐ Don't know

56. Do you have a named nurse who you can contact if you have a worry about your cancer care? *A named nurse is sometimes known as a Clinical Nurse Specialist or Specialist Cancer Nurse.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know

57. Do you know who to contact if you have a concern about any aspect of living with or after cancer?

1 ☐ Yes, definitely
2 ☐ Yes, I think so
3 ☐ No

58. Do you think that hospital staff did everything they could to support you following your cancer treatment?

1 ☐ Yes, all of the time
2 ☐ Only some of the time
3 ☐ Never
4 ☐ I did not need any support

59. Do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?

1 ☐ Yes, all of the time
2 ☐ Only some of the time
3 ☐ Never
4 ☐ My general practice is not involved
5 ☐ I do not need any support

60. Following your initial cancer treatment have you been given enough care and help from health and social services (for example, district nurses, home helps or occupational therapists)?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not need help from health or social services
5 ☐ Don't know / can't remember

61. Would it have been helpful to have had more advice or information on any of the following issues: **(Tick all that apply)**

1 ☐ Diet and lifestyle
2 ☐ Physical activity and exercise
3 ☐ Financial help or benefits
4 ☐ Free prescriptions
5 ☐ Returning to or staying in work
6 ☐ Information / advice for family / friends / carer
7 ☐ The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)
8 ☐ The psychological or emotional aspects of living with and after cancer
9 ☐ I have all the information and advice I need

ABOUT YOU

If you are helping someone to complete this questionnaire, please make sure this information is the patient's and not your own.

62. What **year** were you born?

(Please write in) e.g. 1 9 4 4

Y	Y	Y	Y

63. Are you male or female?

1 ☐ Male
2 ☐ Female

64. Which of the following best describes your sexual orientation?

1 ☐ Heterosexual / straight (opposite sex)
2 ☐ Bisexual (both sexes)
3 ☐ Gay or lesbian (same sex)
4 ☐ Other
5 ☐ Prefer not to answer

65. Which statement best describes your living arrangements?

1 ☐ I live with partner / spouse / family / friends
2 ☐ I live alone
3 ☐ I live in a nursing home, hospital or other long term care home
4 ☐ Other

66. Do you have a long standing health condition? *Please include anything* ***other than your cancer*** *that has troubled you over a period of time or that could affect you over a period of time.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know / can't say

67. Which, if any, of the following conditions do you have? **(Tick all that apply)**

1 ☐ Alzheimer's disease or dementia
2 ☐ Angina
3 ☐ Arthritis
4 ☐ Asthma or other chronic chest problem
5 ☐ Blindness or visual impairment
6 ☐ Deafness or hearing impairment
7 ☐ Diabetes
8 ☐ Epilepsy
9 ☐ Heart condition
10 ☐ High blood pressure
11 ☐ Kidney disease
12 ☐ Learning difficulty
13 ☐ Liver disease
14 ☐ Long term back problems
15 ☐ Long-standing mental health problem
16 ☐ Long-standing neurological problem
17 ☐ Another long-standing condition
18 ☐ I do not have any of these conditions

68. What was your employment status ***before you were diagnosed with cancer***?

1 ☐ Full time employment

2 ☐ Part time employment

3 ☐ Homemaker

4 ☐ Student (in education)

5 ☐ Retired

6 ☐ Unemployed – and seeking work

7 ☐ Unemployed – unable to work for health reasons

8 ☐ Other

69. What is your employment status currently? *If on maternity or sick leave answer in relation to your* ***usual*** *employment status.*

1 ☐ Full time employment

2 ☐ Part time employment

3 ☐ Homemaker

4 ☐ Student (in education)

5 ☐ Retired

6 ☐ Unemployed – and seeking work

7 ☐ Unemployed – unable to work for health reasons

8 ☐ Other

70. If you are currently employed at the moment, are you:

1 ☐ Not working at all

2 ☐ Working less hours than usual

3 ☐ Working your usual hours

4 ☐ Working more hours than usual

5 ☐ This question does not apply to me

71. To which of these ethnic groups would you say you belong? **(Tick ONE only)**

a. WHITE

1 ☐ British

2 ☐ Irish

3 ☐ Any other White background (Please write in box)

☐

b. MIXED

4 ☐ White and Black Caribbean

5 ☐ White and Black African

6 ☐ White and Asian

7 ☐ Any other Mixed background (Please write in box)

☐

c. ASIAN OR ASIAN BRITISH

8 ☐ Indian

9 ☐ Pakistani

10 ☐ Bangladeshi

11 ☐ Any other Asian background (Please write in box)

☐

d. BLACK OR BLACK BRITISH

12 ☐ Caribbean

13 ☐ African

14 ☐ Any other Black background (Please write in box)

☐

e. CHINESE OR OTHER ETHNIC GROUP

15 ☐ Chinese

16 ☐ Any other ethnic group (Please write in box)

☐

COMMENTS

If you have anything else you would like to tell us about living with and beyond cancer, please do so here:

Questions 4 - 8 are EQ-5D-5L. UK (English) v.2 © 2009 EuroQol Group. EQ-5D™ is a trade mark of the EuroQol Group.

Questions 9 – 23 are from FACIT. Copyright 1987, 1997 by David Cella, PhD

Questions 25 – 45 are from the Social Difficulties Inventory. Originators of the Social Difficulties Inventory: Wright, E.P., Cull, A. and Selby, P.

Living with and beyond Prostate Cancer

This questionnaire is about your health and quality of life since being diagnosed with your cancer. Its purpose is to provide information which can help the NHS monitor and improve the quality of health services for future patients.

Who should complete the questionnaire?
The questions should be answered by the person named in the letter enclosed with this questionnaire. If that person needs help to complete the questionnaire, the answers should be given from their point of view – not the point of view of the person who is helping.

Completing the questionnaire
For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please **do not** write your name or address anywhere on the questionnaire.

IMPORTANT INFORMATION

To make sure the information we collect is useful, we need to collect some personal details from you and to access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the quality of life for people who are living with and beyond cancer. These statistics will be used to compare the differences in quality of life for people treated for different types of cancer by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:

- Your personal details and relevant health information can be held and used by an organisation contracted to the Department of Health to analyse the data
- Other information about you held by the Patient Demographics Service, the Secondary Users Service, Cancer Registries and other NHS databases can be held and used by an organisation contracted to the Department of Health to analyse the data
- Your personal details can be used to send you related follow-up questionnaires in the future

Your personal information will be handled securely and anonymised after analysis and before any publication.

Your personal information will not be released by the Department of Health or third party organisations working on its behalf unless required by law or where there is a clear overriding public interest.

You can withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

If you have any queries about the questionnaire,
please call the FREEPHONE helpline number **on 0800 783 1775**

Taking part in this survey is voluntary
Published reports will not contain any personal details

YOUR HEALTH TODAY

The questions in this section are all about your health and how you feel on the day you complete this questionnaire.

1. What treatments have you received for your prostate cancer? **(Tick all that apply)**

1 ☐ Radiotherapy (including brachytherapy) (with or without planned hormonal treatment)

2 ☐ Surgery

3 ☐ Hormone treatment

4 ☐ Chemotherapy (not including hormones)

5 ☐ HIFU

6 ☐ Cryotherapy

7 ☐ Active Surveillance (close monitoring but no current intervention)

2. How long is it since you completed your **initial treatment** for prostate cancer? *Treatment includes any chemotherapy, radiotherapy, or surgery for your prostate cancer. When answering this question please do not include hormone treatments.*

1 ☐ I am still having my initial treatment

2 ☐ It is less than 3 months since my initial treatment

3 ☐ It is between 3 and 12 months since my initial treatment

4 ☐ It is between 1 and 5 years since my initial treatment

5 ☐ It is more than 5 years since my initial treatment

6 ☐ Don’t know / can’t remember

3. How has your prostate cancer responded to treatment?

1 ☐ My prostate cancer has responded fully to treatment (I am in remission)

2 ☐ My prostate cancer has been treated but is still present

3 ☐ My prostate cancer has not been treated at all

4 ☐ My prostate cancer has come back after it was originally treated

5 ☐ I am not certain what is happening with my prostate cancer

YOUR HEALTH TODAY

Under each heading, please tick the ONE box that best describes your health TODAY.

4. MOBILITY

I have no problems in walking about	☐1
I have slight problems in walking about	☐2
I have moderate problems in walking about	☐3
I have severe problems in walking about	☐4
I am unable to walk about	☐5

5. SELF CARE

I have no problems washing or dressing myself	☐1
I have slight problems washing or dressing myself	☐2
I have moderate problems washing or dressing myself	☐3
I have severe problems washing or dressing myself	☐4
I am unable to wash or dress myself	☐5

6. USUAL ACTIVITIES *(work, study, housework, family or leisure activities)*

I have no problems doing my usual activities	☐1
I have slight problems doing my usual activities	☐2
I have moderate problems doing my usual activities	☐3
I have severe problems doing my usual activities	☐4
I am unable to do my usual activities	☐5

7. PAIN / DISCOMFORT

I have no pain or discomfort	☐1
I have slight pain or discomfort	☐2
I have moderate pain or discomfort	☐3
I have severe pain or discomfort	☐4
I have extreme pain or discomfort	☐5

8. ANXIETY / DEPRESSION

I am not anxious or depressed	☐1
I am slightly anxious or depressed	☐2
I am moderately anxious or depressed	☐3
I am severely anxious or depressed	☐4
I am extremely anxious or depressed	☐5

YOUR HEALTH AND WELLBEING IN THE LAST 7 DAYS

The questions in this section are about your health and how you have felt in the past <u>7 days</u>.

Please mark one box per line to give your response.

	During the past 7 days:	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
9.	I am losing weight	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
10.	I have a good appetite	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
11.	I have aches and pains that bother me	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
12.	I have certain parts of my body where I experience pain	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
13.	My pain keeps me from doing things I want to do	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
14.	I am satisfied with my present comfort level	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
15.	I have trouble moving my bowels	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
16.	I have difficulty urinating	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
17.	I urinate more frequently than usual	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
18.	My problems with urinating limit my activities	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
19.	I am able to have and maintain an erection	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
20.	I leak urine	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

21. Do you have any difficulty in controlling your bowels (e.g. any accidents)? 1 ☐ No 2 ☐ Yes

		Monthly	**Weekly**	**Daily**	**Constantly**	**It varies**
22.	If yes, how often do you have difficulties?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

23. In the **past week**, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your heart rate? *This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that is part of your job.*

None	**I day**	**2 days**	**3 days**	**4 days**	**5 days**	**6 days**	**7 days**
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past <u>month</u>.

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These might be to do with things like their family life, social activities, finances and work.

Please tick the response that best describes your answer.

During the past month:	**No difficulty**	**A little**	**Quite a bit**	**Very much**	**Does not apply**
24. Have you had any difficulty in maintaining your independence?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
25. Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
26. Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
27. Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
28. Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
29. Have you had any difficulty with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
30. Have you had any financial difficulties?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
31. Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
32. Have you had any difficulty concerning your work? (or education if you are a student)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
33. Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

During the past month:	No difficulty	A little	Quite a bit	Very much	Does not apply
34. Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
35. Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
36. Have you had any difficulty concerning sexual matters?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
37. Have you had any difficulty concerning plans to have a family?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
38. Have you had any difficulty concerning your appearance or body image?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
39. Have you felt isolated?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
40. Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
41. Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
42. Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
43. Have you had any difficulty with your plans to travel or take a holiday?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
44. Have you had any difficulty with any other area of your everyday life?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Please tick the response that best describes your answer.

		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply to me
45.	I have fears about my cancer spreading	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	6 ☐
46.	I have fears about my cancer coming back	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	6 ☐
47.	I have fears about death and dying	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
48.	I experience memory loss	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
49.	I have trouble sleeping	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
50.	I have trouble concentrating	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
51.	I always feel tired	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
52.	I experience mood swings	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
53.	I am often irritable	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	

OVERALL SUPPORT AND CARE

54. Do you have an up-to-date written care plan? *A care plan is a document that sets out your needs and goals for caring for your cancer.*

1 ☐ Yes, definitely
2 ☐ Yes, I think so
3 ☐ No
4 ☐ I do not need a care plan
5 ☐ Don't know

55. Do you have a named nurse who you can contact if you have a worry about your cancer care? *A named nurse is sometimes known as a Clinical Nurse Specialist or Specialist Cancer Nurse.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know

56. Do you know who to contact if you have a concern about any aspect of living with or after cancer?

1 ☐ Yes, definitely
2 ☐ Yes, I think so
3 ☐ No

57. Do you think that hospital staff did everything they could to support you following your cancer treatment?

1 ☐ Yes, all of the time
2 ☐ Only some of the time
3 ☐ Never
4 ☐ I did not need any support

58. Do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?

1 ☐ Yes, all of the time
2 ☐ Only some of the time
3 ☐ Never
4 ☐ My general practice is not involved
5 ☐ I do not need any support

59. Following your initial cancer treatment have you been given enough care and help from health and social services (for example, district nurses, home helps or occupational therapists)?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not need help from health or social services
5 ☐ Don't know / can't remember

60. Would it have been helpful to have had more advice or information on any of the following issues: **(Tick all that apply)**

1 ☐ Diet and lifestyle
2 ☐ Physical activity and exercise
3 ☐ Financial help or benefits
4 ☐ Free prescriptions
5 ☐ Returning to or staying in work
6 ☐ Information / advice for family / friends / carer
7 ☐ The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)
8 ☐ The psychological or emotional aspects of living with and after cancer
9 ☐ I have all the information and advice I need

ABOUT YOU

If you are helping someone to complete this questionnaire, please make sure this information is the patient's and not your own.

61. What **year** were you born?

(Please write in) e.g. 1 9 4 4

Y	Y	Y	Y

62. Are you male or female?

1 ☐ Male
2 ☐ Female

63. Which of the following best describes your sexual orientation?

1 ☐ Heterosexual / straight (opposite sex)
2 ☐ Bisexual (both sexes)
3 ☐ Gay (same sex)
4 ☐ Other
5 ☐ Prefer not to answer

64. Which statement best describes your living arrangements?

1 ☐ I live with partner/spouse/family/friends
2 ☐ I live alone
3 ☐ I live in a nursing home, hospital or other long term care home
4 ☐ Other

65. Do you have a long standing health condition? *Please include anything **other than your cancer** that has troubled you over a period of time or that could affect you over a period of time.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know / can't say

66. Which, if any, of the following conditions do you have? **(Tick all that apply)**

1 ☐ Alzheimer's disease or dementia
2 ☐ Angina
3 ☐ Arthritis
4 ☐ Asthma or other chronic chest problem
5 ☐ Blindness or visual impairment
6 ☐ Deafness or hearing impairment
7 ☐ Diabetes
8 ☐ Epilepsy
9 ☐ Heart condition
10 ☐ High blood pressure
11 ☐ Kidney disease
12 ☐ Learning difficulty
13 ☐ Liver disease
14 ☐ Long term back problems
15 ☐ Long-standing mental health problem
16 ☐ Long-standing neurological problem
17 ☐ Another long-standing condition
18 ☐ I do not have any of these conditions

67. What was your employment status ***before you were diagnosed with cancer***?

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

68. What is your employment status currently? *If on maternity or sick leave answer in relation to your **usual** employment status.*

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

69. If you are currently employed at the moment, are you:

1 ☐ Not working at all
2 ☐ Working less hours than usual
3 ☐ Working your usual hours
4 ☐ Working more hours than usual
5 ☐ This question does not apply to me

70. To which of these ethnic groups would you say you belong? **(Tick ONE only)**

a. WHITE

1 ☐ British
2 ☐ Irish
3 ☐ Any other White background (Please write in box)

☐

b. MIXED

4 ☐ White and Black Caribbean
5 ☐ White and Black African
6 ☐ White and Asian
7 ☐ Any other Mixed background (Please write in box)

☐

c. ASIAN OR ASIAN BRITISH

8 ☐ Indian
9 ☐ Pakistani
10 ☐ Bangladeshi
11 ☐ Any other Asian background (Please write in box)

☐

d. BLACK OR BLACK BRITISH

12 ☐ Caribbean
13 ☐ African
14 ☐ Any other Black background (Please write in box)

☐

e. CHINESE OR OTHER ETHNIC GROUP

15 ☐ Chinese
16 ☐ Any other ethnic group (Please write in box)

☐

COMMENTS

If you have anything else you would like to tell us about living with and beyond cancer, please do so here:

Questions 4-8 are EQ -5D-5L. UK (English) v.2 © 2009 EuroQol Group. EQ-5D™ is a trade mark of the EuroQol Group.

Questions 9 – 20 are taken from FACIT copyright 1987, 1997 by David Cella, PhD

Questions 24 – 44 are taken from the Social Difficulties Inventory. Originators of the Social Difficulties Inventory: Wright, E.P., Cull, A. and Selby, P.

NIGB
Ethics and Confidentiality Committee

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Simon Phillips
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London
SE1 8UG

18 May 2011

Dear Simon

8-05 (b)/2010 National Cancer Survivorship Initiative – patient reported outcome survey of cancer survivors

Thank you for your application for support under section 251 of the NHS Act 2006 to process patient identifiable information without consent. This application was considered by the Ethics and Confidentiality Committee at its meeting on 01 December 2010.

Context

This application from the Department of Health (acting as sponsor) and Quality Health (the implementation provider) sought support to cover the pilot phase of a proposed national survey of cancer survivors, which is intended to last up until 30 June 2011.

Update: due to slippages in timetables, it has been noted that following notification on 17 May 2011, that the survey will be completed by September 2011.

The purpose of this activity was to aim to improve understanding of quality of life outcomes for cancer survivors and was intended to support the DH National Cancer Survivorship Initiative (NCSI). The activity would build upon the current national Cancer Patient Experience Survey Programme (CPESP) 2010 which focuses on the experience of care of cancer patients.

Section 251 support was sought to enable the legitimate transfer of patient data from the Cancer Registries to Quality Health, and for Quality Health to liaise with cancer centres so that patient questionnaires would be sent to patients under cover of appropriate cancer centre letter headed paper. Support was also required to enable a sample to be identified from the cancer registries. To carry out the activity, Quality Health would require access to name, address, sex, ethnic group, year of birth, NHS number, ICD10 code, speciality code, date of diagnosis, and Trust NACS code for most recent treatment spell.

Outcome

The letter dated 07 December 2010 set out the Committee’s rationale and decision for its recommendation of provisional support, subject to a number of clarifications and conditions of approval. A response was subsequently provided providing copies of requested documentation and further explanation around the clarification areas.

In particular, Members debated the response to the information being sent on GP headed paper, and on balance and in this specific instance, agreed that this would not be feasible.

As all aspects have been satisfactorily addressed, this letter provides confirmation of your final approval, and our Register of approved applications will shortly be updated to include this application.

If you have any queries regarding the outcome of this letter please do not hesitate to contact the NIGB Office on 020 7633 7052. Email queries should be sent to eccapplications@nhs.net.

Yours sincerely

Natasha Dunkley
NIGB Approvals Manager

NIGB
Ethics and Confidentiality Committee

Ethics and Confidentiality Committee
Standard conditions of approval

The support provided under section 251 is subject to the following standard conditions.

The applicant will ensure that:

1. The requested patient identifiable information is only used for the purpose(s) set out in the application.
2. Confidentiality is preserved and that there is no disclosure of information in aggregate or patient level form that may inferentially identify a person, nor will any attempt be made to identify individuals, households or organisations in the data.
3. Requirements of the Statistics and Registration Services Act 2007 are adhered to regarding publication when relevant.
4. All staff with access to patient identifiable information have contractual obligations of confidentiality, enforceable through disciplinary procedures.
5. All staff with access to patient identifiable information have received appropriate ongoing training to ensure they are aware of their responsibilities.
6. Activities are consistent with the Data Protection Act 1998.
7. Audit of data processing by a designated agent of the Secretary of State is facilitated and supported.
8. The wishes of people who have withheld or withdrawn their consent are respected.
9. The NIGB Office is notified of any significant changes which impact on the approval of the application.
10. An annual review to be provided no later than 12 months from date of your final approval letter

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	6
Objectives	3	State specific objectives, including any prespecified hypotheses	6
Methods			
Study design	4	Present key elements of study design early in the paper	7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	7
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	7
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	8-10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	8-10
Bias	9	Describe any efforts to address potential sources of bias	*7-10*
Study size	10	Explain how the study size was arrived at	7
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	10
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	10
		(*b*) Describe any methods used to examine subgroups and interactions	10
		(*c*) Explain how missing data were addressed	12
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	10
		(*e*) Describe any sensitivity analyses	10
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	11
		(b) Give reasons for non-participation at each stage	11
		(c) Consider use of a flow diagram	n/a
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	11
		(b) Indicate number of participants with missing data for each variable of interest	12
Outcome data	15*	Report numbers of outcome events or summary measures	12-16
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	13-15
		(*b*) Report category boundaries when continuous variables were categorized	12-16
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	12-16
Discussion			
Key results	18	Summarise key results with reference to study objectives	17-18
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	17-19
Generalisability	21	Discuss the generalisability (external validity) of the study results	18
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	21

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Patient Reported Outcomes of Cancer Survivors in England 1 to 5 years after Diagnosis: a cross-sectional survey.

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2012-002317.R1
Article Type:	Research
Date Submitted by the Author:	04-Feb-2013
Complete List of Authors:	Glaser, Adam; Leeds Teaching Hospitals NHS Trust, Department of Paediatric Oncology Fraser, Lorna Corner, Jessica Feltbower, Richard Morris, Eva Hartwell, Greg Richards, Sir Mike; Director, National Cancer Action Team,
Primary Subject Heading:	Oncology
Secondary Subject Heading:	Health policy, Public health, Research methods
Keywords:	Adult oncology < ONCOLOGY, Breast tumours < ONCOLOGY, Gastrointestinal tumours < ONCOLOGY, Lymphoma < ONCOLOGY, Urological tumours < ONCOLOGY

Title:

Patient Reported Outcomes of Cancer Survivors in England 1 to 5 years after Diagnosis: a cross-sectional survey.

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Key Words:

Cancer, Survivorship, Quality of Life, Patient Reported Outcomes, EQ5D, FACT

Word Count:

abstract: 302 & main body of paper: 4391

Abstract

Objectives: To determine the feasibility of collecting population based patient reported outcome measures (PROMS) in assessing quality of life (QoL) to inform development of a national PROMS programme for cancer and to begin to describe outcomes in a UK cohort of survivors.

Design: Cross-sectional postal survey of cancer survivors using a population-based sampling approach.

Setting: English National Health Service.

Participants: 4,992 breast, colorectal, prostate and Non-Hodgkin's Lymphoma survivors one to five years from diagnosis.

Primary and Secondary Outcome Measures: Implementation issues, response rates, cancer-specific morbidities utilising items including the EQ5D, tumour-specific sub-scales of the Functional Assessment of Cancer Therapy and Social Difficulties Inventory.

Results:

3,300 (66%) survivors returned completed questionnaires. The majority aged 85+ years did not respond and there was an effect of deprivation on response rates. Response rates did not differ by gender, time since diagnosis or cancer type.

The presence of one or more long term conditions was associated with significantly lower QoL scores. Individuals from most deprived areas reported lower QoL scores and poorer outcomes on other measures, as did those self-reporting recurrent disease or uncertainty about disease status. QoL scores were stable at all time points for all cancers except NHL. QoL scores were lower than those from the general population in Health Survey for England (2008) and General Practice Patient Survey.

47% of patients reported fear of recurrence whilst 20% reported moderate or severe difficulties with mobility or usual activities. Bowel and urinary problems were common among colorectal and prostate patients. Poor bowel and bladder control were significantly associated with lower QoL.

Conclusions: This method of assessing QoL of cancer survivors is feasible and acceptable to most survivors. Routine collection of national population- based PROMS will enable identification of, and support for, the specific needs of survivors whilst allowing for comparison of outcome by service provider.

Funding

This survey was funded by the Department of Health, England.

Article Summary

Article Focus

To determine the feasibility of routinely collecting population-based patient reported outcomes (PROMS) of cancer survivors to gather information on quality of life and cancer related morbidities that can be used to inform the development of a national PROMS programme for cancer.

Key messages

- Collection of population-based information on quality of life from cohorts of cancer patients who are 1 to 5 years post diagnosis through cancer registries is feasible.
- The best quality of life was reported by those in remission and with no other long term conditions.
- Information obtained by widespread extension of this methodology will enable health economies to compare outcome across provider organisations and facilitate provision of enhanced services to meet the needs of cancer survivors.

Strengths and Limitations

- Findings relate to the largest European survey of survivors of multiple cancer types at clearly defined time points from diagnosis.
- The study design eliminates many of the criticisms which have hindered the collection of population-based cancer patient reported outcome data in the past.
- English cancer registries provide a reliable denominator population from which to identify eligible participants.
- The questionnaires for the four cancer groups were identified as having face and content validity by a panel of health and social care professionals prior to use.
- Presence of multiple cancer groups, time points and some missing data may have resulted in a lack of power for certain analyses.

- Selection bias may have arisen through differences in-response rates according to cancer group, deprivation category and age.
- The study excluded those treated in the private sector.

Introduction

1.8 million people are living with and beyond a diagnosis of cancer in England and prevalence is predicted to increase by 3% per annum.[1] Cancer treatments are effectively reducing mortality and extending life, yet there is evidence that physical, psychological and social needs are not being addressed by the health and social care services, with individuals reporting significant unmet needs[2]. There is a lack of robust population-based information from which the prevalence, and impact, of disease and treatment associated morbidity burden can be ascertained and policy for appropriate interventions developed[3]. It has been equally difficult for health economies to compare the quality of health of those following treatment for cancer to those living with other long term conditions (LTC). These deficits have hampered the provision of comprehensive robust services for this growing population[4].

In the United States a number of significant initiatives have been launched to systematically measure health outcomes in cancer survivors using patient reported outcome measures (PROMS) through the National Cancer Institute and American Cancer Society[3 5-6]. In Europe, at least one regional cancer register has started to collect PROMS via approaches made through the treating clinical teams[7-8]. The focus of PROMS work to date has been on refining treatment decision making for individuals and determining methodological approaches to implementation and analysis[5-6 9-11]. These efforts have yet to feed through into major national health system service improvement initiatives. The evaluation of patients' experiences of cancer care in England, through the National Cancer Patient Experience Survey, has resulted in care provider organisations and commissioners being able to identify areas of strengths and weakness in acute cancer care provision[12].

Our objective was to determine the feasibility of routinely collecting population-based PROMS of cancer survivors (via a postal survey of individuals identified from cancer registry information), without introduction from clinicans or researchers known to participants, to gather information on quality of life (QoL) and cancer related morbidities that can be used to inform the development of a national PROMS programme for cancer.

Methods

Study design

A cross-sectional postal survey was undertaken of individuals with a diagnosis of breast, colorectal, non-Hodgkin's lymphoma (NHL) or prostate cancer one, two, three and five years earlier. These four time-points were chosen to gain an understanding of whether PROMS varied over time. Patients attending private healthcare centres were excluded as the aims of the study focused on the assessment of PROMS within the National Health Service (NHS) in England.

Cohort Identification and Survey Process

Three cancer registries (Thames Cancer Registry, Eastern Cancer Registry and Information Centre, West Midlands Cancer Intelligence Unit) were chosen as representative examples of the eight cancer registries in England. They provided information on all relevant cancer diagnoses[12] (Supplementary File 1) between 01/02/2010-30/04/2010, 01/02/2009-30/04/2009, 01/02/2008-30/04/2008, and 01/02/2006-30/04/2006. The individual study cohorts for each cancer at time points one, two, three and five years from date of recorded diagnosis were compiled through identification of the 312 cases diagnosed most closely to a specified time-point (First of February for each year). Cases were excluded if: under the age of 16 years, deceased, or not known to have a UK address.

Identified participants were sent a questionnaire by post by the survey provider, *Quality Health*. This was sent under cover of a standard introductory letter with the letter-head of the cancer centre most recently recorded by the cancer registry as having provided treatment. The survey covered patients attending 70 of 160 (43%) acute NHS Trusts delivering cancer care in England during 2011. Patients consented to taking part in the survey by returning questionnaires and declined by not returning them, or by returning blank questionnaires. . Two reminders were sent to non-responders. Checks for deceased patients were undertaken by the registries at four separate time points in the survey process to ensure attempts were not made to contact deceased individuals.

Details of a dedicated freephone telephone helpline, staffed 24 hours each day, were provided so the queries of any respondents could be resolved.

Questionnaire design and content (Supplementary files 2, 3, 4 and 5)

Questionnaires were developed for each cancer group. Content was identified through literature review, commissioned expert reviews[13-15], consultation with patient groups, cancer charities and expert advisory groups. In this way the views of multi-professional clinicians and service users were captured.

Generic content included:

- Demographic and treatment-related questions adapted from the National Cancer Patient Experience Survey.[12]
- Self-reported response to treatment and disease status
- Amount of physical activity performed each week quantified according to the Chief Medical Officer of England's recommendations[16].
- Presence or absence of long-term conditions (LTCs) other than cancer, using a list widely used in English Department of Health surveys.
- EQ5D: A 5 item generic health-related quality of life measure[17-18] chosen as it is a generic measure of health status widely used to evaluate population health in England[17].
- Social Difficulties Inventory (SDI): A cancer survivor specific measure covering wider QoL domains[19-20,21] including information on the social consequences of cancer.
- Experience of care. Relevant items to these phases of the cancer pathway were taken from the National Cancer Patient Experience Survey Questionnaire.[22]
- Fear of recurrence and dying. These items were generated by the project team and cognitively tested on representative sample goups prior to this pilot survey.
- Individual components on psychological issues and work status identified through the literature as being important to cancer survivors but not covered by other components of the survey[23], [24].

Tumour-specific content included

- Functional Assessment of Cancer Therapy (FACT) tumour specific components (FACT-B, FACT-C , FACT-Lym and FACT-P for breast, colorectal, NHL and prostate cancer respectively)[25].

A detailed description of the qualitative comments provided by respondents are reported in a parallel submission to the BMJ Open.

Cognitive testing was performed on the four site-specific versions of the questionnaire prior to their general use. This was done by sending questionnaires to volunteers (identified through cancer charities and the survey provider) prior to participating in a telephone interview. This style of testing was used to determine the population's ability to complete the questionnaire independently and to follow routing and other instructions in the questionnaire without prompting or help. Appropriate alterations were then made to the questionnaire. The two required changes were omission of a similar item from the FACT-B and FACT-P questionnaires *"I am able to feel like a woman"* and *"I am able to feel like a man".*

Data Handling/Analysis

Age (at time of survey) was categorised as <55, 55-64, 65-74, 75-84, and ≥85 years. Self-reported ethnicity was grouped into white, asian, mixed, black and other. Deprivation category was based on the complete index of multiple deprivation (IMD)[26]. This was derived from the lower super output area (small census area) associated with their place of residence at the time of completing the survey, and used because the survey did not include questions related to income or educational level.

Participants were asked if they had any LTC other than their cancer diagnosis and were asked to tick the appropriate LTCs. This variable was categorised into 'no other', 'one other' and 'two or more LTCs'.

A crosswalk algorithm was used to convert the 5L EQ5D to the 3L version, allowing a weighted health score to be assigned for each individual.[27] United Kingdom population data were used to calculate weighted scores (range -0.5 to 1 [perfect health]). Due to skewness, this outcome variable was categorised and ordered logistic regression undertaken. Three categories representing 'high', 'medium' and 'low' QoL scores were defined for ease of interpretation; these comprised scores equal to 1, less than 1 but greater than or equal to 0.5 and less than 0.5. Odds ratios should be interpreted either as the odds of being in group 2 (medium QoL scores) or group 3 (low QoL scores) compared to group 1 (high QoL scores) *or* the odds of being in group 3 (low QoL scores) compared to group 1 or group 2.

Cancer-specific questions from FACT[25] were used as explanatory variables in this analysis (FACT total score could not be calculated as only the cancer-specific subscale questions were included). Patient reported treatments were used in the analyses and treatment combinations were categorised for each cancer site with the most common used as the reference group. Given the study design, participants who had survived a year or more and who reported still receiving treatments when they completed the survey were likely to be receiving treatment for advanced or recurrent disease.

Statistical methods

Chi-squared tests were used to compare categorical variables. Descriptive statistics were compared across cancer sites but the statistical models were stratified by cancer site. Variables were entered into the logistic regression model based on their *a priori* clinical and public health importance after agreement by the study investigators. Formal variable selection procedures were not invoked primarily due to statistical problems associated with these data-driven procedures[28] and, secondly, so that findings could be compared consistently across cancer sites and time points. Statistical significance was set at 1% to minimise the chances of false-positive associations. All analyses were undertaken using STATA v12.1.

Ethics and governance

Approval was given to approach patients without informed consent by the National Information Governance Board (Supplementary File 6) as the study was performed as service evaluation[29].

Results

Participants

Questionnaires were sent to 4992 individuals, 126 (2·5%) of these had moved or died prior to receiving the questionnaire resulting in a final sample size of 4866. 3300 completed questionnaires were received (66% of the study sample). Of the surveys received by participants, the response rate was 68% (3300/4866).

Response rates

Response rate varied significantly between cancer groups (Table 1a): 69·4% in the prostate group compared to 62·3% in the NHL group (p<0.001).

There was significant difference in the age structure of the non-responders vs. responders with a higher proportion of non-responders in the ≥85 years age group (p<0·001).

Response rates differed according to deprivation status (Table 1a) with a response rate of 71·4% in the least deprived category compared to 57·1% in the most deprived category (p<0·001).

No difference in response rates by time since diagnosis, sex or cancer type was found.

Demographics of respondents (Table 1b)

Overall there were more males than females. Median age was 69 years (range 36-102). There was significant variation in the distribution of ethnicity by cancer group with higher proportions of non-white ethnic groups with NHL. There was no significant difference by deprivation between cancer groups. Overall more than half of patients reported having a LTC. There were fewer reported LTCs in the breast cohort than in other groups but this did not reach statistical significance.

Missing data

Missing data levels were extremely low, typically less than 5% for most fields. SDI had slightly higher levels of missing data with completeness ranging from 80-85%. For the regression modelling (Tables 3a-3d) which used complete case analysis approach, completeness levels were lower and ranged from 60% (colorectal, prostate) to 83% (breast). There was no evidence that the prevalence of missing data was related to the order of the questions after examining levels of completeness for questions at the beginning compared to the end of the form.

Helpline calls and other contact from survey participants

64 calls were made to the helpline, whilst further information about patient status was received via letters from patients (11) and NHS Trusts (2). The total number of enquiries was 77, representing 0.02% of the study cohort.

Generic PROMS

Responses for the five EQ5D questions demonstrated that a higher percentage of NHL patients reported problems with self-care, mobility and usual activities. Two-thirds of breast cancer patients reported some degree of pain (Supplementary Table 1).

When detailed responses for the five EQ5D questions were summarised by time since diagnosis, there were no significant differences for pain, mobility, usual activities or self-care but the percentage reporting anxiety or depression symptoms decreased significantly (p=0·01) (Supplementary Table 2).

Skewed weighted health scores were obtained from the EQ5D by cancer group (Supplementary Figure 1). The prostate group had significantly higher median (0·88) scores than the other three groups (0·84) (p=0·001). The proportion of the populations reporting high QoL scores ranged from 24·4% for breast to 40·0% for prostate cancer (Table 2). Conversely, the proportion reporting low QoL scores ranged from 8.9% for breast to 13.1% for NHL. For all tumour groups, irrespective of remission status, the percentage of

individuals reporting lower QoL scores increased as the number of other LTCs increased (Supplementary Tables 3-4).

Result by Tumour Type

Multivariable ordered logistic regression (Tables 3a-3d) identified three factors which were consistently associated with lower QoL scores irrespective of tumour type: presence of LTCs, undertaking little physical activity and self-reported disease status.

Breast Cancer (Table 3a)

Increasing number of LTCs, having recurrence of disease or being uncertain of disease status were associated with poorer outcomes across all three measures: The presence of one (OR 1·84, 95%CI 1·25,2·70) or two or more (Odds Ratio (OR) 7·30, 95%Confidence Interval (CI) 4·45,11·93) LTCs was significantly associated with lower QoL scores. Individuals self-reporting recurrent disease (OR 4·70, 95%CI 1·92,11·52) or those uncertain about their disease status (OR 2·51, 95%CI 1·27,4·96) were significantly more likely to report lower QoL scores compared to those self-reporting remission.

Increasing age (apart from those aged 85 years or older) and more days undertaking physical activity were significantly associated with better outcomes in EQ5D, SDI and FACT-B measures: Those aged 65-74 reported significantly higher QoL scores compared to under 55s (OR 0·36, 95%CI 0·22,0·58). Increasing physical activity was associated with higher QoL scores with each additional reported day per week of physical activity reducing the odds of a lower score by 12% (OR 0·88, 95%CI 0·82,0·95).

Individuals from the most deprived areas were significantly more likely to report lower EQ5D derived QoL scores than those from the most affluent areas (OR 3·00, 95%CI 1·64-5·50). Poorer outcomes in FACT-B items were associated with being in the most deprived category.

Colorectal Cancer (Table 3b)

The presence of one (OR 2·09, 95%CI 1·29,3·37) or two or more (OR 4·83, 95%CI 2·85,8·21) LTCs was significantly associated with lower QoL scores. Those who completed the

questionnaire whilst undergoing treatment (OR 7·03, 95%CI 2·44,20·21), experiencing recurrent disease (OR 4·56, 95%CI 1·54,13·49) or who were uncertain about their disease status (OR 2·67, 95%CI 1·23,5·79) had significantly increased odds of reporting lower QoL scores compared to those reporting remission.

Increasing physical activity was significantly associated with a 17% decrease in the odds of a lower QoL score with each additional day per week of physical activity (OR 0·83, 95%CI 0·76,0·90).

23·5% reported urinary leakage, 19·0% difficulty controlling their bowels and 19·2% had a stoma. Individuals experiencing any difficulty controlling their bowels were more than twice as likely to report lower QoL scores (OR 2·30, 95%CI 1·43,3·72). The presence of a stoma or urinary leakage was not significantly associated with QoL.

Greater difficulties with holidays and travel were reported by those with colorectal cancer compared to other cancers. For example, only 51% of colorectal respondents reporting no difficulty compared to 64% with breast or prostate cancer.

Non-Hodgkin's Lymphoma (Table 3c)

The presence of one (OR 2·16, 95%CI 1·44,3·24) or two or more (OR 7·26, 95%CI 4·51,11·69) LTCs was significantly associated with lower QoL scores. Those currently being treated (OR 2·57, 95%CI 1·52,4·33), experiencing a recurrence (OR 3·73, 95%CI 1·68,8·29) or who were not sure about their disease status (OR 3·04, 95%CI 1·58,5·84) had increased odds of reporting lower QoL scores compared to those in remission. These same factors were associated with poorer outcomes on the SDI and FACT-Lym items.

A significant positive association between increasing physical activity and QoL was seen with each additional day of physical activity reducing the odds of lower QoL score by 9% (OR 0·91, 95%CI 0·84,0·98). QoL seemed to improve with time from diagnosis for NHL but the trend was not significant (p=0·100).

Prostate Cancer (Table 3d)

The presence of two or more LTCs (OR 4·28, 95%CI 2·62,7·01) or being in the most deprived category (OR 2·57, 95%CI 1·31,5·04) were significantly associated with lower QoL scores, as well as increased social distress and difficulties identified by FACT-P.

Patients who had surgery only (compared to radiotherapy and hormone treatment) had significantly higher QoL scores (OR 0·39, 95%CI 0·21,0·71) as did those reporting more days of physical activity (OR 0·82, 95%CI 0·75,0·88).

38·5% of prostate patients reported some degree of urinary leakage, 12·9% reported difficulty controlling their bowels and 58·4% reported being unable to have an erection with a further 11% reporting significant difficulty in having or maintaining an erection. The presence of urinary leakage was significantly associated with lower QoL scores (OR 3·52, 5%CI 2·32,5·35). Erectile dysfunction and difficulty controlling bowels were not significantly associated with QoL scores.

Prostate survivors had significantly lower overall social distress scores on the SDI as well as fewer problems in all three sub-scales (everyday living, money matters, self and others) compared to other cancer types.

Fear of recurrence and dying

Almost half (47·3%) of patients reported fear of recurrence and over a quarter (26·8%) reported fear of dying (Supplementary Table 5). Both of these fears decreased significantly with time since diagnosis.

Physical activity

Around one-fifth (21·4%) of participants reported taking 30 minutes or more of physical activity at least five days a week (in line with the Chief Medical Officer's recommendations). This varied by cancer: 16·5% for NHL, 19·0% for breast, 20·2% for colorectal and 29·0% for prostate. Overall 29·8% of patients reported doing no physical activity; this varied by cancer

group with 33·5% of NHL, 31·5% of colorectal and 27·4% of both breast and prostate survivors doing no physical activity.

Discussion

This study represents the largest European survey of survivors of multiple cancer types at clearly defined time points from diagnosis and demonstrates the feasibility of this straightforward method of collecting informative self-reported PROMS data on population-based cohorts of individuals living with and beyond a diagnosis of cancer in England. The process eliminates many of the potential biases that have hindered the collection of population-based cancer PROMS data in the past originating from the use of clinical trial data or acute service provider units for recruitment[30]. English cancer registries, which capture approximately 98-99% of all cancers diagnosed in England[31], provide a reliable denominator population from which to identify eligible participants.

Acceptability and Validity

The relatively high response rate, low level of missing data and low number of calls to the dedicated 24 hour helpline suggest that the methodology is acceptable to the majority of participants. However, the finding of lower participation amongst the elderly or those residing in areas with the greatest socio-economic deprivation would suggest that individuals from these vulnerable groups may need to be assessed by alternative methods. Whilst the questionnaires were identified as having face and content validity by a panel of health and social care professionals prior to use this study does not permit us to comment on the responsiveness or reliability of the instruments. However, the core components of the questionnaires had been identified by independent review as being reliable and appropriate for use in this setting[13-15].

Key results

The QoL of survivors for all four cancers was significantly related to self-reported disease status (remission versus relapse/uncertain), age and presence of LTCs. QoL appeared to either remain constant or improve slightly as time from diagnosis increased. This suggests that some problems experienced by cancer patients persist for long periods.

We have quantified the community prevalence of previously known late morbidities and assessed their impact on QoL. Problems relating to urinary and bowel control have been shown to be common, with nearly 40% of prostate survivors reporting urinary leakage and 13% difficulty controlling their bowels. Similarly, amongst colorectal survivors nearly a quarter reported urinary leakage and 19% reported difficulty controlling their bowels. These rates are comparable to other studies of cancer patients[32] but exceed those seen in non-cancer populations where the prevalence of urinary incontinence in adult men was 4·5% overall, rising to 16·0% for over 75 year olds[33]. In this study, the presence of "urinary leakage" in prostate survivors and "of difficulty controlling their bowels" in colorectal survivors were significantly associated with lower QoL scores making such symptoms important to address. Erectile dysfunction in prostate survivors, though common, did not significantly impact on QoL. The finding that QoL or physical problems such as difficulty controlling bowels or incontinence do not appear to be less prevalent five years following treatment may suggest individuals are not receiving adequate help or treatment for these conditions. Greater efforts should be made in prevention and early intervention for problems resulting from cancer treatment, and directed at those most at risk of the long–term problems identified from this study.

Comparison with the General Population Data

Most survivors in this study who were in remission and did not report a LTC were found to have a high QoL score. However, even the subgroup in remission with no LTC reported lower QoL scores than the data available from general population studies (Table 4). Some of this difference may be accounted for by age, as the Health Survey for England (2008)[34] and the General Practice Patient Survey (GPPS)[35] cohorts were substantially younger than the reported cancer study cohort. This assumption is supported from the HSE cohort aged over 45 years (median age 63, n=7672) which reported a reduction in QoL scores (good 45%, moderate 46%, poor 9%).

Long-term Conditions

The presence of one or more LTCs, other than their cancer diagnosis, was associated with lower QoL scores in all four cancer groups and mirrors findings from other studies[2 36]. The presence of multi-morbidity and LTCs identifies sub-sets of survivors who may require more active support than others. This needs to be factored into risk stratification models as health services move away from hospital based cancer follow-up towards a greater focus on self-management.

Physical Activity

The extent to which cancer survivors take physical activity has not previously been reported in England. The findings agree with those from the USA[37], suggesting that prostate survivors are more likely than others to take moderate or vigorous physical activity. We observed an association between higher levels of activity and higher QoL scores, but it is not possible to assess from a cross-sectional survey whether there is a causal relationship.

A smaller percentage of study respondents (21·4%) met the Chief Medical Officer of England's recommendations for physical activity when compared with the HSE(2008) in which 34% of adults met these guidelines[34]. Restricting the HSE data to a similar age profile as the study participants (60-75 years) saw similar levels of physical activity (23%). The HSE data found a trend of decreased physical activity with increasing age, yet, in this study, prostate survivors (the oldest subgroup) reported higher physical activity levels.

Limitations

The presence of multiple cancer groups and time points, along with some missing data (typically <5%), may have resulted in a lack of power for certain analyses. For example, investigating whether the quality of life of those living with recurrent disease differed from those survivors who had been 'cured'. The non-response rate varied significantly by cancer group, deprivation category and age, which could result in selection bias when generalising results. To overcome bias associated with deprivation and age, we propose extension of the pilot study to the largest possible cohorts available nationally; analyses and interpretation of this data will be performed with maximum sensitivity to these areas.

Our study excluded those treated in the private sector (estimated to be under 5% of cancer cases in England[38]). Treatments may also have changed over the 1-5 year period used to select survivors and it is therefore possible the results reflect these changes.

The study relied on self-reporting of long-term conditions, response to treatment and disease status. This information was not independently verified.

The highly skewed EQ5D outcome variable was categorised into three levels for multivariable modelling, which is not a standard approach and meant that information and perhaps discriminatory power was lost. However, our model parameterisation enabled a more natural interpretation of EQ5D QoL data and when comparisons were made with other alternative models, such as tobit regression, findings were very similar. We also acknowledge that measures related to the FACT component are primarily intended for use around the time of treatment rather than for survivorship work. Space limitations precluded a more detailed description of results incorporating the FACT and SDI components. However, a comprehensive report including these additional findings has been compiled and can be accessed via the DH website (https://www.wp.dh.gov.uk/publications/files/2012/12/9284-TSO-2900701-PROMS.pdf).

Where next for Cancer PROMS in England?

The use of cancer PROMS has generally been restricted to clinical research, especially clinical trials or small studies. Whilst important work has been undertaken to develop approaches for the measurement of PROMS, they have not been incorporated into routine measurement at a whole health system level. This study demonstrates that population-based survey approaches are feasible and yield acceptable response rates. This approach could provide important insights into where improvement efforts should be targeted to reduce the long-term burden of cancer and its treatments on the growing number of cancer survivors.

Improving QoL in patients with LTC is one of the key goals of English government health policy (forming Domain 2 of the NHS Outcomes Framework)[39]. The approach we report should be scaled up and integrated within routine health outcome assessment on a national basis so that results can be distilled down to hospital/service provider level, as has been done in relation to the experience of acute care of cancer patients[12]. Improvements in quality of survivor care could then be driven by publishing hospital/provider level data. As a result of the findings of this pilot, a national roll-out to all individuals diagnosed 1-3 years earlier with colorectal cancer in England is being performed in January 2013. A similar roll-out to those diagnosed with prostate cancer is planned whilst pilot questionnaires for those with bladder, cervical, endometrial and ovarian cancer are being prepared. To further understand the develomental trajectory of morbidity burden, a longitudinal survey of respondents to the pilot is being undertaken, with a survey 1 year on having been undertaken and consideration for a further data collection point after another 12 months.

Our findings support the on-going international efforts to identify risk factors for poor health-related QoL outcomes following a cancer diagnosis. These include the presence of other LTCs, deprivation and limited physical activity. These, along with the high prevalence of on-going condition-specific problems such as bowel, urinary and erectile dysfunction, warrant attention by cancer services.

Acknowledgements

Dr Nicola Davies, Professor Jane Maher, Dr Mick Peake, Professor Galina Velikova and Dr Penny Wright provided expert advice regarding questionnaire and study design. Thames Cancer Registry, Eastern Cancer Registry and Information Centre, and West Midlands Cancer Intelligence Unit provided information on all eligible cancer survivors. FACIT provided permission to use components of the FACT questionnaires and Penny Wright granted permission to use the Social Difficulties Inventory.

Funding

This survey was funded by the Department of Health, England.

Open source access for BMJ Open was funded through a grant from Macmillan Cancer Support.

Declaration of Competing Interests

All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: financial support for the submitted work from the Department of Health, England: AWG, GH and MR were employed by the Cancer Policy Team, Department of Health, England, whilst the research was carried out; AWG, LKF, RGF and EF, received financial support from Department of Health, England, to carry out the analysis of data reported; JC and MR co-chaired the Department of Health, England, Cancer Patient Experience Advisory Group.

Data Sharing Statement

Statistical code and dataset are available from the corresponding author at the University of Leeds, who will provide a permanent, citable and open access home for the dataset.

Author Contribution Statement

Adam Glaser contributed to the study design, data collection, data analysis, data interpretation and writing of this manuscript.

Lorna Fraser contributed to the data analysis, data interpretation and writing of this manuscript.

Jessica Corner contributed to the study design, data collection, data interpretation and writing of this manuscript.

Richard Feltbower contributed to the data analysis, data interpretation and writing of this manuscript.

Eva Morris contributed to the data analysis, data interpretation and writing of this manuscript.

Greg Hartwell contributed to the study design and data collection.

Mike Richards contributed to the study design, data interpretation, and writing of this manuscript.

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Table 1a Demographic data of responders and non-responders

Characteristic		**Responders (n=3300)**		**Non Responders (n=1692)**		**Total number approached**	**Overall Percentage Responding**
		n	***%***	***n***	***%***		
Cancer Group	**χ2=18.8, p<0·001**						
Breast		854	*25.9*	394	*23.3*	*1248*	*68.4*
Colorectal		802	*24.3*	446	*26.4*	*1248*	*64.3*
NHL		778	*23.6*	470	*27.8*	*1248*	*62.3*
Prostate		866	*26.2*	382	*22.5*	*1248*	*69.4*
Age	**χ2=108, p<0·001**						
under 55		467	*14·2*	282	*16.7*	*749*	*62.3*
55 to 64		692	*21·0*	335	*19.8*	*1027*	*67.4*
65 to 74		1,108	*33·6*	414	*24.5*	*1522*	*72.8*
75 to 84		835	*25·3*	434	*25.6*	*1269*	*65.8*
85+		198	*6·0*	227	*13.4*	*425*	*46.6*
IMD Category	**χ2=55.9, p<0.001**						
1 least deprived		826	*25·0*	331	*19.6*	*1157*	*71.4*
2		812	*24·6*	357	*21.1*	*1169*	*69.5*
3		703	*21·3*	349	*20.7*	*1052*	*66.8*
4		554	*16·8*	352	*20.7*	*906*	*61.1*
5 most deprived		399	*12·1*	300	*17.7*	*699*	*57.1*
Missing		6	*0·2*	*3*	*0.2*	*9*	*66.7*
Time since Diagnosis	**χ2=4.1, p=0·25**						
1 year		848	*25·7*	400	*23.6*	*1248*	*67.9*
2 years		834	*25·3*	414	*24.5*	*1248*	*66.8*
3 years		806	*24·4*	442	*26.1*	*1248*	*64.6*
5 years		812	*24·6*	436	*25.8*	*1248*	*65.1*

Table 1b. Demographic Data by Cancer Group

Characteristic		Breast (n=854)		Colorectal (n=802)		Non Hodgkin's Lymphoma (n=778)		Prostate (n=866)		Total (n=3300)	
		n	%	n	%	n	%	n	%	n	%
Sex	**χ2=1700, p<0·001**										
Male		10	1·2	435	54·2	419	53·9	848	97·9	1712	51·9
Female		829	97·0	348	43·4	352	45·2	0	0	1529	46·3
Missing		15	1·8	19	2·4	7	0·9	18	2·1	59	1·8
Age	**χ2=401, p<0·001**										
under 55		231	27·0	57	7·1	157	20·2	157	18·1	467	14·2
55 to 64		237	27·8	136	17·0	173	22·2	173	20·0	692	21·0
65 to 74		224	26·2	280	34·9	238	30·6	238	27·5	1,108	33·6
75 to 84		122	14·3	246	30·7	175	22·5	175	20·2	835	25·3
85+		40	4·7	83	10·3	35	4·5	35	4·0	198	6·0
Ethnicity	**χ2=74·6, p<0·001**										
White		768	89·9	740	92·3	688	88·4	786	90·8	2982	90·4
Asian		35	4·1	19	2·3	30	3·9	15	1·7	99	3·0
Black		14	1·6	11	1·4	21	2·7	36	4·2	82	2·5
Mixed		4	0·5	5	0·6	6	0·8	1	0·1	16	0·5
Other		4	0·5	0	0	4	0·5	3	0·3	11	0·3
Missing		29	3·4	27	3·4	29	3·7	25	2·9	110	3·3
IMD Category	**χ2=4·3, p0·97**										
1 least deprived		211	24·7	198	24·7	202	26·0	215	24·8	826	25·0
2		210	24·6	199	24·8	183	23·5	220	25·4	812	24·6
3		184	21·5	159	19·8	177	22·7	183	21·1	703	21·3
4		141	16·5	147	18·3	125	16·1	141	16·3	554	16·8
5 most deprived		104	12·2	98	12·2	91	11·7	106	12·2	399	12·1
Missing		4	0·5	1	0·1	0	0	1	0·1	6	0·2
Time since Diagnosis	**χ2=5·5, p=0·78**										
1 year		215	25·2	202	25·2	197	25·3	234	27·0	848	25·7
2 years		212	24·8	215	26·8	187	24·0	220	25·4	834	25·3
3 years		204	23·9	195	24·3	207	26·6	200	23·1	806	24·4
5 years		223	26·1	190	23·7	187	24·0	212	24·5	812	24·6
Other Long Term Health Condition	**χ2=12·1, p=0·06**										
Yes		435	50·9	432	53·9	435	55·9	501	57·9	1803	54·6
No		353	41·3	309	38·5	287	36·9	299	34·5	1248	37·8
Don't Know		30	6·9	23	2·9	33	4·2	27	3·1	113	3·4
Missing		36	4·2	38	4·7	23	3·0	39	4·5	136	4·1
Disease Status	**χ2=390·0, p<0·001**										
Remission		677	79·3	625	77·9	526	67·6	399	46·1	2227	67·5
Rx but present		26	3·0	32	4·0	81	10·4	144	16·6	283	8·6
Not treated		4	0·5	6	0·7	43	5·5	78	9·0	131	4·0

Recurrence		30	*3·5*	20	*2·5*	30	*3·9*	8	*0.9*	88	*2.6*
Not sure		58	*6·8*	69	*8·6*	53	*6·8*	140	*16·2*	320	*9·7*
Missing		59	*6·9*	50	*6·2*	45	*5·8*	97	*11·2*	251	*7·6*

Table 2. EQ5D outcome category by cancer sub-group

EQ5D Categories	'High' QoL (Scores=1)		Medium QoL (0.5≤Scores<1)		Low QoL (Scores<0.5)		Missing	
	n	%	n	%	n	%	n	%
Breast	208	*24·4*	514	*60·2*	76	*8·9*	56	*6·6*
Colorectal	255	*31·2*	434	*54·1*	87	*10·8*	26	*3·2*
Non Hodgkins Lymphoma	247	*31·7*	398	*51·2*	102	*13·1*	31	*4·0*
Prostate	347	*40·0*	390	*45·0*	81	*9·4*	48	*5·5*
Total	1057	*32·0*	1736	*52·6*	346	*10·5*	161	*4·9*

Table 3a. Ordered Logistic Regression Model EQ5D in Breast Cancer Patients [n=709, pseudoR^2=0·16 p<0·001]

Characteristic	Odds Ratio*	95% CI		P value
Age (years)				
<55 years	REF			
55-64	0·69	0·45	1·06	0·09
65-74	0·36	0·22	0·58	<0·001
75-84	0·59	0·32	1·08	0·09
85+	1·61	0·57	4·52	0·36
Deprivation				
1 least deprived	REF			
2	1·03	0·66	1·62	0·88
3	1·10	0·68	1·77	0·71
4	0·93	0·55	1·56	0·78
5 most deprived	3·00	1·64	5·50	<0·001
Physical Activity†	0·88	0·82	0·95	<0·001
Number of other LTC (excl BP)				
0	REF			
1	1·84	1·25	2·70	0·002
2+	7·30	4·45	11·93	<0·001
Treatment*				
Radio+Chemo+Surgery+Hormone	REF			
Radio +Chemo+Surgery	0·67	0·38	1·20	0·18
Radio+Surgery	0·51	0·29	0·90	0·02
Radio+Surgery+Hormone	0·56	0·33	0·96	0·04
Surgery only	1·00	0·55	1·84	0·99
Other	0·92	0·53	1·58	0·76
Ethnicity				
White	REF			
Mixed	0·50	0·06	4·29	0·53
Asian	1·96	0·77	5·01	0·16
Black	0·29	0·08	0·98	0·05
Other	2·20	0·17	29·32	0·55
Disease Status				
Remission	REF			
Rx but present	1·49	0·56	3·93	0·43
Not treated	·	·	·	·
Recurrence	4·70	1·92	11·52	0·001
Not sure	2·51	1·27	4·96	0·008
Time since Diagnosis				
1 year	REF			
2 years	1·02	0·64	1·62	0·95
3 years	0·88	0·55	1·41	0·60
5 years	0·93	0·59	1·47	0·76

*Odds of reporting ‘medium’ or ‘low’ QoL EQ5D scores compared to ‘high’ QoL scores where ‘high’, ‘medium’ and ‘low’ QoL was defined as scores=1, 0.5≤scores<1 and scores<0.5 respectively.

†Amount of physical activity performed each week quantified according to the Chief Medical Officer of England’s recommendations[16]

Table 3b. Ordered Logistic Regression Model EQ5D in Colorectal Patients [n=485, pseudoR2=0·18, p<0·001]

Characteristic	**Odds Ratio**	**95% CI**		**P value**
Age (years)				
<55 years	REF			
55-64	1·28	0·59	2·75	0·53
65-74	1·16	0·57	2·35	0·69
75-84	1·23	0·57	2·64	0·59
85+	2·45	0·93	6·41	0·07
Sex				
Male	REF			
Female	1·22	0·81	1·82	0·34
Deprivation				
1 least deprived	REF			
2	0·83	0·48	1·43	0·50
3	0·57	0·33	1·00	0·05
4	0·62	0·34	1·13	0·12
5 most deprived	1·17	0·58	2·34	0·66
Physical Activity†	0·83	0·76	0·90	<0·001
Number of other LTC(excl BP)				
0	REF			
1	2·09	1·29	3·37	<0·001
2+	4·83	2·85	8·21	<0·001
Treatment*				
Surgery only	REF			
Radio+Chemo+Surgery	1·15	0·60	2·21	0·67
Chemo+Surgery	1·35	0·85	2·17	0·21
Other	1·58	0·77	3·22	0·21
Ethnicity				
White	REF			
Mixed	1·72	0·24	12·42	0·59
Asian	1·99	0·46	8·54	0·36
Black	1·14	0·26	4·92	0·86
Other	1·72	0·24	12·42	0·59
Disease Status				
Remission	REF			
Rx but present	7·03	2·44	20·21	<0·001
Not treated	0·16	0·01	2·63	0·20
Recurrence	4·56	1·54	13·49	0·01
Not sure	2·67	1·23	5·79	0·01
Stoma				
No	REF			
Yes	1·32	0·80	2·19	0·27
Difficulty Controlling Bowels				
No	REF			
Yes	2·30	1·43	3·72	<0·001
Leak Urine				
No	REF			
Yes	1·41	0·87	2·30	0·16
Time since Diagnosis				
1 year	REF			
2 years	0·72	0·42	1·22	0·22
3 years	1·03	0·59	1·81	0·92
5 years	0·85	0·49	1·48	0·56

*Odds of reporting 'medium' or 'low' QoL EQ5D scores compared to 'high' QoL scores where 'high', 'medium' and 'low' QoL was defined as scores=1, 0.5≤scores<1 and scores<0.5 respectively.

†Amount of physical activity performed each week quantified according to the Chief Medical Officer of England's recommendations[16]

Table 3c. Ordered Logistic Regression Model EQ5D in NHL Patients [n=614, pseudoR2=0·15 p<0·001]

Characteristic	Odds Ratio	95% CI		P value
Age (years)				
<55 years	REF			
55-64	0·89	0·55	1·45	0·65
65-74	1·23	0·75	1·99	0·41
75-84	1·60	0·94	2·73	0·08
85+	2·13	0·84	5·39	0·11
Sex				
Male	REF			
Female	1·25	0·89	1·74	0·19
Deprivation				
1 least deprived	REF			
2	1·06	0·67	1·69	0·80
3	1·21	0·75	1·95	0·43
4	1·64	0·97	2·76	0·07
5 most deprived	1·19	0·65	2·21	0·57
Physical Activity†	0·91	0·84	0·98	0·01
Number of other LTC (excluding BP)				
0	REF			
1	2·16	1·44	3·24	<0·001
2+	7·26	4·51	11·69	<0·001
Treatment*				
Chemo only	REF			
Radio+Chemo	0·81	0·47	1·41	0·46
Chemo + Antibody	0·93	0·55	1·59	0·80
Radio+Chemo+Other	1·55	0·87	2·77	0·14
Other	0·96	0·63	1·46	0·86
Ethnicity				
White	REF			
Mixed	2·78	0·28	27·7	0·38
Asian	0·68	0·29	1·59	0·38
Black	0·91	0·33	2·49	0·85
Other	0·61	0·09	4·39	0·62
Disease Status				
Remission	REF			
Rx but present	2·57	1·52	4·33	<0·001
Not treated	0·83	0·17	3·96	0·82
Recurrence	3·73	1·68	8·29	0·001
Not sure	3·04	1·58	5·84	0·001
Time since Diagnosis				
1 year	REF			
2 years	0·62	0·38	0·99	0·05
3 years	0·60	0·38	0·96	0·03
5 years	0·57	0·36	0·90	0·02

*Odds of reporting ‘medium’ or ‘low’ QoL EQ5D scores compared to ‘high’ QoL scores where ‘high’, ‘medium’ and ‘low’ QoL was defined as scores=1, 0.5≤scores<1 and scores<0.5 respectively.

†Amount of physical activity performed each week quantified according to the Chief Medical Officer of England’s recommendations[16]

Table 3d. Ordered Logistic Regression Model EQ5D in Prostate Patients [n=524, pseudoR2=0·22 p<0·001]

Characteristic	**Odds Ratio**	**95% CI**		**P value**
Age (years)				
<55 years	REF			
55-64	1·32	0·41	4·30	0·64
65-74	1·72	0·55	5·38	0·36
75-84	1·32	0·41	4·30	0·64
85+	1·92	0·42	8·78	0·40
Deprivation				
1 least deprived	REF			
2	1·09	0·64	1·85	0·74
3	1·19	0·68	2·08	0·55
4	1·61	0·88	2·95	0·13
5 most deprived	2·57	1·31	5·04	0·01
Physical Activity†	0·82	0·75	0·88	<0·001
Number of other LTC(excl BP)				
0	REF			
1	1·55	0·94	2·54	0·09
2+	4·28	2·62	7·01	<0·001
Treatment*				
Radio+Hormone	REF			
Surgery only	0·39	0·21	0·71	<0·001
Hormone only	1·68	0·85	3·33	0·14
Radio only	0·94	0·53	1·66	0·83
Active surveillance only	1·16	0·47	2·88	0·75
Other	·	·	·	·
Ethnicity				
White	REF			
Mixed	3·82	0·07	203·44	0·51
Asian	3·21	0·56	18·49	0·19
Black	2·54	0·96	6·73	0·06
Other	0·00	0·00	·	0·98
Disease Status				
Remission	REF			
Rx but present	1·75	0·94	3·26	0·08
Not treated	1·06	0·37	3·05	0·91
Recurrence	1·71	0·17	16·91	0·65
Not sure	1·48	0·85	2·58	0·17
Urinary Leakage				
No	REF			
Yes	3·52	2·32	5·35	<0·001
Erectile Dysfunction				
No	REF			
Yes	1·46	0·96	2·23	0·08
Difficulty Controlling Bowels				
No	REF			
Yes	1·62	0·90	2·92	0·10
Time since Diagnosis				
1 year	REF			
2 years	0·83	0·50	1·40	0·49
3 years	0·80	0·47	1·36	0·41
5 years	0·77	0·45	1·33	0·36

*Odds of reporting 'medium' or 'low' QoL EQ5D scores compared to 'high' QoL scores where 'high', 'medium' and 'low' QoL was defined as scores=1, $0.5 \leq$ scores<1 and scores<0.5 respectively.

†Amount of physical activity performed each week quantified according to the Chief Medical Officer of England's recommendations[16]

Table 4. Comparison of Quality of Life scores with other population data

	Health Survey for England (HSE 2008)[34]		GP Population Survey (GPPS)[35]	GP Population Survey (GPPS)[35]	This survey	
	All ages	Ages≥ 45 years	All	No LTC	All	In remission with no LTC
Number of respondents	14116	7672	426933	193285	3300	848
Median age	48	63	48	39	69·3	63·2
'High' QOL (Scores=1)	56.0%	45·4%	50·6%	73·8%	32·0%	51·4%
'Medium' QOL (0.5≤Scores <1)	37.7%	45·6%	41·6%	25·2%	52·6%	44·3%
'Low' QOL (Scores <0·5)	6.3%	9·0%	7·8%	0·9%	10·5%	2·1%

Supplementary Table 1. Quality of Life Dimension Results (EQ5D) by Cancer Sub group

EQ5D dimension		**Breast (n=854)**		**Colorectal (n=802)**		**Non Hodgkin's Lymphoma (n=778)**		**Prostate (n=866)**		**Total (n=3300)**	
		n	***%***	**n**	***%***	**n**	***%***	**n**	***%***	**n**	***%***
Mobility χ2=51·3, p<0·001	No Problems	567	*66·4*	442	*55·1*	427	*54·9*	535	*61·8*	1971	*59·7*
	Slight Problems	105	*12·3*	159	*19·8*	140	*18·0*	131	*15·1*	535	*16·2*
	Moderate Problems	107	*12·5*	120	*15·0*	120	*15·4*	97	*11·2*	444	*13·5*
	Severe Problems	46	*5·4*	57	*7·1*	71	*9·1*	69	*8·0*	243	*7·4*
	Cannot walk	8	*0·9*	13	*1·6*	6	*0·8*	4	*0·4*	31	*0·9*
	Missing	21	*2·5*	11	*1·4*	14	*1·8*	30	*3·5*	76	*2·3*
Self Care χ2=30·4, p=0·002	No Problems	716	*83·8*	651	*81·2*	611	*78·5*	704	*81·3*	2682	*81·3*
	Slight Problems	47	*5·5*	67	*8·4*	66	*8·5*	78	*9·0*	258	*7·8*
	Moderate Problems	45	*5·3*	46	*5·7*	71	*9·1*	44	*5·1*	206	*6·2*
	Severe Problems	12	*1·4*	18	*2·2*	12	*1·5*	9	*1·0*	51	*1·5*
	Cannot wash/dress	6	*0·7*	9	*1·1*	4	*0·5*	4	*0·5*	23	*0·7*
	Missing	28	*3·3*	11	*1·4*	14	*1·8*	27	*3·1*	80	*2·4*
Usual Activities χ2=34·5, p<0·001	No Problems	513	*60·1*	429	*53·5*	411	*52·8*	533	*61·5*	1886	*57·2*
	Slight Problems	162	*19·0*	173	*21·6*	156	*20·1*	145	*16·7*	636	*19·3*
	Moderate Problems	111	*13·0*	113	*14·1*	127	*16·3*	104	*12·1*	455	*13·7*
	Severe Problems	31	*3·6*	48	*6·0*	49	*6·3*	43	*5·0*	171	*5·2*
	Cannot do usual activities	14	*1·6*	24	*3·0*	26	*3·3*	15	*1·7*	79	*2·4*
	Missing	23	*2·7*	15	*1·8*	9	*1·2*	26	*3·0*	73	*2·2*
Pain χ2=134·3, p<0·001	No Pain	329	*38·5*	429	*53·5*	408	*52·4*	526	*60·7*	1692	*51·3*
	Slight Pain	341	*39·9*	220	*27·4*	180	*23·1*	169	*19·5*	910	*27·6*
	Moderate Pain	113	*13·2*	92	*11·5*	120	*15·4*	101	*11·7*	426	*12·9*
	Severe Pain	39	*4·6*	35	*4·4*	51	*6·6*	38	*4·4*	163	*4·9*
	Extreme Pain	5	*0·6*	9	*1·1*	10	*1·3*	3	*0·3*	27	*0·8*
	Missing	27	*3·2*	17	*2·1*	9	*1·2*	29	*3·3*	82	*2·5*
Anxiety/ depression χ2=37·1, p<0·001	No anxiety/depression	475	*55·6*	504	*62·8*	464	*59·6*	566	*65·4*	2009	*60·9*
	Slight anxiety/depression	241	*28·2*	196	*24·4*	186	*23·9*	183	*21·1*	806	*24·4*
	Moderate anxiety/depression	78	*9·1*	78	*9·7*	83	*10·7*	76	*8·8*	315	*9·5*
	Severe anxiety/depression	21	*2·5*	6	*0·8*	21	*2·7*	8	*0·9*	56	*1·7*
	Extreme anxiety/depression	10	*1·2*	4	*0·5*	8	*1·0*	4	*0·5*	26	*0·8*
	Missing	29	*3·4*	14	*1·8*	16	*2·1*	29	*3·3*	88	*2·7*

Supplementary Table 2 Quality of Life Dimension Results (EQ5D) by time since diagnosis of cancer

		1 year (n=848)		2 years (n=834)		3 years (n=806)		5 years (n=812)		Total (n=3300)	
		N	%	N	%	N	%	N	%	N	%
Mobility	No Problems	521	*61.4*	501	*60.1*	486	*60.3*	463	*57.0*	1971	*59.7*
χ2=21.1, p=0.05	Slight Problems	150	*17.7*	123	*14.7*	127	*15.8*	135	*16.6*	535	*16.2*
	Moderate Problems	93	*11.0*	116	*13.9*	104	*12.9*	131	*13.1*	444	*13.5*
	Severe Problems	62	*7.3*	62	*7.4*	56	*6.9*	63	*7.8*	243	*7.4*
	Cannot walk	2	*0.2*	8	*9.6*	13	*1.6*	8	*1.0*	31	*0.9*
	Missing	20	*2.4*	24	*2.9*	20	*2.5*	12	*1.5*	76	*2.3*
Self Care	No Problems	696	*82.1*	674	*80.8*	659	*81.8*	653	*80.4*	2682	*81.3*
χ2=10.2, p=0.59	Slight Problems	59	*6.9*	65	*7.8*	61	*7.6*	73	*9.0*	258	*7.8*
	Moderate Problems	57	*6.7*	56	*6.7*	42	*5.2*	51	*6.3*	206	*6.2*
	Severe Problems	12	*1.4*	12	*1.4*	14	*1.7*	13	*1.6*	51	*1.5*
	Cannot wash/dress	3	*0.4*	4	*0.5*	10	*1.2*	6	*0.7*	23	*0.7*
	Missing	21	*2.5*	23	*2.8*	20	*2.5*	16	*2.0*	80	*2.4*
Usual Activities	No Problems	465	*54.8*	474	*56.8*	465	*57.7*	482	*59.4*	1886	*57.2*
χ2=13.9, p=0.31	Slight Problems	181	*21.3*	157	*18.8*	161	*20.0*	137	*16.9*	636	*19.3*
	Moderate Problems	131	*15.4*	112	*13.4*	95	*11.8*	117	*14.4*	455	*13.7*
	Severe Problems	35	*4.1*	45	*5.4*	44	*5.5*	47	*5.8*	171	*5.2*
	Cannot do usual activities	18	*2.1*	19	*2.3*	23	*2.8*	19	*2.3*	79	*2.4*
	Missing	18	*2.1*	27	*3.2*	18	*2.2*	10	*1.2*	73	*2.2*
Pain	No Pain	421	*49.6*	412	*49.4*	435	*54.0*	424	*52.2*	1692	*51.3*
χ2=18.0, p=0.12	Slight Pain	262	*30.9*	237	*28.4*	198	*24.6*	213	*26.2*	910	*27.6*
	Moderate Pain	101	*11.9*	112	*13.4*	105	*13.0*	108	*13.3*	426	*12.9*
	Severe Pain	34	*4.0*	44	*5.3*	38	*4.7*	47	*5.8*	163	*4.9*
	Extreme Pain	7	*0.8*	6	*0.7*	11	*1.4*	3	*0.4*	27	*0.8*
	Missing	23	*2.7*	23	*2.8*	19	*2.4*	17	*2.1*	82	*2.5*
Anxiety/depression	No anxiety/depression	466	*55.0*	505	*60.6*	499	*61.9*	539	*66.4*	2009	*60.9*
χ2=25.8, p=0.01	Slight anxiety/depression	244	*28.8*	195	*23.4*	196	*24.3*	171	*21.1*	806	*24.4*
	Moderate anxiety/depression	88	*10.4*	86	*10.3*	68	*8.4*	73	*9.0*	315	*9.5*
	Severe anxiety/depression	20	*2.4*	13	*1.5*	13	*1.6*	10	*1.2*	56	*1.7*
	Extreme anxiety/depression	6	*0.7*	8	*1.0*	6	*0.7*	6	*0.7*	26	*0.8*
	Missing	24	*2.8*	27	*3.2*	24	*3.0*	13	*1.6*	88	*2.7*

Supplementary Table 3. EQ5D outcome category by the number of Long Term Conditions (LTC) in patients in remission

EQ5D Categories	High QoL (Scores=1)		Medium QoL (0.5≤Scores<1)		Low QoL (Scores<0.5)		Missing		Total
	n	%	n	%	n	%	n	%	
No LTC	436	51·4	376	44·3	18	2·1	18	2·1	848
1 LTC	250	36·2	378	54·7	40	5·8	23	3·3	691
≥2 LTC	129	18·8	419	60·9	119	17·3	21	3·1	688
Total	815	36·6	1,173	52·7	177	7·9	62	2·8	2,227

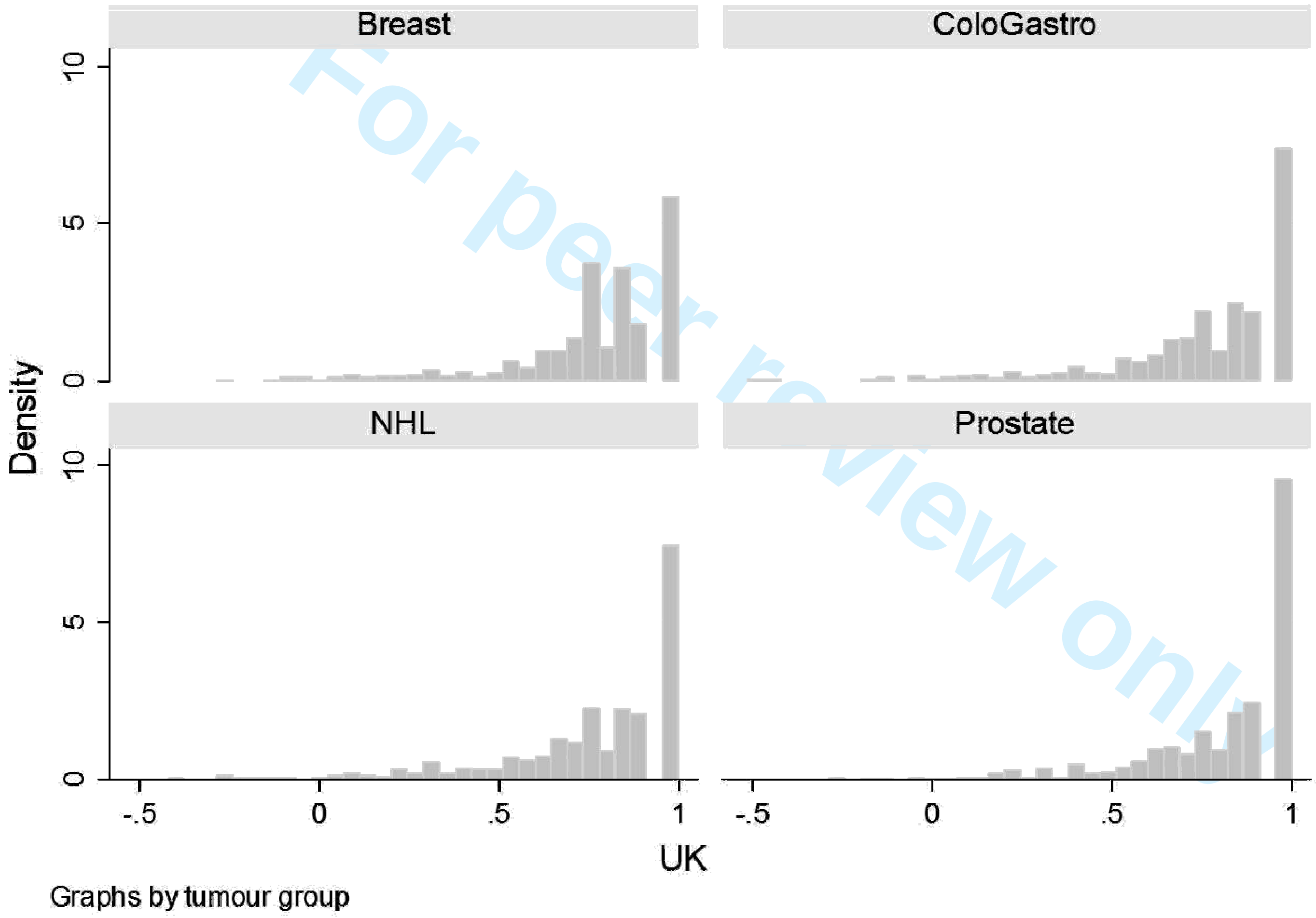
Supplementary Table 4. EQ5D outcome category by the number of Long Term Conditions (LTC) in patients not in remission

EQ5D Categories	High QoL (Scores=1)		Medium QoL (0.5≤Scores<1)		Low QoL (Scores<0.5)		Missing		Total
	n	%	n	%	n	%	n	%	
No LTC	79	33·9	130	55·8	15	6·4	9	3·9	233
1 LTC	64	23·1	175	63·2	25	9·0	13	4·7	277
≥2 LTC	37	11·9	166	53·2	94	30·1	15	4·8	312
Total	180	21·9	471	57·3	134	16·3	37	4·5	822

Supplementary Table 5. Fear of Dying and Recurrence of Disease by Time since Diagnosis

Fear of Dying	Yes%		No		Missing		Total
	n	%	n	%	n	%	
1 year ago	256	*30·2*	542	*63·9*	50	*5·9*	848
2 years ago	233	*27·9*	543	*65·1*	58	*7·0*	834
3 years ago	214	*26·6*	531	*65·9*	61	*7·6*	806
5 years ago	180	*22·2*	583	*71·8*	49	*6·0*	812
Total	883	*26·8*	2,199	*66·6*	218	*6·6*	3,300
Fear of Recurrence	n	%	n	%	n	%	
1 year ago	437	*51·5*	369	*43·5*	42	*5·0*	848
2 years ago	403	*48·3*	398	*47·7*	33	*4·0*	834
3 years ago	376	*46·7*	384	*47·6*	46	*5·7*	806
5 years ago	345	*42·5*	427	*52·6*	40	*4·9*	812
Total	1,561	*47·3*	1,578	*47·8*	161	*4·9*	3,300

Supplementary Figure 1. Distribution of EQ5D summary scores by cancer sub-type



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Title:

Patient Reported Outcomes of Cancer Survivors in England 1 to 5 years after Diagnosis: a cross-sectional survey.

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Key Words:

Cancer, Survivorship, Quality of Life, Patient Reported Outcomes, EQ5D, FACT

Word Count:

abstract: 302~~0~~ & main body of paper: 4391~~3994~~

Abstract

Objectives: To determine the feasibility of collecting population based patient reported outcome measures (PROMS) in assessing quality of life (QoL) to inform development of a national PROMS programme for cancer and to begin to describe outcomes in a UK cohort of survivors.

Design: Cross-sectional postal survey of cancer survivors using a population-based sampling approach.

Setting: English National Health Service.

Participants: 4,992 breast, colorectal, prostate and Non-Hodgkin's Lymphoma survivors one to five years from diagnosis.

Primary and Secondary Outcome Measures: Implementation issues, response rates, cancer-specific morbidities utilising items including the EQ5D, tumour-specific sub-scales of the Functional Assessment of Cancer Therapy and Social Difficulties Inventory.

Results:

3,300 (66%) survivors returned completed questionnaires. The majority aged 85+ years did not respond and there was an effect of deprivation on response rates. Response rates did not differ by gender, time since diagnosis or cancer type.

The presence of one or more long term conditions was associated with significantly lower QoL scores. Individuals from most deprived areas reported lower QoL scores and poorer outcomes on other measures, as did those self-reporting recurrent disease or uncertainty about disease status. QoL scores were stable at all time points for all cancers except NHL. QoL scores were lower than those from the general population in Health Survey for England (2008) and General Practice Patient Survey.

47% of patients reported fear of recurrence whilst 20% reported moderate or severe difficulties with mobility or usual activities. Bowel and urinary problems were common among colorectal and prostate patients. Poor bowel and bladder control were significantly associated with lower QoL.

Conclusions: This method of assessing QoL of cancer survivors is feasible and acceptable to most survivors. Routine collection of national population- based PROMS will enable identification of, and support for, the specific needs of survivors whilst allowing for comparison of outcome by service provider.

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~~**Conclusions:** This method of assessing QoL of cancer survivors is feasible and acceptable to most survivors. Inclusion of PROMS as a routinely collected health dataset will enable identification of, and support for, the specific needs of survivors whilst allowing for comparison of outcome by service provider.~~

Funding

This survey was funded by the Department of Health, England.

Article Summary

Article Focus

To determine the feasibility of routinely collecting population-based patient reported outcomes (PROMS) of cancer survivors to gather information on quality of life and cancer related morbidities that can be used to inform the development of a national PROMS programme for cancer.

Key messages

- Collection of population-based information on quality of life from cohorts of cancer patients who are 1 to 5 years post diagnosis through cancer registries is feasible.
- The best quality of life was reported by those in remission and with no other long term conditions.
- I~~This i~~nformation obtained by widespread extension of this methodology will enable health economies to compare outcome across provider organisations and facilitate provision of enhanced services to meet the needs of cancer survivors.

Strengths and Limitations

- Findings relate to the largest European survey of survivors of multiple cancer types at clearly defined time points from diagnosis.
- The study design eliminates many of the criticisms which have hindered the collection of population-based cancer patient reported outcome data in the past.
- English cancer registries provide a reliable denominator population from which to identify eligible participants.
- The questionnaires for the four cancer groups were identified as having face and content validity by a panel of health and social care professionals prior to use.
- Presence of multiple cancer groups, time points and some missing data may have resulted in a lack of power for certain analyses.

- Selection bias may have arisen through differences in-response rates according to cancer group, deprivation category and age.
- The study excluded those treated in the private sector.

Introduction

1.8 million people are living with and beyond a diagnosis of cancer in England and prevalence is predicted to increase by 3% per annum.[1] Cancer treatments are effectively reducing mortality and extending life, yet there is evidence that physical, psychological and social needs are not being addressed by the health and social care services, with individuals reporting significant unmet needs[2]. There is a lack of robust population-based information from which the prevalence, and impact, of disease and treatment associated morbidity burden can be ascertained and policy for appropriate interventions developed[3]. It has been equally difficult for health economies to compare the quality of health of those following treatment for cancer to those living with other long term conditions (LTC). These deficits have hampered the provision of comprehensive robust services for this growing population[4].

In the United States a number of significant initiatives have been launched to systematically measure health outcomes in cancer survivors using patient reported outcome measures (PROMS) through the National Cancer Institute and American Cancer Society[3 5-6]. In Europe, at least one regional cancer register has started to collect PROMS via approaches made through the treating clinical teams[7-8] . The focus of PROMS work to date has been on refining treatment decision making for individuals and determining methodological approaches to implementation and analysis[5-6 9-11]. These efforts have yet to feed through into major national health system service improvement initiatives. The evaluation of patients' experiences of cancer care in England, through the National Cancer Patient Experience Survey, has resulted in care provider organisations and commissioners being able to identify areas of strengths and weakness in acute cancer care provision[12].

Our objective was to determine the feasibility of routinely collecting population-based PROMS of cancer survivors (via a postal survey of individuals identified from cancer registry information), without introduction from clinicans or researchers known to participants, to gather information on quality of life (QoL) and cancer related morbidities that can be used to inform the development of a national PROMS programme for cancer.

Methods

Study design

A cross-sectional postal survey was undertaken of individuals with a diagnosis of breast, colorectal, non-Hodgkin's lymphoma (NHL) or prostate cancer one, two, three and five years earlier. These four time-points were chosen to gain an understanding of whether PROMS varied over time. Patients attending private healthcare centres were excluded as the aims of the study focused on the assessment of PROMS within the National Health Service (NHS) in England.

Cohort Identification and Survey Process

Three cancer registries (Thames Cancer Registry, Eastern Cancer Registry and Information Centre, West Midlands Cancer Intelligence Unit) were chosen as representative examples of the eight cancer registries in England. They provided information on all relevant cancer diagnoses[12] (Supplementary File 1) between 01/02/2010-30/04/2010, 01/02/2009-30/04/2009, 01/02/2008-30/04/2008, and 01/02/2006-30/04/2006. The individual study cohorts for each cancer at time points one, two, three and five years from date of recorded diagnosis were compiled through identification of the 312 cases diagnosed most closely to a specified time-point (First of February for each year). Cases were excluded if: under the age of 16 years, deceased, or not known to have a UK address.

Identified participants were sent a questionnaire by post by the survey provider, *Quality Health*. This was sent under cover of a standard introductory letter with the letter-head of the cancer centre most recently recorded by the cancer registry as having provided treatment. The survey covered patients attending 70 of 160 (43%) acute NHS Trusts delivering cancer care in England during 2011. Patients consented to taking part in the survey by returning questionnaires and declined by not returning them, or by returning blank questionnaires. ~~Two reminders were sent to non-responders. Checks for deceased patients were undertaken by the registries via the Demographic Batch Service at four separate time points in the survey process~~. Two reminders were sent to non-responders. Checks for deceased patients were undertaken by the registries at four separate time points in the survey process to ensure attempts were not made to contact deceased individuals.

Details of a dedicated freephone telephone helpline, staffed 24 hours each day, were provided so the queries of any respondents could be resolved.~~.~~

Questionnaire design and content (Supplementary files 2, 3, 4 and 5)

Questionnaires were developed for each cancer group. Content was identified through literature review, commissioned expert reviews[13-15], consultation with patient groups, cancer charities and expert advisory groups. In this way the views of multi-professional clinicians and service users were captured.

Generic content included:

- Demographic and treatment-related questions adapted from the National Cancer Patient Experience Survey.[12]
- Self-reported response to treatment and disease status
- Amount of physical activity performed each week quantified according to the Chief Medical Officer of England's recommendations[16].
- Presence or absence of long-term conditions (LTCs) other than cancer, using a list widely used in English Department of Health surveys.
- EQ5D: A 5 item generic health-related quality of life measure[17-18] chosen as it is a generic measure of health status widely used to evaluate population health in England[17].
- Social Difficulties Inventory (SDI): A cancer survivor specific measure covering wider QoL domains[19-20,21] including information on the social consequences of cancer.
- Experience of care. Relevant items to these phases of the cancer pathway were taken from the National Cancer Patient Experience Survey Questionnaire.[22]
- Fear of recurrence and dying. These items were generated by the project team and cognitively tested on representative sample goups prior to this pilot survey.

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- Individual components on psychological issues and work status identified through the literature as being important to cancer survivors but not covered by other components of the survey[23], [24].

Tumour-specific content included

- Functional Assessment of Cancer Therapy (FACT) tumour specific components (FACT-B, FACT-C , FACT-Lym and FACT-P for breast, colorectal, NHL and prostate cancer respectively)[25].

A detailed description of the qualitative comments provided by respondents are reported in a parallel submission to the BMJ Open.

Cognitive testing was performed on the four site-specific versions of the questionnaire prior to their general use. This was done by sending questionnaires to volunteers (identified through cancer charities and the survey provider) prior to participating in a telephone interview. This style of testing was used to determine the population's ability to complete the questionnaire independently and to follow routing and other instructions in the questionnaire without prompting or help. Appropriate alterations were then made to the questionnaire. The two required changes were omission of a similar item from the FACT-B and FACT-P questionnaires "*I am able to feel like a woman*" and "*I am able to feel like a man*".

Data Handling/Analysis

Age (at time of survey) was categorised as <55, 55-64, 65-74, 75-84, and ≥85 years. Self-reported ethnicity was grouped into white, asian, mixed, black and other. Deprivation category was based on the complete index of multiple deprivation (IMD)[26]. This was derived from the lower super output area (small census area) associated with their place of residence at the time of completing the survey, and used because the survey did not include questions related to income or educational level.

Participants were asked if they had any LTC other than their cancer diagnosis and were asked to tick the appropriate LTCs. This variable was categorised into 'no other', 'one other' and 'two or more LTCs'.

A crosswalk algorithm was used to convert the 5L EQ5D to the 3L version, allowing a weighted health score to be assigned for each individual.[27] United Kingdom population data were used to calculate weighted scores (range -0.5 to 1 [perfect health]). Due to skewness, this outcome variable was categorised and ordered logistic regression undertaken. Three categories representing 'high', 'medium' and 'low' QoL scores were defined for ease of interpretation; these comprised scores equal to 1, less than 1 but greater than or equal to 0.5 and less than 0.5. Odds ratios should be interpreted either as the odds of being in group 2 (medium QoL scores) or group 3 (low QoL scores) compared to group 1 (high QoL scores) *or* the odds of being in group 3 (low QoL scores) compared to group 1 or group 2.

~~Cancer-specific questions from FACT[25] were used as explanatory variables in this analysis (FACT total score could not be calculated as only the cancer-specific subscale questions were included). Patient reported treatments were used in the analyses and treatment combinations were categorised for each cancer site with the most common used as the reference group.~~

Cancer-specific questions from FACT[25] were used as explanatory variables in this analysis (FACT total score could not be calculated as only the cancer-specific subscale questions were included). Patient reported treatments were used in the analyses and treatment combinations were categorised for each cancer site with the most common used as the reference group. Given the study design, participants who had survived a year or more and who reported still receiving treatments when they completed the survey were likely to be receiving treatment for advanced or recurrent disease.

Statistical methods

Chi-squared tests were used to compare categorical variables. Descriptive statistics were compared across cancer sites but the statistical models were stratified by cancer site. Variables were entered into the logistic regression model based on their *a priori* clinical and public health importance after agreement by the study investigators. Formal variable selection procedures were not invoked primarily due to statistical problems associated with these data-driven procedures[28] and, secondly, so that findings could be compared consistently across cancer sites and time points. Statistical significance was set at 1% to

minimise the chances of false-positive associations. All analyses were undertaken using STATA v12.1.

Ethics and governance

Approval was given to approach patients without informed consent by the National Information Governance Board (Supplementary File 6) as the study was performed as service evaluation[29].

Results

Participants

Questionnaires were sent to 4992 individuals, 126 (2·5%) of these had moved or died prior to receiving the questionnaire resulting in a final sample size of 4866. 3300 completed questionnaires were received (66% of the study sample). Of the surveys received by participants, the response rate was 68% (3300/4866).

Response rates

Response rate varied significantly between cancer groups (Table 1a): 69·4% in the prostate group compared to 62·3% in the NHL group (p<0.001).

There was significant difference in the age structure of the non-responders vs. responders with a higher proportion of non-responders in the ≥85 years age group (p<0·001).

Response rates differed according to deprivation status (Table 1a) with a response rate of 71·4% in the least deprived category compared to 57·1% in the most deprived category (p<0·001).

No difference in response rates by time since diagnosis, sex or cancer type was found.

Demographics of respondents (Table 1b)

Overall there were more males than females. Median age was 69 years (range 36-102). There was significant variation in the distribution of ethnicity by cancer group with higher proportions of non-white ethnic groups with NHL. There was no significant difference by deprivation between cancer groups. Overall more than half of patients reported having a LTC. ~~Breast cancer responders displayed a similar age profile to the overall UK incident population.~~ There were fewer reported LTCs in the breast cohort than in other groups but this did not reach statistical significance.

Missing data

Missing data levels were extremely low, typically less than 5% for most fields. SDI had slightly higher levels of missing data with completeness ranging from 80-85%. For the regression modelling (Tables 3a-3d) which used complete case analysis approach, completeness levels were lower and ranged from 60% (colorectal, prostate) to 83% (breast). There was no evidence that the prevalence of missing data was related to the order of the questions after examining levels of completeness for questions at the beginning compared to the end of the form.

Helpline calls and other contact from survey participants

64 calls were made to the helpline, whilst further information about patient status was received via letters from patients (11) and NHS Trusts (2). The total number of enquiries was 77, representing 0.02% of the study cohort.

Generic PROMS

Responses for the five EQ5D questions demonstrated that a higher percentage of NHL patients reported problems with self-care, mobility and usual activities. Two-thirds of breast cancer patients reported some degree of pain (Supplementary Table 1).

When detailed responses for the five EQ5D questions were summarised by time since diagnosis, there were no significant differences for pain, mobility, usual activities or self-care but the percentage reporting anxiety or depression symptoms decreased significantly (p=0·01) (Supplementary Table 2).

Skewed weighted health scores were obtained from the EQ5D by cancer group (Supplementary Figure 1). The prostate group had significantly higher median (0·88) scores than the other three groups (0·84) (p=0·001). The proportion of the populations reporting high QoL scores ranged from 24·4% for breast to 40·0% for prostate cancer (Table 2). Conversely, the proportion reporting low QoL scores ranged from 8.9% for breast to 13.1% for NHL. For all tumour groups, irrespective of remission status, the percentage of

individuals reporting lower QoL scores increased as the number of other LTCs increased (Supplementary Tables 3-4).

Result by Tumour Type

Multivariable ordered logistic regression (Tables 3a-3d) identified three factors which were consistently associated with lower QoL scores irrespective of tumour type: presence of LTCs, undertaking little physical activity and self-reported disease status.

Breast Cancer (Table 3a)

Increasing number of LTCs, having recurrence of disease or being uncertain of disease status were associated with poorer outcomes across all three measures: The presence of one (OR 1·84, 95%CI 1·25,2·70) or two or more (Odds Ratio (OR) 7·30, 95%Confidence Interval (CI) 4·45,11·93) LTCs was significantly associated with lower QoL scores. Individuals self-reporting recurrent disease (OR 4·70, 95%CI 1·92,11·52) or those uncertain about their disease status (OR 2·51, 95%CI 1·27,4·96) were significantly more likely to report lower QoL scores compared to those self-reporting remission.

Increasing age –(apart from those aged 85 years or older) and more days undertaking physical activity were significantly associated with better outcomes in EQ5D, SDI and FACT-B measures: Those aged 65-74 reported significantly higher QoL scores compared to under 55s (OR 0·36, 95%CI 0·22,0·58). Increasing physical activity was associated with higher QoL scores with each additional reported day per week of physical activity reducing the odds of a lower score by 12% (OR 0·88, 95%CI 0·82,0·95).

Individuals from the most deprived areas were significantly more likely to report lower EQ5D derived QoL scores than those from the most affluent areas (OR 3·00, 95%CI 1·64-5·50). Poorer outcomes in FACT-B items were associated with being in the most deprived category.

Colorectal Cancer (Table 3b)

The presence of one (OR 2·09, 95%CI 1·29,3·37) or two or more (OR 4·83, 95%CI 2·85,8·21) LTCs was significantly associated with lower QoL scores. Those who completed the

questionnaire whilst undergoing treatment (OR 7·03, 95%CI 2·44,20·21), experiencing recurrent disease (OR 4·56, 95%CI 1·54,13·49) or who were uncertain about their disease status (OR 2·67, 95%CI 1·23,5·79) had significantly increased odds of reporting lower QoL scores compared to those reporting remission.

Increasing physical activity was significantly associated with a 17% decrease in the odds of a lower QoL score with each additional day per week of physical activity (OR 0·83, 95%CI 0·76,0·90).

23·5% reported urinary leakage, 19·0% difficulty controlling their bowels and 19·2% had a stoma. Individuals experiencing any difficulty controlling their bowels were more than twice as likely to report lower QoL scores (OR 2·30, 95%CI 1·43,3·72). The presence of a stoma or urinary leakage was not significantly associated with QoL.

Greater difficulties with holidays and travel were reported by those with colorectal cancer compared to other cancers. For example, only 51% of colorectal respondents reporting no difficulty compared to 64% with breast or prostate cancer.

Non-Hodgkin's Lymphoma (Table 3c)

The presence of one (OR 2·16, 95%CI 1·44,3·24) or two or more (OR 7·26, 95%CI 4·51,11·69) LTCs was significantly associated with lower QoL scores. Those currently being treated (OR 2·57, 95%CI 1·52,4·33), experiencing a recurrence (OR 3·73, 95%CI 1·68,8·29) or who were not sure about their disease status (OR 3·04, 95%CI 1·58,5·84) had increased odds of reporting lower QoL scores compared to those in remission. These same factors were associated with poorer outcomes on the SDI and FACT-Lym items.

A significant positive association between increasing physical activity and QoL was seen with each additional day of physical activity reducing the odds of lower QoL score by 9% (OR 0·91, 95%CI 0·84,0·98). QoL seemed to improve with time from diagnosis for NHL but the trend was not significant (p=0·100).

Prostate Cancer (Table 3d)

The presence of two or more LTCs (OR 4·28, 95%CI 2·62,7·01) or being in the most deprived category (OR 2·57, 95%CI 1·31,5·04) were significantly associated with lower QoL scores, as well as increased social distress and difficulties identified by FACT-P.

Patients who had surgery only (compared to radiotherapy and hormone treatment) had significantly higher QoL scores (OR 0·39, 95%CI 0·21,0·71) as did those reporting more days of physical activity (OR 0·82, 95%CI 0·75,0·88).

38·5% of prostate patients reported some degree of urinary leakage, 12·9% reported difficulty controlling their bowels and 58·4% reported being unable to have an erection with a further 11% reporting significant difficulty in having or maintaining an erection. The presence of urinary leakage was significantly associated with lower QoL scores (OR 3·52, 5%CI 2·32,5·35). Erectile dysfunction and difficulty controlling bowels were not significantly associated with QoL scores.

Prostate survivors had significantly lower overall social distress scores on the SDI as well as fewer problems in all three sub-scales (everyday living, money matters, self and others) compared to other cancer types.

Fear of recurrence and dying

Almost half (47·3%) of patients reported fear of recurrence and over a quarter (26·8%) reported fear of dying (Supplementary Table 5). Both of these fears decreased significantly with time since diagnosis.

Physical activity

Around one-fifth (21·4%) of participants reported taking 30 minutes or more of physical activity at least five days a week (in line with the Chief Medical Officer's recommendations). This varied by cancer: 16·5% for NHL, 19·0% for breast, 20·2% for colorectal and 29·0% for prostate. Overall 29·8% of patients reported doing no physical activity; this varied by cancer

group with 33·5% of NHL, 31·5% of colorectal and 27·4% of both breast and prostate survivors doing no physical activity.

Discussion

This study represents the largest European survey of survivors of multiple cancer types at clearly defined time points from diagnosis and demonstrates the feasibility of this straightforward method of collecting informative self-reported PROMS data on population-based cohorts of individuals living with and beyond a diagnosis of cancer in England. The process eliminates many of the potential biases that have hindered the collection of population-based cancer PROMS data in the past originating from the use of clinical trial data or acute service provider units for recruitment[30]. English cancer registries, which capture approximately 98-99% of all cancers diagnosed in England[31], provide a reliable denominator population from which to identify eligible participants.

Acceptability and Validity

The relatively high response rate, low level of missing data and low number of calls to the dedicated 24 hour helpline suggest that the methodology is acceptable to the majority of participants. However, the finding of lower participation amongst the elderly or those residing in areas with the greatest socio-economic deprivation would suggest that individuals from these vulnerable groups may need to be assessed by alternative methods. Whilst the questionnaires were identified as having face and content validity by a panel of health and social care professionals prior to use this study does not permit us to comment on the responsiveness or reliability of the instruments. However, the core components of the questionnaires had been identified by independent review as being reliable and appropriate for use in this setting[13-15].

Key results

The QoL of survivors for all four cancers was significantly related to self-reported disease status (remission versus relapse/uncertain), age and presence of LTCs. QoL appeared to either remain constant or improve slightly as time from diagnosis increased. This suggests that some problems experienced by cancer patients persist for long periods.

We have quantified the community prevalence of previously known late morbidities and assessed their impact on QoL. Problems relating to urinary and bowel control have been shown to be common, with nearly 40% of prostate survivors reporting urinary leakage and 13% difficulty controlling their bowels. Similarly, amongst colorectal survivors nearly a quarter reported urinary leakage and 19% reported difficulty controlling their bowels. These rates are comparable to other studies of cancer patients[32] but exceed those seen in non-cancer populations where the prevalence of urinary incontinence in adult men was 4·5% overall, rising to 16·0% for over 75 year olds[33]. In this study, the presence of "urinary leakage" in prostate survivors and "of difficulty controlling their bowels" in colorectal survivors were significantly associated with lower QoL scores making such symptoms important to address. Erectile dysfunction in prostate survivors, though common, did not significantly impact on QoL. The finding that QoL or physical problems such as difficulty controlling bowels or incontinence do not appear to be less prevalent five years following treatment may suggest individuals are not receiving adequate help or treatment for these conditions. Greater efforts should be made in prevention and early intervention for problems resulting from cancer treatment, and directed at those most at risk of the long–term problems identified from this study.

Comparison with the General Population Data

Most survivors in this study who were in remission and did not report a LTC were found to have a high QoL score. However, even the subgroup in remission with no LTC reported lower QoL scores than the data available from general population studies (Table 4). Some of this difference may be accounted for by age, as the Health Survey for England (2008)[34] and the General Practice Patient Survey (GPPS)[35] cohorts were substantially younger than the reported cancer study cohort. This assumption is supported from the HSE cohort aged over 45 years (median age 63, n=7672) which reported a reduction in QoL scores (good 45%, moderate 46%, poor 9%).

Long-term Conditions

The presence of one or more LTCs, other than their cancer diagnosis, was associated with lower QoL scores in all four cancer groups and mirrors findings from other studies[2 36]. The presence of multi-morbidity and LTCs identifies sub-sets of survivors who may require more active support than others. This needs to be factored into risk stratification models as health services move away from hospital based cancer follow-up towards a greater focus on self-management.

Physical Activity

The extent to which cancer survivors take physical activity has not previously been reported in England. The findings agree with those from the USA[37], suggesting that prostate survivors are more likely than others to take moderate or vigorous physical activity. We observed an association between higher levels of activity and higher QoL scores, but it is not possible to assess from a cross-sectional survey whether there is a causal relationship.

A smaller percentage of study respondents (21·4%) met the Chief Medical Officer of England's recommendations for physical activity when compared with the HSE(2008) in which 34% of adults met these guidelines[34]. Restricting the HSE data to a similar age profile as the study participants (60-75 years) saw similar levels of physical activity (23%). The HSE data found a trend of decreased physical activity with increasing age, yet, in this study, prostate survivors (the oldest subgroup) reported higher physical activity levels.

Limitations

The presence of multiple cancer groups and time points, along with some missing data (typically <5%), may have resulted in a lack of power for certain analyses. For example, investigating whether the quality of life of those living with recurrent disease differed from those survivors who had been 'cured'. The non-response rate varied significantly by cancer group, deprivation category and age, which could result in selection bias when generalising results. ~~Our study excluded those treated in the private sector (estimated to be under 5% of cancer cases in England[38]).~~ To overcome bias associated with deprivation and age, we propose extension of the pilot study to the largest possible cohorts available nationally; analyses and interpretation of this data will be performed with maximum sensitivity to these areas.

Our study excluded those treated in the private sector (estimated to be under 5% of cancer cases in England[38]). Treatments may also have changed over the 1-5 year period used to select survivors and it is therefore possible ~~for~~ the results ~~to~~ reflect these changes.

The study relied on self-reporting of long-term conditions, response to treatment and disease status. This information was not independently verified.

The highly skewed EQ5D outcome variable was categorised into three levels for multivariable modelling, which is not a standard approach and meant that information and perhaps discriminatory power was lost. However, our model parameterisation enabled a more natural interpretation of EQ5D QoL data and when comparisons were made with other alternative models, such as tobit regression, findings were very similar. We also acknowledge that measures related to the FACT component are primarily intended for use around the time of treatment rather than for survivorship work. Space limitations precluded a more detailed description of results incorporating the FACT and SDI components. However, a comprehensive report including these additional findings has been compiled and can be accessed via the DH website (https://www.wp.dh.gov.uk/publications/files/2012/12/9284-TSO-2900701-PROMS.pdf)~~URL <????>~~.

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Where next for Cancer PROMS in England?

The use of cancer PROMS has generally been restricted to clinical research, especially clinical trials or small studies. Whilst important work has been undertaken to develop approaches for the measurement of PROMS, they have not been incorporated into routine measurement at a whole health system level. This study demonstrates that population-based survey approaches are feasible and ~~,~~ yield acceptable response rates ~~and are cost-effective~~. This approach could provide important insights into where improvement efforts should be targeted to reduce the long-term burden of cancer and its treatments on the growing number of cancer survivors.

Improving QoL in patients with LTC is one of the key goals of English government health policy (forming Domain 2 of the NHS Outcomes Framework)[39]. The approach we report should be scaled up and integrated within routine health outcome assessment on a national basis so that results can be distilled down to hospital/service provider level, as has been done in relation to the experience of acute care of cancer patients[12]. Improvements in quality of survivor care could then be driven by publishing hospital/provider level data. As a result of the findings of this pilot, a national roll-out to all individuals diagnosed 1-3 years earlier with colorectal cancer in England is being performed in January 2013. A similar roll-out to those diagnosed with prostate cancer is planned whilst pilot questionnaires for those with bladder, cervical, endometrial and ovarian cancer are being prepared. To further understand the develomental trajectory of morbidity burden, a longitudinal survey of respondents to the pilot is being undertaken, with a survey 1 year on having been undertaken and consideration for a further data collection point after another 12 months.

Our findings support the on-going international efforts to identify risk factors for poor health-related QoL outcomes following a cancer diagnosis. These include the presence of other LTCs, deprivation and limited physical activity. These, along with the high prevalence of on-going condition-specific problems such as bowel, urinary and erectile dysfunction, warrant attention by cancer services.

Acknowledgements

Dr Nicola Davies, Professor Jane Maher, Dr Mick Peake, Professor Galina Velikova and Dr Penny Wright provided expert advice regarding questionnaire and study design. Thames Cancer Registry, Eastern Cancer Registry and Information Centre, and West Midlands Cancer Intelligence Unit provided information on all eligible cancer survivors. FACIT provided permission to use components of the FACT questionnaires and Penny Wright granted permission to use the Social Difficulties Inventory.

Funding

This survey was funded by the Department of Health, England.

Open source access for BMJ Open was funded through a grant from Macmillan Cancer Support.

Declaration of Competing Interests

All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: financial support for the submitted work from the Department of Health, England: AWG, GH and MR were employed by the Cancer Policy Team, Department of Health, England, whilst the research was carried out; AWG, LKF, RGF and EF, received financial support from Department of Health, England, to carry out the analysis of data reported; JC and MR co-chaired the Department of Health, England, Cancer Patient Experience Advisory Group.

Data Sharing Statement

Statistical code and dataset are available from the corresponding author at the University of Leeds, who will provide a permanent, citable and open access home for the dataset.

Author Contribution Statement

Adam Glaser contributed to the study design, data collection, data analysis, data interpretation and writing of this manuscript.

Lorna Fraser contributed to the data analysis, data interpretation and writing of this manuscript.

Jessica Corner contributed to the study design, data collection, data interpretation and writing of this manuscript.

Richard Feltbower contributed to the data analysis, data interpretation and writing of this manuscript.

Eva Morris contributed to the data analysis, data interpretation and writing of this manuscript.

Greg Hartwell contributed to the study design and data collection.

Mike Richards contributed to the study design, data interpretation, and writing of this manuscript.

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Table 1a Demographic data of responders and non-responders

Characteristic		Responders (n=3300)		Non Responders (n=1692)		Total number approached	Overall Percentage Responding
		n	*%*	*n*	*%*		
Cancer Group	**χ2=18.8, p<0·001**						
Breast		854	*25.9*	394	*23.3*	*1248*	*68.4*
Colorectal		802	*24.3*	446	*26.4*	*1248*	*64.3*
NHL		778	*23.6*	470	*27.8*	*1248*	*62.3*
Prostate		866	*26.2*	382	*22.5*	*1248*	*69.4*
Age	**χ2=108, p<0·001**						
under 55		467	*14·2*	282	*16.7*	*749*	*62.3*
55 to 64		692	*21·0*	335	*19.8*	*1027*	*67.4*
65 to 74		1,108	*33·6*	414	*24.5*	*1522*	*72.8*
75 to 84		835	*25·3*	434	*25.6*	*1269*	*65.8*
85+		198	*6·0*	227	*13.4*	*425*	*46.6*
IMD Category	**χ2=55.9, p<0.001**						
1 least deprived		826	*25·0*	331	*19.6*	*1157*	*71.4*
2		812	*24·6*	357	*21.1*	*1169*	*69.5*
3		703	*21·3*	349	*20.7*	*1052*	*66.8*
4		554	*16·8*	352	*20.7*	*906*	*61.1*
5 most deprived		399	*12·1*	300	*17.7*	*699*	*57.1*
Missing		6	*0·2*	*3*	*0.2*	*9*	*66.7*
Time since Diagnosis	**χ2=4.1, p=0·25**						
1 year		848	*25·7*	400	*23.6*	*1248*	*67.9*
2 years		834	*25·3*	414	*24.5*	*1248*	*66.8*
3 years		806	*24·4*	442	*26.1*	*1248*	*64.6*
5 years		812	*24·6*	436	*25.8*	*1248*	*65.1*

Table 1b. Demographic Data by Cancer Group

Characteristic		Breast (n=854)		Colorectal (n=802)		Non Hodgkin's Lymphoma (n=778)		Prostate (n=866)		Total (n=3300)	
		n	%	n	%	n	%	n	%	n	%
Sex	**χ2=1700, p<0·001**										
Male		10	*1·2*	435	*54·2*	419	*53·9*	848	*97·9*	1712	*51·9*
Female		829	*97·0*	348	*43·4*	352	*45·2*	0	*0*	1529	*46·3*
Missing		15	*1·8*	19	*2·4*	7	*0·9*	18	*2·1*	59	*1·8*
Age	**χ2=401, p<0·001**										
under 55		231	*27·0*	57	*7·1*	157	*20·2*	157	*18·1*	467	*14·2*
55 to 64		237	*27·8*	136	*17·0*	173	*22·2*	173	*20·0*	692	*21·0*
65 to 74		224	*26·2*	280	*34·9*	238	*30·6*	238	*27·5*	1,108	*33·6*
75 to 84		122	*14·3*	246	*30·7*	175	*22·5*	175	*20·2*	835	*25·3*
85+		40	*4·7*	83	*10·3*	35	*4·5*	35	*4·0*	198	*6·0*
Ethnicity	**χ2=74·6, p<0·001**										
White		768	*89·9*	740	*92·3*	688	*88·4*	786	*90·8*	2982	*90·4*
Asian		35	*4·1*	19	*2·3*	30	*3·9*	15	*1·7*	99	*3·0*
Black		14	*1·6*	11	*1·4*	21	*2·7*	36	*4·2*	82	*2·5*
Mixed		4	*0·5*	5	*0·6*	6	*0·8*	1	*0·1*	16	*0·5*
Other		4	*0·5*	0	*0*	4	*0·5*	3	*0·3*	11	*0·3*
Missing		29	*3·4*	27	*3·4*	29	*3·7*	25	*2·9*	110	*3·3*
IMD Category	**χ2=4·3, p0·97**										
1 least deprived		211	*24·7*	198	*24·7*	202	*26·0*	215	*24·8*	826	*25·0*
2		210	*24·6*	199	*24·8*	183	*23·5*	220	*25·4*	812	*24·6*
3		184	*21·5*	159	*19·8*	177	*22·7*	183	*21·1*	703	*21·3*
4		141	*16·5*	147	*18·3*	125	*16·1*	141	*16·3*	554	*16·8*
5 most deprived		104	*12·2*	98	*12·2*	91	*11·7*	106	*12·2*	399	*12·1*
Missing		4	*0·5*	1	*0·1*	0	*0*	1	*0·1*	6	*0·2*
Time since Diagnosis	**χ2=5·5, p=0·78**										
1 year		215	*25·2*	202	*25·2*	197	*25·3*	234	*27·0*	848	*25·7*
2 years		212	*24·8*	215	*26·8*	187	*24·0*	220	*25·4*	834	*25·3*
3 years		204	*23·9*	195	*24·3*	207	*26·6*	200	*23·1*	806	*24·4*
5 years		223	*26·1*	190	*23·7*	187	*24·0*	212	*24·5*	812	*24·6*
Other Long Term Health Condition	**χ2=12·1, p=0·06**										
Yes		435	*50·9*	432	*53·9*	435	*55·9*	501	*57·9*	1803	*54·6*
No		353	*41·3*	309	*38·5*	287	*36·9*	299	*34·5*	1248	*37·8*
Don't Know		30	*6·9*	23	*2·9*	33	*4·2*	27	*3·1*	113	*3·4*
Missing		36	*4·2*	38	*4·7*	23	*3·0*	39	*4·5*	136	*4·1*
Disease Status	**χ2=390·0, p<0·001**										
Remission		677	*79·3*	625	*77·9*	526	*67·6*	399	*46·1*	2227	*67·5*
Rx but present		26	*3·0*	32	*4·0*	81	*10·4*	144	*16·6*	283	*8·6*
Not treated		4	*0·5*	6	*0·7*	43	*5·5*	78	*9·0*	131	*4·0*

Recurrence		30	*3·5*	20	*2·5*	30	*3·9*	8	*0.9*	88	*2.6*
Not sure		58	*6·8*	69	*8·6*	53	*6·8*	140	*16·2*	320	*9·7*
Missing		59	*6·9*	50	*6·2*	45	*5·8*	97	*11·2*	251	*7·6*

Table 2. EQ5D outcome category by cancer sub-group

EQ5D Categories	'High' QoL (Scores=1)		Medium QoL (0.5≤Scores<1)		Low QoL (Scores<0.5)		Missing	
	n	*%*	n	*%*	n	*%*	n	*%*
Breast	208	*24·4*	514	*60·2*	76	*8·9*	56	*6·6*
Colorectal	255	*31·2*	434	*54·1*	87	*10·8*	26	*3·2*
Non Hodgkins Lymphoma	247	*31·7*	398	*51·2*	102	*13·1*	31	*4·0*
Prostate	347	*40·0*	390	*45·0*	81	*9·4*	48	*5·5*
Total	1057	*32·0*	1736	*52·6*	346	*10·5*	161	*4·9*

Table 3a. Ordered Logistic Regression Model EQ5D in Breast Cancer Patients [n=709, pseudoR^2=0·16 p<0·001]

Characteristic	Odds Ratio*	95% CI		P value
Age (years)				
<55 years	REF			
55-64	0·69	0·45	1·06	0·09
65-74	0·36	0·22	0·58	<0·001
75-84	0·59	0·32	1·08	0·09
85+	1·61	0·57	4·52	0·36
Deprivation				
1 least deprived	REF			
2	1·03	0·66	1·62	0·88
3	1·10	0·68	1·77	0·71
4	0·93	0·55	1·56	0·78
5 most deprived	3·00	1·64	5·50	<0·001
Physical Activity†	0·88	0·82	0·95	<0·001
Number of other LTC (excl BP)				
0	REF			
1	1·84	1·25	2·70	0·002
2+	7·30	4·45	11·93	<0·001
Treatment*				
Radio+Chemo+Surgery+Hormone	REF			
Radio +Chemo+Surgery	0·67	0·38	1·20	0·18
Radio+Surgery	0·51	0·29	0·90	0·02
Radio+Surgery+Hormone	0·56	0·33	0·96	0·04
Surgery only	1·00	0·55	1·84	0·99
Other	0·92	0·53	1·58	0·76
Ethnicity				
White	REF			
Mixed	0·50	0·06	4·29	0·53
Asian	1·96	0·77	5·01	0·16
Black	0·29	0·08	0·98	0·05
Other	2·20	0·17	29·32	0·55
Disease Status				
Remission	REF			
Rx but present	1·49	0·56	3·93	0·43
Not treated	.	.	.	.
Recurrence	4·70	1·92	11·52	0·001
Not sure	2·51	1·27	4·96	0·008
Time since Diagnosis				
1 year	REF			
2 years	1·02	0·64	1·62	0·95
3 years	0·88	0·55	1·41	0·60
5 years	0·93	0·59	1·47	0·76

*Odds of reporting 'medium' or 'low' QoL EQ5D scores compared to 'high' QoL scores where 'high', 'medium' and 'low' QoL was defined as scores=1, 0.5≤scores<1 and scores<0.5 respectively.

†Amount of physical activity performed each week quantified according to the Chief Medical Officer of England's recommendations[16]

Table 3b. Ordered Logistic Regression Model EQ5D in Colorectal Patients [n=485, pseudoR2=0·18, p<0·001]

Characteristic	Odds Ratio	95% CI		P value
Age (years)				
<55 years	REF			
55-64	1·28	0·59	2·75	0·53
65-74	1·16	0·57	2·35	0·69
75-84	1·23	0·57	2·64	0·59
85+	2·45	0·93	6·41	0·07
Sex				
Male	REF			
Female	1·22	0·81	1·82	0·34
Deprivation				
1 least deprived	REF			
2	0·83	0·48	1·43	0·50
3	0·57	0·33	1·00	0·05
4	0·62	0·34	1·13	0·12
5 most deprived	1·17	0·58	2·34	0·66
Physical Activity†	0·83	0·76	0·90	<0·001
Number of other LTC(excl BP)				
0	REF			
1	2·09	1·29	3·37	<0·001
2+	4·83	2·85	8·21	<0·001
Treatment*				
Surgery only	REF			
Radio+Chemo+Surgery	1·15	0·60	2·21	0·67
Chemo+Surgery	1·35	0·85	2·17	0·21
Other	1·58	0·77	3·22	0·21
Ethnicity				
White	REF			
Mixed	1·72	0·24	12·42	0·59
Asian	1·99	0·46	8·54	0·36
Black	1·14	0·26	4·92	0·86
Other	1·72	0·24	12·42	0·59
Disease Status				
Remission	REF			
Rx but present	7·03	2·44	20·21	<0·001
Not treated	0·16	0·01	2·63	0·20
Recurrence	4·56	1·54	13·49	0·01
Not sure	2·67	1·23	5·79	0·01
Stoma				
No	REF			
Yes	1·32	0·80	2·19	0·27
Difficulty Controlling Bowels				
No	REF			
Yes	2·30	1·43	3·72	<0·001
Leak Urine				
No	REF			
Yes	1·41	0·87	2·30	0·16
Time since Diagnosis				
1 year	REF			
2 years	0·72	0·42	1·22	0·22
3 years	1·03	0·59	1·81	0·92
5 years	0·85	0·49	1·48	0·56

*Odds of reporting ‘medium’ or ‘low’ QoL EQ5D scores compared to ‘high’ QoL scores where ‘high’, ‘medium’ and ‘low’ QoL was defined as scores=1, 0.5≤scores<1 and scores<0.5 respectively.

†Amount of physical activity performed each week quantified according to the Chief Medical Officer of England’s recommendations[16]

Table 3c. Ordered Logistic Regression Model EQ5D in NHL Patients [n=614, pseudoR2=0·15 p<0·001]

Characteristic	Odds Ratio	95% CI		P value
Age (years)				
<55 years	REF			
55-64	0·89	0·55	1·45	0·65
65-74	1·23	0·75	1·99	0·41
75-84	1·60	0·94	2·73	0·08
85+	2·13	0·84	5·39	0·11
Sex				
Male	REF			
Female	1·25	0·89	1·74	0·19
Deprivation				
1 least deprived	REF			
2	1·06	0·67	1·69	0·80
3	1·21	0·75	1·95	0·43
4	1·64	0·97	2·76	0·07
5 most deprived	1·19	0·65	2·21	0·57
Physical Activity†	0·91	0·84	0·98	0·01
Number of other LTC (excluding BP)				
0	REF			
1	2·16	1·44	3·24	<0·001
2+	7·26	4·51	11·69	<0·001
Treatment*				
Chemo only	REF			
Radio+Chemo	0·81	0·47	1·41	0·46
Chemo + Antibody	0·93	0·55	1·59	0·80
Radio+Chemo+Other	1·55	0·87	2·77	0·14
Other	0·96	0·63	1·46	0·86
Ethnicity				
White	REF			
Mixed	2·78	0·28	27·7	0·38
Asian	0·68	0·29	1·59	0·38
Black	0·91	0·33	2·49	0·85
Other	0·61	0·09	4·39	0·62
Disease Status				
Remission	REF			
Rx but present	2·57	1·52	4·33	<0·001
Not treated	0·83	0·17	3·96	0·82
Recurrence	3·73	1·68	8·29	0·001
Not sure	3·04	1·58	5·84	0·001
Time since Diagnosis				
1 year	REF			
2 years	0·62	0·38	0·99	0·05
3 years	0·60	0·38	0·96	0·03
5 years	0·57	0·36	0·90	0·02

*Odds of reporting 'medium' or 'low' QoL EQ5D scores compared to 'high' QoL scores where 'high', 'medium' and 'low' QoL was defined as scores=1, 0.5≤scores<1 and scores<0.5 respectively.

†Amount of physical activity performed each week quantified according to the Chief Medical Officer of England's recommendations[16]

Table 3d. Ordered Logistic Regression Model EQ5D in Prostate Patients [n=524, pseudoR2=0·22 p<0·001]

Characteristic	Odds Ratio	95% CI		P value
Age (years)				
<55 years	REF			
55-64	1·32	0·41	4·30	0·64
65-74	1·72	0·55	5·38	0·36
75-84	1·32	0·41	4·30	0·64
85+	1·92	0·42	8·78	0·40
Deprivation				
1 least deprived	REF			
2	1·09	0·64	1·85	0·74
3	1·19	0·68	2·08	0·55
4	1·61	0·88	2·95	0·13
5 most deprived	2·57	1·31	5·04	0·01
Physical Activity†	0·82	0·75	0·88	<0·001
Number of other LTC(excl BP)				
0	REF			
1	1·55	0·94	2·54	0·09
2+	4·28	2·62	7·01	<0·001
Treatment*				
Radio+Hormone	REF			
Surgery only	0·39	0·21	0·71	<0·001
Hormone only	1·68	0·85	3·33	0·14
Radio only	0·94	0·53	1·66	0·83
Active surveillance only	1·16	0·47	2·88	0·75
Other	·	·	·	·
Ethnicity				
White	REF			
Mixed	3·82	0·07	203·44	0·51
Asian	3·21	0·56	18·49	0·19
Black	2·54	0·96	6·73	0·06
Other	0·00	0·00	·	0·98
Disease Status				
Remission	REF			
Rx but present	1·75	0·94	3·26	0·08
Not treated	1·06	0·37	3·05	0·91
Recurrence	1·71	0·17	16·91	0·65
Not sure	1·48	0·85	2·58	0·17
Urinary Leakage				
No	REF			
Yes	3·52	2·32	5·35	<0·001
Erectile Dysfunction				
No	REF			
Yes	1·46	0·96	2·23	0·08
Difficulty Controlling Bowels				
No	REF			
Yes	1·62	0·90	2·92	0·10
Time since Diagnosis				
1 year	REF			
2 years	0·83	0·50	1·40	0·49
3 years	0·80	0·47	1·36	0·41
5 years	0·77	0·45	1·33	0·36

*Odds of reporting 'medium' or 'low' QoL EQ5D scores compared to 'high' QoL scores where 'high', 'medium' and 'low' QoL was defined as scores=1, 0.5≤scores<1 and scores<0.5 respectively.

†Amount of physical activity performed each week quantified according to the Chief Medical Officer of England's recommendations[16]

Table 4. Comparison of Quality of Life scores with other population data

	Health Survey for England (HSE 2008)[34]		GP Population Survey (GPPS)[35]	GP Population Survey (GPPS)[35]	This survey	
	All ages	Ages≥ 45 years	All	No LTC	All	In remission with no LTC
Number of respondents	14116	7672	426933	193285	3300	848
Median age	48	63	48	39	69·3	63·2
'High' QOL (Scores=1)	56.0%	45·4%	50·6%	73·8%	32·0%	51·4%
'Medium' QOL (0.5≤Scores <1)	37.7%	45·6%	41·6%	25·2%	52·6%	44·3%
'Low' QOL (Scores <0·5)	6.3%	9·0%	7·8%	0·9%	10·5%	2·1%

Supplementary Table 1. Quality of Life Dimension Results (EQ5D) by Cancer Sub group

EQ5D dimension		Breast (n=854)		Colorectal (n=802)		Non Hodgkin's Lymphoma (n=778)		Prostate (n=866)		Total (n=3300)	
		n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Mobility χ2=51·3, p<0·001	No Problems	567	*66·4*	442	*55·1*	427	*54·9*	535	*61·8*	1971	*59·7*
	Slight Problems	105	*12·3*	159	*19·8*	140	*18·0*	131	*15·1*	535	*16·2*
	Moderate Problems	107	*12·5*	120	*15·0*	120	*15·4*	97	*11·2*	444	*13·5*
	Severe Problems	46	*5·4*	57	*7·1*	71	*9·1*	69	*8·0*	243	*7·4*
	Cannot walk	8	*0·9*	13	*1·6*	6	*0·8*	4	*0·4*	31	*0·9*
	Missing	21	*2·5*	11	*1·4*	14	*1·8*	30	*3·5*	76	*2·3*
Self Care χ2=30·4, p=0·002	No Problems	716	*83·8*	651	*81·2*	611	*78·5*	704	*81·3*	2682	*81·3*
	Slight Problems	47	*5·5*	67	*8·4*	66	*8·5*	78	*9·0*	258	*7·8*
	Moderate Problems	45	*5·3*	46	*5·7*	71	*9·1*	44	*5·1*	206	*6·2*
	Severe Problems	12	*1·4*	18	*2·2*	12	*1·5*	9	*1·0*	51	*1·5*
	Cannot wash/dress	6	*0·7*	9	*1·1*	4	*0·5*	4	*0·5*	23	*0·7*
	Missing	28	*3·3*	11	*1·4*	14	*1·8*	27	*3·1*	80	*2·4*
Usual Activities χ2=34·5, p<0·001	No Problems	513	*60·1*	429	*53·5*	411	*52·8*	533	*61·5*	1886	*57·2*
	Slight Problems	162	*19·0*	173	*21·6*	156	*20·1*	145	*16·7*	636	*19·3*
	Moderate Problems	111	*13·0*	113	*14·1*	127	*16·3*	104	*12·1*	455	*13·7*
	Severe Problems	31	*3·6*	48	*6·0*	49	*6·3*	43	*5·0*	171	*5·2*
	Cannot do usual activities	14	*1·6*	24	*3·0*	26	*3·3*	15	*1·7*	79	*2·4*
	Missing	23	*2·7*	15	*1·8*	9	*1·2*	26	*3·0*	73	*2·2*
Pain χ2=134·3, p<0·001	No Pain	329	*38·5*	429	*53·5*	408	*52·4*	526	*60·7*	1692	*51·3*
	Slight Pain	341	*39·9*	220	*27·4*	180	*23·1*	169	*19·5*	910	*27·6*
	Moderate Pain	113	*13·2*	92	*11·5*	120	*15·4*	101	*11·7*	426	*12·9*
	Severe Pain	39	*4·6*	35	*4·4*	51	*6·6*	38	*4·4*	163	*4·9*
	Extreme Pain	5	*0·6*	9	*1·1*	10	*1·3*	3	*0·3*	27	*0·8*
	Missing	27	*3·2*	17	*2·1*	9	*1·2*	29	*3·3*	82	*2·5*
Anxiety/ depression χ2=37·1, p<0·001	No anxiety/depression	475	*55·6*	504	*62·8*	464	*59·6*	566	*65·4*	2009	*60·9*
	Slight anxiety/depression	241	*28·2*	196	*24·4*	186	*23·9*	183	*21·1*	806	*24·4*
	Moderate anxiety/depression	78	*9·1*	78	*9·7*	83	*10·7*	76	*8·8*	315	*9·5*
	Severe anxiety/depression	21	*2·5*	6	*0·8*	21	*2·7*	8	*0·9*	56	*1·7*
	Extreme anxiety/depression	10	*1·2*	4	*0·5*	8	*1·0*	4	*0·5*	26	*0·8*
	Missing	29	*3·4*	14	*1·8*	16	*2·1*	29	*3·3*	88	*2·7*

Supplementary Table 2 Quality of Life Dimension Results (EQ5D) by time since diagnosis of cancer

		1 year (n=848)		2 years (n=834)		3 years (n=806)		5 years (n=812)		Total (n=3300)	
		N	***%***	**N**	***%***	**N**	***%***	**N**	***%***	**N**	***%***
Mobility	No Problems	521	*61.4*	501	*60.1*	486	*60.3*	463	*57.0*	1971	*59.7*
χ2=21.1, p=0.05	Slight Problems	150	*17.7*	123	*14.7*	127	*15.8*	135	*16.6*	535	*16.2*
	Moderate Problems	93	*11.0*	116	*13.9*	104	*12.9*	131	*13.1*	444	*13.5*
	Severe Problems	62	*7.3*	62	*7.4*	56	*6.9*	63	*7.8*	243	*7.4*
	Cannot walk	2	*0.2*	8	*9.6*	13	*1.6*	8	*1.0*	31	*0.9*
	Missing	20	*2.4*	24	*2.9*	20	*2.5*	12	*1.5*	76	*2.3*
Self Care	No Problems	696	*82.1*	674	*80.8*	659	*81.8*	653	*80.4*	2682	*81.3*
χ2=10.2, p=0.59	Slight Problems	59	*6.9*	65	*7.8*	61	*7.6*	73	*9.0*	258	*7.8*
	Moderate Problems	57	*6.7*	56	*6.7*	42	*5.2*	51	*6.3*	206	*6.2*
	Severe Problems	12	*1.4*	12	*1.4*	14	*1.7*	13	*1.6*	51	*1.5*
	Cannot wash/dress	3	*0.4*	4	*0.5*	10	*1.2*	6	*0.7*	23	*0.7*
	Missing	21	*2.5*	23	*2.8*	20	*2.5*	16	*2.0*	80	*2.4*
Usual Activities	No Problems	465	*54.8*	474	*56.8*	465	*57.7*	482	*59.4*	1886	*57.2*
χ2=13.9, p=0.31	Slight Problems	181	*21.3*	157	*18.8*	161	*20.0*	137	*16.9*	636	*19.3*
	Moderate Problems	131	*15.4*	112	*13.4*	95	*11.8*	117	*14.4*	455	*13.7*
	Severe Problems	35	*4.1*	45	*5.4*	44	*5.5*	47	*5.8*	171	*5.2*
	Cannot do usual activities	18	*2.1*	19	*2.3*	23	*2.8*	19	*2.3*	79	*2.4*
	Missing	18	*2.1*	27	*3.2*	18	*2.2*	10	*1.2*	73	*2.2*
Pain	No Pain	421	*49.6*	412	*49.4*	435	*54.0*	424	*52.2*	1692	*51.3*
χ2=18.0, p=0.12	Slight Pain	262	*30.9*	237	*28.4*	198	*24.6*	213	*26.2*	910	*27.6*
	Moderate Pain	101	*11.9*	112	*13.4*	105	*13.0*	108	*13.3*	426	*12.9*
	Severe Pain	34	*4.0*	44	*5.3*	38	*4.7*	47	*5.8*	163	*4.9*
	Extreme Pain	7	*0.8*	6	*0.7*	11	*1.4*	3	*0.4*	27	*0.8*
	Missing	23	*2.7*	23	*2.8*	19	*2.4*	17	*2.1*	82	*2.5*
Anxiety/depression	No anxiety/depression	466	*55.0*	505	*60.6*	499	*61.9*	539	*66.4*	2009	*60.9*
χ2=25.8, p=0.01	Slight anxiety/depression	244	*28.8*	195	*23.4*	196	*24.3*	171	*21.1*	806	*24.4*
	Moderate anxiety/depression	88	*10.4*	86	*10.3*	68	*8.4*	73	*9.0*	315	*9.5*
	Severe anxiety/depression	20	*2.4*	13	*1.5*	13	*1.6*	10	*1.2*	56	*1.7*
	Extreme anxiety/depression	6	*0.7*	8	*1.0*	6	*0.7*	6	*0.7*	26	*0.8*
	Missing	24	*2.8*	27	*3.2*	24	*3.0*	13	*1.6*	88	*2.7*

Supplementary Table 3. EQ5D outcome category by the number of Long Term Conditions (LTC) in patients in remission

EQ5D Categories	**High QoL (Scores=1)**		**Medium QoL (0.5≤Scores<1)**		**Low QoL (Scores<0.5)**		**Missing**		**Total**
	n	*%*	n	*%*	n	*%*	n	*%*	
No LTC	436	51·4	376	44·3	18	2·1	18	2·1	848
1 LTC	250	36·2	378	54·7	40	5·8	23	3·3	691
≥2 LTC	129	18·8	419	60·9	119	17·3	21	3·1	688
Total	815	36·6	1,173	52·7	177	7·9	62	2·8	2,227

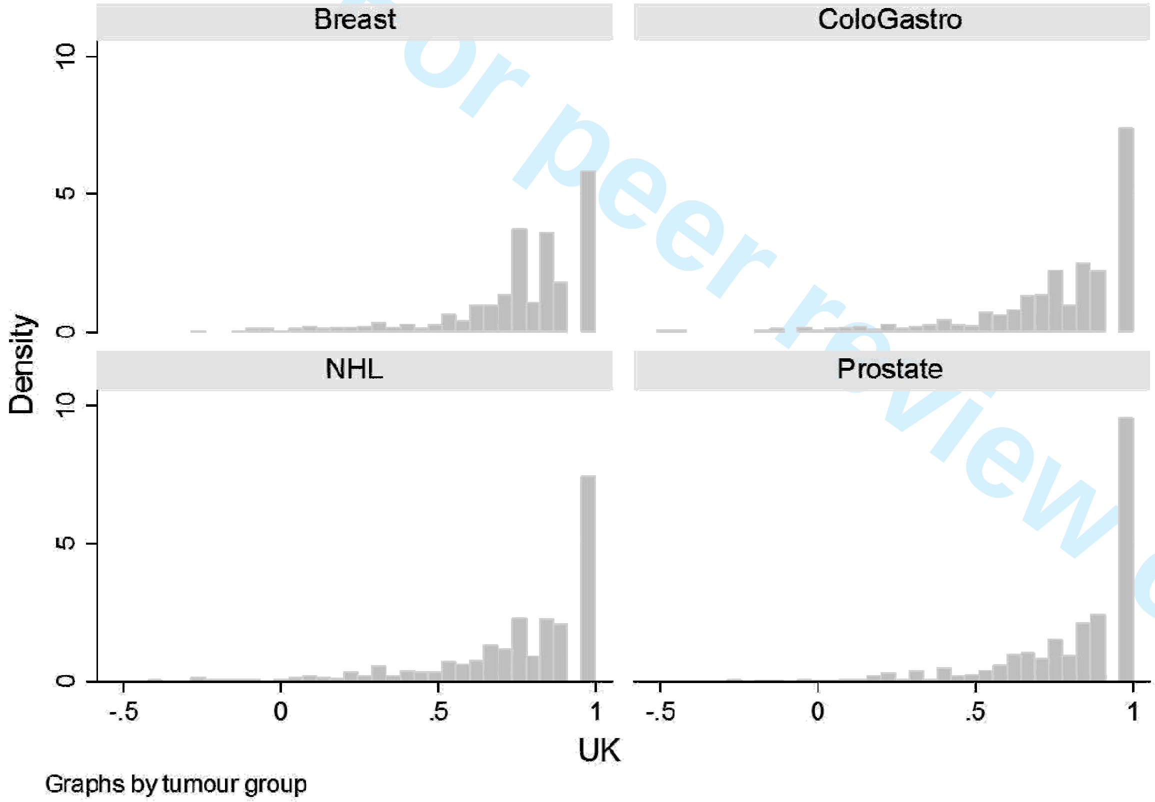
Supplementary Table 4. EQ5D outcome category by the number of Long Term Conditions (LTC) in patients not in remission

EQ5D Categories	**High QoL (Scores=1)**		**Medium QoL (0.5≤Scores<1)**		**Low QoL (Scores<0.5)**		**Missing**		**Total**
	n	*%*	n	*%*	n	*%*	n	*%*	
No LTC	79	33·9	130	55·8	15	6·4	9	3·9	233
1 LTC	64	23·1	175	63·2	25	9·0	13	4·7	277
≥2 LTC	37	11·9	166	53·2	94	30·1	15	4·8	312
Total	180	21·9	471	57·3	134	16·3	37	4·5	822

Supplementary Table 5. Fear of Dying and Recurrence of Disease by Time since Diagnosis

Fear of Dying	Yes%		No		Missing		Total
	n	%	n	%	n	%	
1 year ago	256	*30·2*	542	*63·9*	50	*5·9*	848
2 years ago	233	*27·9*	543	*65·1*	58	*7·0*	834
3 years ago	214	*26·6*	531	*65·9*	61	*7·6*	806
5 years ago	180	*22·2*	583	*71·8*	49	*6·0*	812
Total	883	*26·8*	2,199	*66·6*	218	*6·6*	3,300
Fear of Recurrence	n	%	n	%	n	%	
1 year ago	437	*51·5*	369	*43·5*	42	*5·0*	848
2 years ago	403	*48·3*	398	*47·7*	33	*4·0*	834
3 years ago	376	*46·7*	384	*47·6*	46	*5·7*	806
5 years ago	345	*42·5*	427	*52·6*	40	*4·9*	812
Total	1,561	*47·3*	1,578	*47·8*	161	*4·9*	3,300

Supplementary Figure 1. Distribution of EQ5D summary scores by cancer sub-type



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4 February 2013

Dear Mr Sands and Colleagues,

We are grateful for the opportunity to make revisions to the submitted manuscript. We have made a number of changes to the manuscript that we feel significantly enhance its quality. One or two of the very helpful reviewer's comments have not led to changes in the manuscript and we have commented as to why we have not felt changes necessary.

To aid interpretation of changes, I have copied the reviewers’ comments below and provided responses in CAPITALS in the appropriate sections of these.

Please do not hesitate to contact me if further clarification is required or if you would suggest further amendments.

Yours sincerely,

ADAM GLASER

Reviewer(s) Reports:

Reviewer: Simon N Rogers
Professor, EPRC, Edge Hill University and Consultant Oral and Maxillofacial Surgeon, Aintree University Hospital, UK
I have no competing interests.

This is a very well undertaken and presented piece of clinical outcomes research. PROMS in cancer is very important.
The study comprises of a very large cohort albeit restricted to breast, colorectal, prostate and non-hodgkins. It is not clear why these four were selected. Was it because they are common forms of cancer or was there an expected theoretical expected difference of outcome based on patient and clinical characteristics? THESE WERE CHOSEN AS THEY ARE COMMON AND THERE ARE LARGE NUMBERS LIVING BEYOND CANCER TREATMENT.
Allowing comparison to Health Survey (2008) and General Practice Survey adds value to the study as does the other facets such as the relationship with the presence of one or more long-term condition. Cancer patients surviving into older age will have other comorbidities that impact on their Patient Report Outcome yet are not directly related to their cancer. It can be hard to tease this out and apportion weighting.
There is an ccceptable response rate for the cross-sectional survey (66%). Though two reminders were sent to non-responders. There is a cost associated with this. Also confirmation that the patient is alive as sending a questionnaire to a dead patient can cause considerable family distress.

The PROMs used are appropriate. There are various measures such as EQ-5D, FACT (cancer specific), Social Difficulties Inventory (SDI), Experience of care etc . The data tends to focus on the EQ-5D.

It is not clear which questionnaire was used to assess the fear of recurrence and dying. Also is this something that is expected to be common following cancer, however the severity of this concern might be low. Perhaps more mention around recurrence fears is appropriate given that 47% reported fear of recurrence. In many ways it is a natural and healthy reaction to having cancer. The fact that a quarter had fear of dying again might be reasonable and needs to be compared to normative data. THESE ITEMS WERE MADE UP BY THE PROJECT TEAM AND THEN COGNITIVIELY TESTED PRIOR TO THIS PILOT. WE HAVE ADDED DETAIL TO PAGE 8.

Deprivation influenced response rate and outcome. This is a challenge when trying to assess PRO in the more vulnerable groups of society. What solutions are there to attempt to address this? IT IS VERY HARD TO SELECT POPULATIONS WITHOUT SKEWING THE DATA. HOWEVER, WITH ROLL-OUT OF THE PILOT TO LARGE COHORTS WE WILL PERFORM ANALYSES AND INTERPRETATION WITH SENSITIVITY TO THESE ISSUES. WE PROPOSE NATIONAL ROLL-OUT AND SO WILL CAPTURE AS MANY PATIENTS AS POSSIBLE . SECTION ADDED TO "STUDY LIMITATIONS" IN DISCUSSION, P19.

Very good presentation of data – the detail in the tables is to be commended.

The study has two aims. Firstly to determine feasibility of PROM in assessing QOL. This is already well established and this study tests a limited aspect of 'feasibility'. Linking to this the authors' second aim is to inform the development of a national PROMS programme for cancer. It is unclear how this study does that.

There are issues around the conclusion of this study. Questionnaires are already acknowledged as feasible and acceptable to most survivors. There are significant challenges to routinely collecting PROMS. THE PILOT STUDY WAS PERFORMED TO DETERMINE THE FEASIBILITY AND ACCEPTABILITY OF THE DESCRIBED APPROACH TO IDENTIFY PARTICIPANTS AND THEN CONTACT THEM AT THESE TIME-POINTS BY MAIL WITHOUT INTRODUCTION DIRECTLY BY A CLINICIAN OR RESEARCHER KNOWN TO THEM. THERE IS NO LITERATURE TO SUPPORT THIS METHODOLOGICAL DESIGN OF POPULATION-BASED PROMS DATA COLLECTION. WE HAVE ADDED CLARIFICATION TO THE OBJECTIVES ON P6 AND IN THE ABSTRACT.Most HRQOL questionnaires have limited utility in the identification of specific needs as they are limited by the questionnaire items themselves, range, wording, scoring. Comparing HRQOL across service provides as an outcome is not without it problems based on patients priorities in cancer, response shift, adaptation, limitations inherent in HRQOL questionnaires, confounding variables.

The key messages are weak – they are already well appreciated (first two appoints) or ill-advised (third point). HRQOL measures as used in this study are likely to fail to give clinically meaningful health economics comparison across provides and fail to really facilitate service provision across the diverse needs at cancer patients have. WE RECOGNISE THAT THE OVERALL SAMPLE REPORTED IS LARGE. HOWEVER, WHEN BROKEN DOWN BY THE DISEASE GROUPS AND TIMES FROM DIAGNOSIS IT IS SMALL.

HENCE, WE FELT UNABLE TO MAKE DETAILED CLAIMS REGARDING THE QUALITY OF OUTCOMES NOR WERE WE KEEN TO OVER-INTERPRET FINDINGS OTHER THAN GIVE A FEEL FOR WHAT WILL BE ACHIEVABLE THROUGH A NATIONAL ROLL-OUT OF THE METHODOLOGY/PROGRAMME. WE ARE CURRENTLY COLLECTING DATA ON 35,000 INDIVIDUALS WITH COLORECTAL CANCER AND THIS EXPANDED DATA-SET WILL ALLOW US TO ANSWER THE IMPORTANT POINTS RAISED BY THE REVIEWER. CHANGES TO THE ABSTRACT, DISCUSSION AND CONCLUSIONS HAVE BEN MADE TO EXPLAIN THESE POINTS.

Reviewer: A/Prof Michael Jefford
Consultant Medical Oncologist
Australian Cancer Survivorship Centre, A Richard Pratt Legacy
Peter MacCallum Cancer Centre
Melbourne, Victoria, Australia

I recently authored a paper with Glaser, Richards
I spent part of my sabbatical in 2011 working with Glaser, Richards and briefly Hartwell, Corner

This is an important, interesting paper describing the largest population-based evaluation of European cancer survivors' PROs

It confirms the feasibility of collecting data in this manner and provides useful baseline data

One aspect that should be mentioned is that we don't know how many people are disease-free and how many are living with advanced cancer. It's worth stating this. Some studies have included 'survivors' who are cancer-free, making comparisons with this study somewhat problematic. The authors might consider describing QoL for people who are apparently disease-free and for those who report that they are living with cancer THESE ARE IMPORTANT POINTS. WE HAVE ADDED COMMENTS TO P10 AND P19 IN THE "STUDY LIMITATIONS". THE NUMBERS IN THE SAMPLES PREVENT IN-DEPTH ANALYSIS OF DISEASE-FREE VERSUS THOSE WITH ACTIVE DISEASE.

The paper is strong, but could be improved by considering aspects below

Abstract

- Objectives do not really reflect the results. Surely the objectives include a desire to describe PROs, determine predictors of QoL, as well as look at feasibility, etc THE STUDY WAS DONE PURELY AS A FEASIBILITY STUDY PRIOR TO THE MAJOR INVESTMENT OF A NATIONAL STUDY. AGAIN, THE NUMBERS ARE TOO SMALL FOR DETAILED ANALYSIS AND WE WERE CAUTIOUS OF OVER INTERPRETATION IN DESCRIBING PROs,

IDENTIFYING PREDICTIVE FACTORS FOR OUTCOMES ETC. WE HAVE ADJUSTED THE WORDING OF THE OBJECTIVES INT HE ABSTRACT.

- Results – ‘QoL scores were stable over time’ – careful, as people were not followed longitudinally. WE HAVE ADJUSTED THE WORDING OF THE RESULTS SECTION OF THE ABSTRACT.

Article summary

- Article focus - “to inform the development of a national PROMS programme for cancer” – this is not really discussed in the paper (but probably should be)
- Strengths and limitations – 4th bullet (face and content validity) – questionnaires were not reviewed by consumers (patients, survivors) so I don’t know whether this is a strength or a weakness THE QUESTIONNAIRES WERE REVIEWED BY CONSUMERS IN A PROCESS OF COGNITIVE TESTING AND THROUGH INVOLVEMENT OF ESTABLISHED NATIONAL ADVISORY GROUPS AND CONSULTATION WITH MAJOR CANCER CHARITIES. COGNITIVE TESTING DESCRIBED P9..

Introduction

- final paragraph – ‘determine the feasibility of routinely collecting’ – consider adding the ‘how’ here – perhaps “by considering response rate, completion, participant complaints” WE HAVE MODIFIED THE FINAL PARAGRAPH OF THE INTRODUCTION.
- same paragraph – add extra goals – to report QoL and describe associations between QoL and other disease / patient factors WE HAVE TRIED TO STEER CLEAR OF THIS AS WE KNEW THE SAMPLE SIZES WOULD BE SMALL AND WE WILL HAVE MORE RELIABLE AND INTERPREATBLE DATA FORM THE NATIONAL ROLL-OUT OF THE PROGRAMME.

Methods, study design

- why 1, 2, 3, 5 years? Why not 1, 3, 5, 8 (as an example)? There seems a lot of sampling 1 YEAR WAS CHOSEN AS A BASELINE WHEN IT WAS FELT THE VAST MAJORITY WOULD HAVE COMPLETED PRIMARY CANCER THERAPY (PRO DATA IS COLLECTED BY NATIONAL CANCER PATIENT EXPERIENCE PROGRAMME WITHIN THE FIRST YEAR FROM DIAGNOSIS IN ENGLAND). 2 YEARS REFLECTS THE RE-ADJUSTMENT PERIOD AND 3 AND 5 YEARS WERE ARBITARILY CHOSEN TO EXAMINE THE DEVELOPMENTAL TRAJECTORY OF MORBIDITY BURDEN.
- add the ‘<5%’ line from the discussion in here in reference to private centres.

Methods, cohort identification

- ‘covered 70 of 160 (43%) acute NHS Trusts’ – are these typical of all NHS Trusts? THERE IS NO WAY OF KNOWING THIS, BUT WE HAVE NO REASON TO SUSPECT THEY ARE NOT "TYPICAL".
- Explain ‘Demographic Batch Service’ REMOVED THE TERM AND ADJUSTED EXPLANATION OF DEATH CHECKS.
- ‘a dedicated freephone telephone helpline’ – add what the purpose of this was. Was it for assistance / to make a complaint? Were people

adequately advised of the purpose of the service? CLARIFICATION HAS BEEN ADDED TO P8.

Methods, questionnaire design and content

- add more about development – the process of consultation with patient groups, etc FURTHER EXPLANATION HAS BEEN ADDED ON 8 AND P9.
- briefly describe the rationale for including each of the measures, eg why ask about exercise? (but not about smoking, drinking, etc) THESE ARE DESCRIBED IN MORE DETAIL N THE REFERENCED DEPARTMENT OF HEALTH REPORT. WE INCLUDED PHYSICAL ACTIVITY AS IT IS EMERGING AS A KEY FACTOR IN OUTCOMES. ITEM SELECTION WAS PERFORMED FOLLOWING LITERATURE REVIEW AND SIGNIFICANTLY INFORMED BY REPORTS FOR THE DEPARTMENT OF HEALTH BY PROF RAY FITZPATRICK(OXFORD) PLUS CONSULTATION WITH EXPERT CLINICAL ADVISORY PANELS.
- comment on readability of the final questionnaires – the front page of the survey looks like it would frighten off people with health literacy difficulties
- generic content – describe the validity of ‘self-reported response to treatment and disease status’ and also reporting of long-term conditions ADDED COMMENTS TO "STUDY LIMITATIONS" IN DISCUSSION.
- describe the ‘experience of care’ survey ADDED SENTENCE TO P8
- how was fear of recurrence and fear of death assessed (ie what tools) – this is important as there are many instruments available
- have all the data from the measures been reported? If not, why not? NO THEY HAVE NOT, WE HAVE BEEN SELECTIVE AS THERE WAS TOO MUCH INFORMATION FOR ONE MANUSCRIPT. A COMPREHENSIVE REPORT HAS BEEN COMPILED AND IS NOW REFERENCED IN THE DISCUSSION, P20.
- FACT measures are really intended for use around treatment. This needs to be acknowledged (i.e they’re not really ‘survivorship’ measures) THIS IS NOW DISCUSSED ON P20.
- cognitive testing – was there pretesting to determine that people understood and answered correctly?
- Why were the questions on feeling like a man (prostate ca) or a woman (breast ca) omitted? ACTION TAKEN AS THESE QUESTIONS WERE FOUND TO BE CONFUSING AND UNACCEPTABLE TO THOSE PATIENTS/SURVIVORS PARTICIPATING IN THE COGNITIVE TESTING EXERCISE.

Methods, data analysis

- is the categorization of QoL into high , medium, low a standard procedure? If so, reference it. If not, explain this A SECTION HAS BEEN ADDED TO THE "STUDY LIMITATIONS" IN THE DISCUSSION.

Results

- response rates - no difference in RR by sex – this data is not shown THE FULL RESULTS ARE INT HE PREVIOUSLY MENTIONED AND REFERENCED DEPARTMENT OF HEALTH REPORT.
- demographics of respondents – breast ca respondents similar age profile to incident cases – seems odd as you might expect that people would

be 1, 2, 3, 5 years older than incident cases. Add whether other cancer types are reflective of the age expected in the population THIS STATEMENT HAS BEEN REMOVED AS THE RESPONDERS' DATA PRESENTED IN TABLE 1b IS NOT SIMULTANEOUSLY STRATIFIED BY AGE AND TIME FROM DIAGNOSIS.

- missing data – 'no evidence … missing data was related to the order of the questions' – was different order tried? Or do you mean that missing data was no more common at the end c/w earlier questions? THIS HAS BEEN AMENDED IN THE MANUSCRIPT.
- Generic PROMS – worth adding in the data for "percentage reporting anxiety or depression symptoms decreased significantly" as this is likely to be of interest. Adding comparisons to the general population (or mentioning in the discussion) would be interesting AGREE, BUT THIS IS IN THE FULL REFERENCED REPORT AND SPACE CONSTRAINTS PREVENTED INCLUSION.
- Breast cancer (page 13, lines 28-30) "Increasing age … better outcomes in EQ5D" – not really, as 85+ have an OR of 1.61 THE SENTENCE HAS BEEN AMENDED TO CLARIFY THE STATEMENT.
- Colorectal cancer (lines 54, 55) – regarding the comment 'whilst undergoing treatment' – people undergoing treatment are likely those with advanced or recurrent cancer. Has this been examined? Worth mentioning when describing the initial study sample DISCUSSION ADDED TO "STUDY LIMITATIONS".
- NHL, page 14, line 49 – "QoL seemed to improve with time from diagnosis" – qualify this to say that they are not the same patients who have been followed longitudinally DISCUSSION ADDED TO "STUDY LIMITATIONS" AND "WHERE NEXT FOR CANCER PROMs IN ENGLAND".
- CRC and prostate ca (page 14, lines 15-21 and page 15, lines 19-28) – this seems like quite selective reporting from the disease-specific FACT measures. Consider how to present this data more completely (for all cancer types) AGAIN, HIGHLIGHTED THAT FULL RESULTS ARE AVAILABLE IN THE DH REPORT.
- Fear of recurrence and dying – this data is important and worth describing in more detail (perhaps not in a supplementary table). Also, include whether these fears are related to psychological morbidity / inferior QoL. WE ARE CAUTIOUS ABOUT OVER-INTERPRETATION OF THE DATA DUE TO SMALL SAMPLE SIZES. WE PLAN TO WAIT UPON THE DATA FROM THE NATIONAL ROLL-OUT.

Discussion

- This generally lacks oomph, and restates the results a little too much. I'm still left with a feeling of 'so what?' and 'so what now?'
- There is a major focus on the EQ5D and associations with inferior QoL. Other factors that might impact QoL were not recorded, eg ongoing physical symptoms, depression – explain why all factors known to impact QoL were not included
- It would be useful to include consideration of (i) other large studies of cancer survivors (e.g. compare to reference #2 – what does this data add?), (ii) consideration of possible mechanisms – why / how do the significant factors (eg age, deprivation, LTC, disease status) impact on QoL? (iii)

potential interventions based on the data, IN RESPONSE TO THE ABOVE 3 COMMENTS RELATING TO THE DISCUSSION: AS PREVIOUSLY STATED WE ARE CAUTIOUS ABOUT OVER-INTERPRETATION. CERTAIN CONFOUNDING FACTORS SUCH AS THOSE DESCRIBED ABOVE WERE NOT CONSIDERED DUE TO SMALL NUMBERS AND SOME OF THESE ARE LIKELY TO BE HIGHLY CORRELATED WITH FACTORS WE DID ADJUST FOR SUCH AS DEPRIVATION. HENCE, INCLUDING ALL POSSIBLE "CONFOUNDERS" WOULD LEAD TO BIAS.
(iv) future steps – will the survey be repeated? Why / when? agree, SECTION ADDED TO "WHERE NEXT FOR CANCER PROMS IN ENGLAND" IN DISCUSSION -OUTLINES THE PROPOSED AND, IN PLACE, NATIONAL ROLL-OUT.

- There should also be discussion of the possibility that treatments have changed over the 1-5 years and thus results might reflect treatment changes / change in practice agree agree, ADDED TO "STUDY LIMITATIONS" AND DISCUSSION.
- Comparison with the general population – odd to include a new table in the discussion – consider summarizing and moving to the results section. In this comparison, please justify the comparison – were the same QoL measures used? If not, how can data be compared? THIS WAS ADDED TO GIVE A "FLAVOUR" OF WHAT COULD BE ACHIEVED WHEN ALL DATA FROM NATIONAL ROLL-OUT BECOMES AVAILABLE. WE ARE NOT KEN ON MOVING THIS TO THE RESULTS DUE TO RISK OF OVER-INTERPRETATION.
- Limitations – more needs to be said about the validity of self-report, use of measures that were not designed for a survivor population, effect of patient deaths, changes in treatments / treatment practices, missing data, etc agree, SECTION ADDED TO "STUDY LIMITATIONS" IN DISCUSSION.
- Where next for cancer PROMs in England? – NHS Outcomes Framework needs description – unlikely to be understood by non-UK readers (whereas the paper will be of broad international interest) SEE COMMENT ABOVE AND EXPANSION OF THIS SECTION IN MANUSCRIPT.
- Worth discussing how to get to elderly / low SES – probably some discussion of health literacy goes here
- Page 17, lines 38-42 “the core components … had been identified … as being reliable and appropriate” – add more detail here. Is there really evidence that these measures work well for the elderly / low SES? SEE STUDY LIMITATIONS.
- Page 20, lines 7/8 “…and are cost effective” – no data is shown to justify this REMOVED.
- Page 20, lines 8-12 “…insights into where improvement efforts should be targeted to reduce the long-term burden of cancer and its treatments on the growing number of cancer survivors” – can you give some suggestions? WE ARE WAITING FOR THE RESULTS FROM THE NATIONAL ROLL-OUT.
- Final paragraph lacks impact

Table 1a

- suggest a solid vertical line to separate the 2 right columns as the %s work differently to the responders / non-responders columns (it's a bit confusing) CHANGED

Table 3a-c

- explain 'physical activity' as it's not clear that this refers to increased activity CHANGED

References

- several are incomplete, eg 16, 25 NOW COMPLETE

Supplementary File 1	**ICD10 Codes included in the Study**
Breast Cancer	ICD10 Codes C50 & D05
Colorectal/Lower G.I.	ICD10 Codes C18, C19, C20, and C21
Non-Hodgkin's Lymphoma	ICD10 Codes C82, C83, C84 & C85
Prostate	ICD10 Code C61

Living with and beyond Breast Cancer

This questionnaire is about your health and quality of life since being diagnosed with your cancer. Its purpose is to provide information which can help the NHS monitor and improve the quality of health services for future patients.

Who should complete the questionnaire?

The questions should be answered by the person named in the letter enclosed with this questionnaire. If that person needs help to complete the questionnaire, the answers should be given from their point of view – not the point of view of the person who is helping.

Completing the questionnaire

For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please **do not** write your name or address anywhere on the questionnaire.

IMPORTANT INFORMATION

To make sure the information we collect is useful, we need to collect some personal details from you and to access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the quality of life for people who are living with and beyond cancer. These statistics will be used to compare the differences in quality of life for people treated for different types of cancer by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:

- Your personal details and relevant health information can be held and used by an organisation contracted to the Department of Health to analyse the data
- Other information about you held by the Patient Demographics Service, the Secondary Users Service, Cancer Registries and other NHS databases can be held and used by an organisation contracted to the Department of Health to analyse the data
- Your personal details can be used to send you related follow-up questionnaires in the future

Your personal information will be handled securely and anonymised after analysis and before any publication.

Your personal information will not be released by the Department of Health or third party organisations working on its behalf unless required by law or where there is a clear overriding public interest.

You can withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

If you have any queries about the questionnaire,
please call the FREEPHONE helpline number **on 0800 783 1775**

Taking part in this survey is voluntary
Published reports will not contain any personal details

YOUR HEALTH TODAY

The questions in this section are all about your health and how you feel on the day you complete this questionnaire.

1. What treatments have you received for your breast cancer? **(Tick all that apply)**

1 ☐ Radiotherapy

2 ☐ Chemotherapy (excluding hormone treatment)

3 ☐ Hormone treatment

4 ☐ Surgery

2. How long is it since you completed your **initial treatment** for breast cancer? *Treatment includes any chemotherapy, radiotherapy, or surgery for your breast cancer. When answering this question please do not include hormone treatments such as Tamoxifen.*

1 ☐ I am still having my initial treatment

2 ☐ It is less than 3 months since my initial treatment

3 ☐ It is between 3 and 12 months since my initial treatment

4 ☐ It is between 1 and 5 years since my initial treatment

5 ☐ It is more than 5 years since my initial treatment

6 ☐ Don't know / can't remember

3. How has your breast cancer responded to treatment?

1 ☐ My breast cancer has responded fully to treatment (I am in remission)

2 ☐ My breast cancer has been treated but is still present

3 ☐ My breast cancer has not been treated at all

4 ☐ My breast cancer has come back after it was originally treated

5 ☐ I am not certain what is happening with my breast cancer

4. If you have had breast surgery, do any of the following apply to you? **(Tick all that apply)**

1 ☐ I have had a lumpectomy

2 ☐ I have had a mastectomy

3 ☐ I have had breast reconstruction

4 ☐ I am awaiting or considering breast reconstruction

5 ☐ None of these apply to me

YOUR HEALTH TODAY

Under each heading, please tick the ONE box that best describes your health TODAY.

5. MOBILITY

I have no problems in walking about	☐1
I have slight problems in walking about	☐2
I have moderate problems in walking about	☐3
I have severe problems in walking about	☐4
I am unable to walk about	☐5

6. SELF CARE

I have no problems washing or dressing myself	☐1
I have slight problems washing or dressing myself	☐2
I have moderate problems washing or dressing myself	☐3
I have severe problems washing or dressing myself	☐4
I am unable to wash or dress myself	☐5

7. USUAL ACTIVITIES *(work, study, housework, family or leisure activities)*

I have no problems doing my usual activities	☐1
I have slight problems doing my usual activities	☐2
I have moderate problems doing my usual activities	☐3
I have severe problems doing my usual activities	☐4
I am unable to do my usual activities	☐5

8. PAIN / DISCOMFORT

I have no pain or discomfort	☐1
I have slight pain or discomfort	☐2
I have moderate pain or discomfort	☐3
I have severe pain or discomfort	☐4
I have extreme pain or discomfort	☐5

9. ANXIETY / DEPRESSION

I am not anxious or depressed	☐1
I am slightly anxious or depressed	☐2
I am moderately anxious or depressed	☐3
I am severely anxious or depressed	☐4
I am extremely anxious or depressed	☐5

YOUR HEALTH AND WELLBEING IN THE LAST 7 DAYS

The questions in this section are about your health and how you have felt in the past _7 days_.

Please mark one box per line to give your response.

	During the past 7 days:	Not at all	A little bit	Some-what	Quite a bit	Very much
10.	I have been short of breath	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
11.	I am self conscious about the way I dress	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
12.	One or both of my arms are swollen or tender	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
13.	I feel sexually attractive	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
14.	I am bothered by hair loss	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
15.	I worry that other members of my family might someday get the same illness I have	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
16.	I worry about the effect of stress on my illness	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
17.	I am bothered by a change in weight	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
18.	I have certain parts of my body where I experience pain	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

19. In the **past week**, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your heart rate? *This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that is part of your job.*

None	I day	2 days	3 days	4 days	5 days	6 days	7 days
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These might be to do with things like their family life, social activities, finances and work.

Please tick the response that best describes your answer.

	During the past month:	**No difficulty**	**A little**	**Quite a bit**	**Very much**	**Does not apply**
20.	Have you had any difficulty in maintaining your independence?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
21.	Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
22.	Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
23.	Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
24.	Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
25.	Have you had any difficulty with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
26.	Have you had any financial difficulties?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
27.	Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
28.	Have you had any difficulty concerning your work? (or education if you are a student)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
29.	Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

During the past month:	**No difficulty**	**A little**	**Quite a bit**	**Very much**	**Does not apply**
30. Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
31. Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
32. Have you had any difficulty concerning sexual matters?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
33. Have you had any difficulty concerning plans to have a family?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
34. Have you had any difficulty concerning your appearance or body image?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
35. Have you felt isolated?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
36. Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
37. Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
38. Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
39. Have you had any difficulty with your plans to travel or take a holiday?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
40. Have you had any difficulty with any other area of your everyday life?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Please tick the response that best describes your answer.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply to me
41. I have fears about my cancer spreading	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	6 ☐
42. I have fears about my cancer coming back	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	6 ☐
43. I have fears about death and dying	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
44. I experience memory loss	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
45. I have trouble sleeping	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
46. I have trouble concentrating	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
47. I always feel tired	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
48. I experience mood swings	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
49. I am often irritable	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	

OVERALL SUPPORT AND CARE

50. Do you have an up-to-date written care plan? *A care plan is a document that sets out your needs and goals for caring for your cancer.*

1 ☐ Yes, definitely
2 ☐ Yes, I think so
3 ☐ No
4 ☐ I do not need a care plan
5 ☐ Don't know

51. Do you have a named nurse who you can contact if you have a worry about your cancer care? *A named nurse is sometimes known as a Clinical Nurse Specialist or Specialist Cancer Nurse.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know

52. Do you know who to contact if you have a concern about any aspect of living with or after cancer?

1 ☐ Yes, definitely
2 ☐ Yes, I think so
3 ☐ No

53. Do you think that hospital staff did everything they could to support you following your cancer treatment?

1 ☐ Yes, all of the time
2 ☐ Only some of the time
3 ☐ Never
4 ☐ I did not need any support

54. Do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?

1 ☐ Yes, all of the time
2 ☐ Only some of the time
3 ☐ Never
4 ☐ My general practice is not involved
5 ☐ I do not need any support

55. Following your initial cancer treatment have you been given enough care and help from health and social services (for example, district nurses, home helps or occupational therapists)?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not need help from health or social services
5 ☐ Don't know / can't remember

56. Would it have been helpful to have had more advice or information on any of the following issues: **(Tick all that apply)**

1 ☐ Diet and lifestyle
2 ☐ Physical activity and exercise
3 ☐ Financial help or benefits
4 ☐ Free prescriptions
5 ☐ Returning to or staying in work
6 ☐ Information / advice for family / friends / carer
7 ☐ The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)
8 ☐ The psychological or emotional aspects of living with and after cancer
9 ☐ I have all the information and advice I need

ABOUT YOU

If you are helping someone to complete this questionnaire, please make sure this information is the patient's and not your own.

57. What **year** were you born?

(Please write in) e.g. | 1 | 9 | 4 | 4 |

| Y | Y | Y | Y |

58. Are you male or female?

1 ☐ Male
2 ☐ Female

59. Which of the following best describes your sexual orientation?

1 ☐ Heterosexual / straight (opposite sex)
2 ☐ Bisexual (both sexes)
3 ☐ Lesbian (same sex)
4 ☐ Other
5 ☐ Prefer not to answer

60. Which statement best describes your living arrangements?

1 ☐ I live with partner/spouse/family/friends
2 ☐ I live alone
3 ☐ I live in a nursing home, hospital or other long term care home
4 ☐ Other

61. Do you have a long standing health condition? *Please include anything* ***other than your cancer*** *that has troubled you over a period of time or that could affect you over a period of time.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know / can't say

62. Which, if any, of the following conditions do you have? **(Tick all that apply)**

1 ☐ Alzheimer's disease or dementia
2 ☐ Angina
3 ☐ Arthritis
4 ☐ Asthma or other chronic chest problem
5 ☐ Blindness or visual impairment
6 ☐ Deafness or hearing impairment
7 ☐ Diabetes
8 ☐ Epilepsy
9 ☐ Heart condition
10 ☐ High blood pressure
11 ☐ Kidney disease
12 ☐ Learning difficulty
13 ☐ Liver disease
14 ☐ Long term back problems
15 ☐ Long-standing mental health problem
16 ☐ Long-standing neurological problem
17 ☐ Another long-standing condition
18 ☐ I do not have any of these conditions

63. What was your employment status ***before you were diagnosed with cancer***?

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

64. What is your employment status currently? *If on maternity or sick leave answer in relation to your **usual** employment status*

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

65. If you are currently employed at the moment, are you:

1 ☐ Not working at all
2 ☐ Working less hours than usual
3 ☐ Working your usual hours
4 ☐ Working more hours than usual
5 ☐ This question does not apply to me

66. To which of these ethnic groups would you say you belong? **(Tick ONE only)**

a. WHITE

1 ☐ British
2 ☐ Irish
3 ☐ Any other White background (Please write in box)

b. MIXED

4 ☐ White and Black Caribbean
5 ☐ White and Black African
6 ☐ White and Asian
7 ☐ Any other Mixed background (Please write in box)

c. ASIAN OR ASIAN BRITISH

8 ☐ Indian
9 ☐ Pakistani
10 ☐ Bangladeshi
11 ☐ Any other Asian background (Please write in box)

d. BLACK OR BLACK BRITISH

12 ☐ Caribbean
13 ☐ African
14 ☐ Any other Black background (Please write in box)

e. CHINESE OR OTHER ETHNIC GROUP

15 ☐ Chinese
16 ☐ Any other ethnic group (Please write in box)

COMMENTS

If you have anything else you would like to tell us about living with and beyond cancer, please do so here:

Questions 5-9 are EQ- 5D-5L. UK (English) v.2 © 2009 EuroQol Group. EQ-5D™ is a trade mark of the EuroQol Group.

Questions 10 – 18 are from FACIT copyright 1987, 1997 by David Cella, PhD

Questions 20 – 40 are from the Social Difficulties Inventory. Originators of the Social Difficulties Inventory: Wright, E.P., Cull, A. and Selby, P.

Living with and beyond Colorectal / Gastro Intestinal Cancer

This questionnaire is about your health and quality of life since being diagnosed with your cancer. Its purpose is to provide information which can help the NHS monitor and improve the quality of health services for future patients.

Who should complete the questionnaire?
The questions should be answered by the person named in the letter enclosed with this questionnaire. If that person needs help to complete the questionnaire, the answers should be given from their point of view – not the point of view of the person who is helping.

Completing the questionnaire
For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please **do not** write your name or address anywhere on the questionnaire.

IMPORTANT INFORMATION

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- Other information about you held by the Patient Demographics Service, the Secondary Users Service, Cancer Registries and other NHS databases can be held and used by an organisation contracted to the Department of Health to analyse the data
- Your personal details can be used to send you related follow-up questionnaires in the future

Your personal information will be handled securely and anonymised after analysis and before any publication.

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You can withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

If you have any queries about the questionnaire,
please call the FREEPHONE helpline number **on 0800 783 1775**

Taking part in this survey is voluntary
Published reports will not contain any personal details

YOUR HEALTH TODAY

The questions in this section are all about your health and how you feel on the day you complete this questionnaire.

1. What treatments have you received for your colorectal / GI cancer? **(Tick all that apply)**

1 ☐ Radiotherapy

2 ☐ Chemotherapy

3 ☐ Surgery

2. How long is it since you completed your **initial treatment** for colorectal / GI cancer? *Treatment includes any chemotherapy, radiotherapy, or surgery for your colorectal / GI cancer.*

1 ☐ I am still having my initial treatment

2 ☐ It is less than 3 months since my initial treatment

3 ☐ It is between 3 and 12 months since my initial treatment

4 ☐ It is between 1 and 5 years since my initial treatment

5 ☐ It is more than 5 years since my initial treatment

6 ☐ Don't know / can't remember

3. How has your colorectal / GI cancer responded to treatment?

1 ☐ My colorectal / GI cancer has responded fully to treatment (I am in remission)

2 ☐ My colorectal / GI cancer has been treated but is still present

3 ☐ My colorectal / GI cancer has not been treated at all

4 ☐ My colorectal / GI cancer has come back after it was originally treated

5 ☐ I am not certain what is happening with my colorectal / GI cancer

4. If you have a stoma (e.g. colostomy) is it:

1 ☐ Still present

2 ☐ Reversed

3 ☐ This does not apply to me

YOUR HEALTH TODAY

Under each heading, please tick the ONE box that best describes your health TODAY.

5. MOBILITY

I have no problems in walking about	☐1
I have slight problems in walking about	☐2
I have moderate problems in walking about	☐3
I have severe problems in walking about	☐4
I am unable to walk about	☐5

6. SELF CARE

I have no problems washing or dressing myself	☐1
I have slight problems washing or dressing myself	☐2
I have moderate problems washing or dressing myself	☐3
I have severe problems washing or dressing myself	☐4
I am unable to wash or dress myself	☐5

7. USUAL ACTIVITIES *(work, study, housework, family or leisure activities)*

I have no problems doing my usual activities	☐1
I have slight problems doing my usual activities	☐2
I have moderate problems doing my usual activities	☐3
I have severe problems doing my usual activities	☐4
I am unable to do my usual activities	☐5

8. PAIN / DISCOMFORT

I have no pain or discomfort	☐1
I have slight pain or discomfort	☐2
I have moderate pain or discomfort	☐3
I have severe pain or discomfort	☐4
I have extreme pain or discomfort	☐5

9. ANXIETY / DEPRESSION

I am not anxious or depressed	☐1
I am slightly anxious or depressed	☐2
I am moderately anxious or depressed	☐3
I am severely anxious or depressed	☐4
I am extremely anxious or depressed	☐5

YOUR HEALTH AND WELL BEING IN THE LAST 7 DAYS

The questions in this section are about your health and how you have felt in the past 7 days.

Please mark one box per line to give your response.

	During the past 7 days:	Not at all	A little bit	Some-what	Quite a bit	Very much
10.	I have swelling or cramps in my stomach area	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
11.	I am losing weight	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
12.	I have control of my bowels	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
13.	I can digest my food well	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
14.	I have diarrhoea	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
15.	I have a good appetite	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
16.	I like the appearance of my body	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
17.	I have difficulty urinating	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
18.	I urinate more frequently than usual	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
19.	I leak urine	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

20. Do you have an ostomy appliance / stoma? 1 ☐ No 2 ☐ Yes

	If yes, please answer the next two items:	Not at all	A little bit	Some-what	Quite a bit	Very much
21.	I am embarrassed by my ostomy appliance / stoma	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
22.	Caring for my ostomy appliance / stoma is difficult	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

23. Do you have any difficulty in controlling your bowels (e.g. any accidents)? 1 ☐ No 2 ☐ Yes

		Monthly	Weekly	Daily	Constantly	It varies
24.	If yes, how often do you have difficulties?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

25. In the **past week**, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your heart rate? *This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that is part of your job.*

None	I day	2 days	3 days	4 days	5 days	6 days	7 days
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These might be to do with things like their family life, social activities, finances and work.

Please tick the response that best describes your answer.

	During the past month:	**No difficulty**	**A little**	**Quite a bit**	**Very much**	**Does not apply**
26.	Have you had any difficulty in maintaining your independence?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
27.	Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
28.	Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
29.	Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
30.	Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
31.	Have you had any difficulty with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
32.	Have you had any financial difficulties?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
33.	Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
34.	Have you had any difficulty concerning your work? (or education if you are a student)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
35.	Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

	During the past month:	**No difficulty**	**A little**	**Quite a bit**	**Very much**	**Does not apply**
36.	Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
37.	Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
38.	Have you had any difficulty concerning sexual matters?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
39.	Have you had any difficulty concerning plans to have a family?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
40.	Have you had any difficulty concerning your appearance or body image?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
41.	Have you felt isolated?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
42.	Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
43.	Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
44.	Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
45.	Have you had any difficulty with your plans to travel or take a holiday?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
46.	Have you had any difficulty with any other area of your everyday life?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Please tick the response that best describes your answer.

		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply to me
47.	I have fears about my cancer spreading	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
48.	I have fears about my cancer coming back	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
49.	I have fears about death and dying	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
50.	I experience memory loss	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
51.	I have trouble sleeping	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
52.	I have trouble concentrating	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
53.	I always feel tired	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
54.	I experience mood swings	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
55.	I am often irritable	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	

OVERALL SUPPORT AND CARE

56. Do you have an up-to-date written care plan? *A care plan is a document that sets out your needs and goals for caring for your cancer.*

1 ☐ Yes, definitely

2 ☐ Yes, I think so

3 ☐ No

4 ☐ I do not need a care plan

5 ☐ Don't know

57. Do you have a named nurse who you can contact if you have a worry about your cancer care? *A named nurse is sometimes known as a Clinical Nurse Specialist or Specialist Cancer Nurse.*

1 ☐ Yes

2 ☐ No

3 ☐ Don't know

58. Do you know who to contact if you have a concern about any aspect of living with or after cancer?

1 ☐ Yes, definitely

2 ☐ Yes, I think so

3 ☐ No

59. Do you think that hospital staff did everything they could to support you following your cancer treatment?

1 ☐ Yes, all of the time

2 ☐ Only some of the time

3 ☐ Never

4 ☐ I did not need any support

60. Do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?

1 ☐ Yes, all of the time

2 ☐ Only some of the time

3 ☐ Never

4 ☐ My general practice is not involved

5 ☐ I do not need any support

61. Following your initial cancer treatment have you been given enough care and help from health and social services (for example, district nurses, home helps or occupational therapists)?

1 ☐ Yes, definitely

2 ☐ Yes, to some extent

3 ☐ No

4 ☐ I did not need help from health or social services

5 ☐ Don't know / can't remember

62. Would it have been helpful to have had more advice or information on any of the following issues: **(Tick all that apply)**

1 ☐ Diet and lifestyle

2 ☐ Physical activity and exercise

3 ☐ Financial help or benefits

4 ☐ Free prescriptions

5 ☐ Returning to or staying in work

6 ☐ Information / advice for family / friends / carer

7 ☐ The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)

8 ☐ The psychological or emotional aspects of living with and after cancer

9 ☐ I have all the information and advice I need

ABOUT YOU

If you are helping someone to complete this questionnaire, please make sure this information is the patient's and not your own.

63. What **year** were you born?

(Please write in) e.g. | 1 | 9 | 4 | 4 |

Y	Y	Y	Y

64. Are you male or female?

1 ☐ Male
2 ☐ Female

65. Which of the following best describes your sexual orientation?

1 ☐ Heterosexual / straight (opposite sex)
2 ☐ Bisexual (both sexes)
3 ☐ Gay or lesbian (same sex)
4 ☐ Other
5 ☐ Prefer not to answer

66. Which statement best describes your living arrangements?

1 ☐ I live with partner/spouse/family/friends
2 ☐ I live alone
3 ☐ I live in a nursing home, hospital or other long term care home
4 ☐ Other

67. Do you have a long standing health condition? *Please include anything **other than your cancer** that has troubled you over a period of time or that could affect you over a period of time.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know / can't say

68. Which, if any, of the following conditions do you have? **(Tick all that apply)**

1 ☐ Alzheimer's disease or dementia
2 ☐ Angina
3 ☐ Arthritis
4 ☐ Asthma or other chronic chest problem
5 ☐ Blindness or visual impairment
6 ☐ Deafness or hearing impairment
7 ☐ Diabetes
8 ☐ Epilepsy
9 ☐ Heart condition
10 ☐ High blood pressure
11 ☐ Kidney disease
12 ☐ Learning difficulty
13 ☐ Liver disease
14 ☐ Long term back problems
15 ☐ Long-standing mental health problem
16 ☐ Long-standing neurological problem
17 ☐ Another long-standing condition
18 ☐ I do not have any of these conditions

69. What was your employment status ***before you were diagnosed with cancer***?

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

70. What is your employment status currently? *If on maternity or sick leave answer in relation to your **usual** employment status.*

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

71. If you are currently employed at the moment, are you:

1 ☐ Not working at all
2 ☐ Working less hours than usual
3 ☐ Working your usual hours
4 ☐ Working more hours than usual
5 ☐ This question does not apply to me

72. To which of these ethnic groups would you say you belong? **(Tick ONE only)**

a. WHITE

1 ☐ British
2 ☐ Irish
3 ☐ Any other White background (Please write in box)

b. MIXED

4 ☐ White and Black Caribbean
5 ☐ White and Black African
6 ☐ White and Asian
7 ☐ Any other Mixed background (Please write in box)

c. ASIAN OR ASIAN BRITISH

8 ☐ Indian
9 ☐ Pakistani
10 ☐ Bangladeshi
11 ☐ Any other Asian background (Please write in box)

d. BLACK OR BLACK BRITISH

12 ☐ Caribbean
13 ☐ African
14 ☐ Any other Black background (Please write in box)

e. CHINESE OR OTHER ETHNIC GROUP

15 ☐ Chinese
16 ☐ Any other ethnic group (Please write in box)

COMMENTS

If you have anything else you would like to tell us about living with and beyond cancer, please do so here:

Questions 5-9 are EQ -5D-5L. UK (English) v.2 © 2009 EuroQol Group. EQ-5D™ is a trade mark of the EuroQol Group.

Questions 10 – 18 and 20 - 22 are taken from FACIT copyright 1987, 1997 by David Cella, PhD

Questions 26 – 46 are taken from the Social Difficulties Inventory. Originators of the Social Difficulties Inventory: Wright, E.P., Cull, A. and Selby, P.

NHS

Living with and beyond Non Hodgkin's Lymphoma

This questionnaire is about your health and quality of life since being diagnosed with your cancer. Its purpose is to provide information which can help the NHS monitor and improve the quality of health services for future patients.

Who should complete the questionnaire?
The questions should be answered by the person named in the letter enclosed with this questionnaire. If that person needs help to complete the questionnaire, the answers should be given from their point of view – not the point of view of the person who is helping.

Completing the questionnaire
For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please **do not** write your name or address anywhere on the questionnaire.

IMPORTANT INFORMATION

To make sure the information we collect is useful, we need to collect some personal details from you and to access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the quality of life for people who are living with and beyond cancer. These statistics will be used to compare the differences in quality of life for people treated for different types of cancer by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:

- Your personal details and relevant health information can be held and used by an organisation contracted to the Department of Health to analyse the data
- Other information about you held by the Patient Demographics Service, the Secondary Users Service, Cancer Registries and other NHS databases can be held and used by an organisation contracted to the Department of Health to analyse the data
- Your personal details can be used to send you related follow-up questionnaires in the future

Your personal information will be handled securely and anonymised after analysis and before any publication.

Your personal information will not be released by the Department of Health or third party organisations working on its behalf unless required by law or where there is a clear overriding public interest.

You can withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

If you have any queries about the questionnaire,
please call the FREEPHONE helpline number **on 0800 783 1775**

Taking part in this survey is voluntary
Published reports will not contain any personal details

YOUR HEALTH TODAY

The questions in this section are all about your health and how you feel on the day you complete this questionnaire.

1. What treatments have you received for your Non Hodgkin's Lymphoma (NHL)? **(Tick all that apply)**

1 ☐ Radiotherapy

2 ☐ Chemotherapy

3 ☐ Surgery

4 ☐ Antibody therapy (including Rituximab)

5 ☐ Stem cell transplant

2. How long is it since you completed your **initial treatment** for NHL? *Treatment includes any chemotherapy, radiotherapy, or surgery for your NHL. When answering this question please do not include antibody (Rituximab) treatment which you may have been given as a maintenance treatment following chemotherapy.*

1 ☐ I am still having my initial treatment

2 ☐ It is less than 3 months since my initial treatment

3 ☐ It is between 3 and 12 months since my initial treatment

4 ☐ It is between 1 and 5 years since my initial treatment

5 ☐ It is more than 5 years since my initial treatment

6 ☐ Don't know / can't remember

3. How has your NHL responded to treatment?

1 ☐ My NHL has responded fully to treatment (I am in remission)

2 ☐ My NHL has been treated but is still present

3 ☐ My NHL has not been treated at all

4 ☐ My NHL has come back after it was originally treated

5 ☐ I am not certain what is happening with my NHL

YOUR HEALTH TODAY

Under each heading, please tick the ONE box that best describes your health TODAY.

4. MOBILITY

I have no problems in walking about	☐ 1
I have slight problems in walking about	☐ 2
I have moderate problems in walking about	☐ 3
I have severe problems in walking about	☐ 4
I am unable to walk about	☐ 5

5. SELF CARE

I have no problems washing or dressing myself	☐ 1
I have slight problems washing or dressing myself	☐ 2
I have moderate problems washing or dressing myself	☐ 3
I have severe problems washing or dressing myself	☐ 4
I am unable to wash or dress myself	☐ 5

6. USUAL ACTIVITIES *(work, study, housework, family or leisure activities)*

I have no problems doing my usual activities	☐ 1
I have slight problems doing my usual activities	☐ 2
I have moderate problems doing my usual activities	☐ 3
I have severe problems doing my usual activities	☐ 4
I am unable to do my usual activities	☐ 5

7. PAIN / DISCOMFORT

I have no pain or discomfort	☐ 1
I have slight pain or discomfort	☐ 2
I have moderate pain or discomfort	☐ 3
I have severe pain or discomfort	☐ 4
I have extreme pain or discomfort	☐ 5

8. ANXIETY / DEPRESSION

I am not anxious or depressed	☐ 1
I am slightly anxious or depressed	☐ 2
I am moderately anxious or depressed	☐ 3
I am severely anxious or depressed	☐ 4
I am extremely anxious or depressed	☐ 5

YOUR HEALTH AND WELL BEING IN THE LAST 7 DAYS

The questions in this section are about your health and how you have felt in the past 7 days.

Please mark one box per line to give your response.

	During the past 7 days:	Not at all	A little bit	Some-what	Quite a bit	Very much
9.	I have certain parts of my body where I experience pain	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
10.	I am bothered by lumps or swelling in certain parts of my body (e.g. neck, armpits, or groin)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
11.	I am bothered by fevers (episodes of high body temperature)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
12.	I have night sweats	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
13.	I am bothered by itching	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
14.	I have trouble sleeping at night	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
15.	I get tired easily	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
16.	I am losing weight	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
17.	I have a loss of appetite	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
18.	I have trouble concentrating	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
19.	I worry about getting infections	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
20.	I worry that I might get new symptoms of my illness	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
21.	I feel isolated from others because of my illness or treatment	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
22.	I have emotional ups and downs	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
23.	Because of my illness, I have difficulty planning for the future	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

24. In the **past week**, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your heart rate? *This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that is part of your job.*

None	I day	2 days	3 days	4 days	5 days	6 days	7 days
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These might be to do with things like their family life, social activities, finances and work.

Please tick the response that best describes your answer.

	During the past month:	**No difficulty**	**A little**	**Quite a bit**	**Very much**	**Does not apply**
25.	Have you had any difficulty in maintaining your independence?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
26.	Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
27.	Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
28.	Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
29.	Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
30.	Have you had any difficulty with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
31.	Have you had any financial difficulties?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
32.	Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
33.	Have you had any difficulty concerning your work? (or education if you are a student)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
34.	Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

	During the past month:	No difficulty	A little	Quite a bit	Very much	Does not apply
35.	Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
36.	Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
37.	Have you had any difficulty concerning sexual matters?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
38.	Have you had any difficulty concerning plans to have a family?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
39.	Have you had any difficulty concerning your appearance or body image?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
40.	Have you felt isolated?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
41.	Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
42.	Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
43.	Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
44.	Have you had any difficulty with your plans to travel or take a holiday?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
45.	Have you had any difficulty with any other area of your everyday life?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Please tick the response that best describes your answer.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply to me
46. I have fears about my cancer spreading	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
47. I have fears about my cancer coming back	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
48. I have fears about death and dying	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
49. I experience memory loss	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
50. I have trouble sleeping	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
51. I have trouble concentrating	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
52. I always feel tired	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
53. I experience mood swings	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
54. I am often irritable	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	

OVERALL SUPPORT AND CARE

55. Do you have an up-to-date written care plan? *A care plan is a document that sets out your needs and goals for caring for your cancer.*

1 ☐ Yes, definitely
2 ☐ Yes, I think so
3 ☐ No
4 ☐ I do not need a care plan
5 ☐ Don't know

56. Do you have a named nurse who you can contact if you have a worry about your cancer care? *A named nurse is sometimes known as a Clinical Nurse Specialist or Specialist Cancer Nurse.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know

57. Do you know who to contact if you have a concern about any aspect of living with or after cancer?

1 ☐ Yes, definitely
2 ☐ Yes, I think so
3 ☐ No

58. Do you think that hospital staff did everything they could to support you following your cancer treatment?

1 ☐ Yes, all of the time
2 ☐ Only some of the time
3 ☐ Never
4 ☐ I did not need any support

59. Do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?

1 ☐ Yes, all of the time
2 ☐ Only some of the time
3 ☐ Never
4 ☐ My general practice is not involved
5 ☐ I do not need any support

60. Following your initial cancer treatment have you been given enough care and help from health and social services (for example, district nurses, home helps or occupational therapists)?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not need help from health or social services
5 ☐ Don't know / can't remember

61. Would it have been helpful to have had more advice or information on any of the following issues: **(Tick all that apply)**

1 ☐ Diet and lifestyle
2 ☐ Physical activity and exercise
3 ☐ Financial help or benefits
4 ☐ Free prescriptions
5 ☐ Returning to or staying in work
6 ☐ Information / advice for family / friends / carer
7 ☐ The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)
8 ☐ The psychological or emotional aspects of living with and after cancer
9 ☐ I have all the information and advice I need

ABOUT YOU

If you are helping someone to complete this questionnaire, please make sure this information is the patient's and not your own.

62. What **year** were you born?

(Please write in) e.g. 1 9 4 4

Y	Y	Y	Y

63. Are you male or female?

1 ☐ Male
2 ☐ Female

64. Which of the following best describes your sexual orientation?

1 ☐ Heterosexual / straight (opposite sex)
2 ☐ Bisexual (both sexes)
3 ☐ Gay or lesbian (same sex)
4 ☐ Other
5 ☐ Prefer not to answer

65. Which statement best describes your living arrangements?

1 ☐ I live with partner / spouse / family / friends
2 ☐ I live alone
3 ☐ I live in a nursing home, hospital or other long term care home
4 ☐ Other

66. Do you have a long standing health condition? *Please include anything* ***other than your cancer*** *that has troubled you over a period of time or that could affect you over a period of time.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know / can't say

67. Which, if any, of the following conditions do you have? **(Tick all that apply)**

1 ☐ Alzheimer's disease or dementia
2 ☐ Angina
3 ☐ Arthritis
4 ☐ Asthma or other chronic chest problem
5 ☐ Blindness or visual impairment
6 ☐ Deafness or hearing impairment
7 ☐ Diabetes
8 ☐ Epilepsy
9 ☐ Heart condition
10 ☐ High blood pressure
11 ☐ Kidney disease
12 ☐ Learning difficulty
13 ☐ Liver disease
14 ☐ Long term back problems
15 ☐ Long-standing mental health problem
16 ☐ Long-standing neurological problem
17 ☐ Another long-standing condition
18 ☐ I do not have any of these conditions

68. What was your employment status ***before you were diagnosed with cancer***?

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

69. What is your employment status currently? *If on maternity or sick leave answer in relation to your **usual** employment status.*

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

70. If you are currently employed at the moment, are you:

1 ☐ Not working at all
2 ☐ Working less hours than usual
3 ☐ Working your usual hours
4 ☐ Working more hours than usual
5 ☐ This question does not apply to me

71. To which of these ethnic groups would you say you belong? **(Tick ONE only)**

a. WHITE
1 ☐ British
2 ☐ Irish
3 ☐ Any other White background (Please write in box)

☐

b. MIXED
4 ☐ White and Black Caribbean
5 ☐ White and Black African
6 ☐ White and Asian
7 ☐ Any other Mixed background (Please write in box)

☐

c. ASIAN OR ASIAN BRITISH
8 ☐ Indian
9 ☐ Pakistani
10 ☐ Bangladeshi
11 ☐ Any other Asian background (Please write in box)

☐

d. BLACK OR BLACK BRITISH
12 ☐ Caribbean
13 ☐ African
14 ☐ Any other Black background (Please write in box)

☐

e. CHINESE OR OTHER ETHNIC GROUP
15 ☐ Chinese
16 ☐ Any other ethnic group (Please write in box)

☐

COMMENTS

If you have anything else you would like to tell us about living with and beyond cancer, please do so here:

Questions 4 - 8 are EQ-5D-5L. UK (English) v.2 © 2009 EuroQol Group. EQ-5D™ is a trade mark of the EuroQol Group.

Questions 9 – 23 are from FACIT. Copyright 1987, 1997 by David Cella, PhD

Questions 25 – 45 are from the Social Difficulties Inventory. Originators of the Social Difficulties Inventory: Wright, E.P., Cull, A. and Selby, P.

Living with and beyond Prostate Cancer

This questionnaire is about your health and quality of life since being diagnosed with your cancer. Its purpose is to provide information which can help the NHS monitor and improve the quality of health services for future patients.

Who should complete the questionnaire?
The questions should be answered by the person named in the letter enclosed with this questionnaire. If that person needs help to complete the questionnaire, the answers should be given from their point of view – not the point of view of the person who is helping.

Completing the questionnaire
For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please **do not** write your name or address anywhere on the questionnaire.

IMPORTANT INFORMATION

To make sure the information we collect is useful, we need to collect some personal details from you and to access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the quality of life for people who are living with and beyond cancer. These statistics will be used to compare the differences in quality of life for people treated for different types of cancer by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:

- Your personal details and relevant health information can be held and used by an organisation contracted to the Department of Health to analyse the data
- Other information about you held by the Patient Demographics Service, the Secondary Users Service, Cancer Registries and other NHS databases can be held and used by an organisation contracted to the Department of Health to analyse the data
- Your personal details can be used to send you related follow-up questionnaires in the future

Your personal information will be handled securely and anonymised after analysis and before any publication.

Your personal information will not be released by the Department of Health or third party organisations working on its behalf unless required by law or where there is a clear overriding public interest.

You can withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

If you have any queries about the questionnaire,
please call the FREEPHONE helpline number **on 0800 783 1775**

Taking part in this survey is voluntary
Published reports will not contain any personal details

YOUR HEALTH TODAY

The questions in this section are all about your health and how you feel on the day you complete this questionnaire.

1. What treatments have you received for your prostate cancer? **(Tick all that apply)**

1 ☐ Radiotherapy (including brachytherapy) (with or without planned hormonal treatment)
2 ☐ Surgery
3 ☐ Hormone treatment
4 ☐ Chemotherapy (not including hormones)
5 ☐ HIFU
6 ☐ Cryotherapy
7 ☐ Active Surveillance (close monitoring but no current intervention)

2. How long is it since you completed your **initial treatment** for prostate cancer? *Treatment includes any chemotherapy, radiotherapy, or surgery for your prostate cancer. When answering this question please do not include hormone treatments.*

1 ☐ I am still having my initial treatment
2 ☐ It is less than 3 months since my initial treatment
3 ☐ It is between 3 and 12 months since my initial treatment
4 ☐ It is between 1 and 5 years since my initial treatment
5 ☐ It is more than 5 years since my initial treatment
6 ☐ Don't know / can't remember

3. How has your prostate cancer responded to treatment?

1 ☐ My prostate cancer has responded fully to treatment (I am in remission)
2 ☐ My prostate cancer has been treated but is still present
3 ☐ My prostate cancer has not been treated at all
4 ☐ My prostate cancer has come back after it was originally treated
5 ☐ I am not certain what is happening with my prostate cancer

YOUR HEALTH TODAY

Under each heading, please tick the ONE box that best describes your health TODAY.

4. MOBILITY

I have no problems in walking about ☐1
I have slight problems in walking about ☐2
I have moderate problems in walking about ☐3
I have severe problems in walking about ☐4
I am unable to walk about ☐5

5. SELF CARE

I have no problems washing or dressing myself ☐1
I have slight problems washing or dressing myself ☐2
I have moderate problems washing or dressing myself ☐3
I have severe problems washing or dressing myself ☐4
I am unable to wash or dress myself ☐5

6. USUAL ACTIVITIES *(work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ☐1
I have slight problems doing my usual activities ☐2
I have moderate problems doing my usual activities ☐3
I have severe problems doing my usual activities ☐4
I am unable to do my usual activities ☐5

7. PAIN / DISCOMFORT

I have no pain or discomfort ☐1
I have slight pain or discomfort ☐2
I have moderate pain or discomfort ☐3
I have severe pain or discomfort ☐4
I have extreme pain or discomfort ☐5

8. ANXIETY / DEPRESSION

I am not anxious or depressed ☐1
I am slightly anxious or depressed ☐2
I am moderately anxious or depressed ☐3
I am severely anxious or depressed ☐4
I am extremely anxious or depressed ☐5

YOUR HEALTH AND WELLBEING IN THE LAST 7 DAYS

The questions in this section are about your health and how you have felt in the past 7 days.

Please mark one box per line to give your response.

	During the past 7 days:	Not at all	A little bit	Some-what	Quite a bit	Very much
9.	I am losing weight	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
10.	I have a good appetite	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
11.	I have aches and pains that bother me	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
12.	I have certain parts of my body where I experience pain	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
13.	My pain keeps me from doing things I want to do	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
14.	I am satisfied with my present comfort level	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
15.	I have trouble moving my bowels	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
16.	I have difficulty urinating	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
17.	I urinate more frequently than usual	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
18.	My problems with urinating limit my activities	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
19.	I am able to have and maintain an erection	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
20.	I leak urine	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

21. Do you have any difficulty in controlling your bowels (e.g. any accidents)? 1 ☐ No 2 ☐ Yes

		Monthly	Weekly	Daily	Constantly	It varies
22.	If yes, how often do you have difficulties?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

23. In the **past week**, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your heart rate? *This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that is part of your job.*

None	I day	2 days	3 days	4 days	5 days	6 days	7 days
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These might be to do with things like their family life, social activities, finances and work.

Please tick the response that best describes your answer.

	During the past month:	**No difficulty**	**A little**	**Quite a bit**	**Very much**	**Does not apply**
24.	Have you had any difficulty in maintaining your independence?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
25.	Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
26.	Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
27.	Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
28.	Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
29.	Have you had any difficulty with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
30.	Have you had any financial difficulties?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
31.	Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
32.	Have you had any difficulty concerning your work? (or education if you are a student)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
33.	Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

During the past month:	No difficulty	A little	Quite a bit	Very much	Does not apply
34. Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
35. Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
36. Have you had any difficulty concerning sexual matters?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
37. Have you had any difficulty concerning plans to have a family?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
38. Have you had any difficulty concerning your appearance or body image?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
39. Have you felt isolated?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
40. Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
41. Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
42. Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
43. Have you had any difficulty with your plans to travel or take a holiday?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
44. Have you had any difficulty with any other area of your everyday life?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past <u>month</u>.

Please tick the response that best describes your answer.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply to me
45. I have fears about my cancer spreading	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	6 ☐
46. I have fears about my cancer coming back	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	6 ☐
47. I have fears about death and dying	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
48. I experience memory loss	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
49. I have trouble sleeping	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
50. I have trouble concentrating	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
51. I always feel tired	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
52. I experience mood swings	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
53. I am often irritable	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	

OVERALL SUPPORT AND CARE

54. Do you have an up-to-date written care plan? *A care plan is a document that sets out your needs and goals for caring for your cancer.*

1 ☐ Yes, definitely
2 ☐ Yes, I think so
3 ☐ No
4 ☐ I do not need a care plan
5 ☐ Don't know

55. Do you have a named nurse who you can contact if you have a worry about your cancer care? *A named nurse is sometimes known as a Clinical Nurse Specialist or Specialist Cancer Nurse.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know

56. Do you know who to contact if you have a concern about any aspect of living with or after cancer?

1 ☐ Yes, definitely
2 ☐ Yes, I think so
3 ☐ No

57. Do you think that hospital staff did everything they could to support you following your cancer treatment?

1 ☐ Yes, all of the time
2 ☐ Only some of the time
3 ☐ Never
4 ☐ I did not need any support

58. Do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?

1 ☐ Yes, all of the time
2 ☐ Only some of the time
3 ☐ Never
4 ☐ My general practice is not involved
5 ☐ I do not need any support

59. Following your initial cancer treatment have you been given enough care and help from health and social services (for example, district nurses, home helps or occupational therapists)?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not need help from health or social services
5 ☐ Don't know / can't remember

60. Would it have been helpful to have had more advice or information on any of the following issues: **(Tick all that apply)**

1 ☐ Diet and lifestyle
2 ☐ Physical activity and exercise
3 ☐ Financial help or benefits
4 ☐ Free prescriptions
5 ☐ Returning to or staying in work
6 ☐ Information / advice for family / friends / carer
7 ☐ The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)
8 ☐ The psychological or emotional aspects of living with and after cancer
9 ☐ I have all the information and advice I need

ABOUT YOU

If you are helping someone to complete this questionnaire, please make sure this information is the patient's and not your own.

61. What **year** were you born?

(Please write in) e.g. | 1 | 9 | 4 | 4 |

Y	Y	Y	Y

62. Are you male or female?

1 ☐ Male

2 ☐ Female

63. Which of the following best describes your sexual orientation?

1 ☐ Heterosexual / straight (opposite sex)

2 ☐ Bisexual (both sexes)

3 ☐ Gay (same sex)

4 ☐ Other

5 ☐ Prefer not to answer

64. Which statement best describes your living arrangements?

1 ☐ I live with partner/spouse/family/friends

2 ☐ I live alone

3 ☐ I live in a nursing home, hospital or other long term care home

4 ☐ Other

65. Do you have a long standing health condition? *Please include anything **other than your cancer** that has troubled you over a period of time or that could affect you over a period of time.*

1 ☐ Yes

2 ☐ No

3 ☐ Don't know / can't say

66. Which, if any, of the following conditions do you have? **(Tick all that apply)**

1 ☐ Alzheimer's disease or dementia

2 ☐ Angina

3 ☐ Arthritis

4 ☐ Asthma or other chronic chest problem

5 ☐ Blindness or visual impairment

6 ☐ Deafness or hearing impairment

7 ☐ Diabetes

8 ☐ Epilepsy

9 ☐ Heart condition

10 ☐ High blood pressure

11 ☐ Kidney disease

12 ☐ Learning difficulty

13 ☐ Liver disease

14 ☐ Long term back problems

15 ☐ Long-standing mental health problem

16 ☐ Long-standing neurological problem

17 ☐ Another long-standing condition

18 ☐ I do not have any of these conditions

67. What was your employment status ***before you were diagnosed with cancer***?

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

68. What is your employment status currently? *If on maternity or sick leave answer in relation to your **usual** employment status.*

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

69. If you are currently employed at the moment, are you:

1 ☐ Not working at all
2 ☐ Working less hours than usual
3 ☐ Working your usual hours
4 ☐ Working more hours than usual
5 ☐ This question does not apply to me

70. To which of these ethnic groups would you say you belong? **(Tick ONE only)**

a. WHITE

1 ☐ British
2 ☐ Irish
3 ☐ Any other White background (Please write in box)

b. MIXED

4 ☐ White and Black Caribbean
5 ☐ White and Black African
6 ☐ White and Asian
7 ☐ Any other Mixed background (Please write in box)

c. ASIAN OR ASIAN BRITISH

8 ☐ Indian
9 ☐ Pakistani
10 ☐ Bangladeshi
11 ☐ Any other Asian background (Please write in box)

d. BLACK OR BLACK BRITISH

12 ☐ Caribbean
13 ☐ African
14 ☐ Any other Black background (Please write in box)

e. CHINESE OR OTHER ETHNIC GROUP

15 ☐ Chinese
16 ☐ Any other ethnic group (Please write in box)

COMMENTS

If you have anything else you would like to tell us about living with and beyond cancer, please do so here:

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NIGB

Ethics and Confidentiality Committee

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Simon Phillips
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Room 403, Wellington House
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SE1 8UG

18 May 2011

Dear Simon

8-05 (b)/2010 National Cancer Survivorship Initiative – patient reported outcome survey of cancer survivors

Thank you for your application for support under section 251 of the NHS Act 2006 to process patient identifiable information without consent. This application was considered by the Ethics and Confidentiality Committee at its meeting on 01 December 2010.

Context

This application from the Department of Health (acting as sponsor) and Quality Health (the implementation provider) sought support to cover the pilot phase of a proposed national survey of cancer survivors, which is intended to last up until 30 June 2011.

Update: due to slippages in timetables, it has been noted that following notification on 17 May 2011, that the survey will be completed by September 2011.

The purpose of this activity was to aim to improve understanding of quality of life outcomes for cancer survivors and was intended to support the DH National Cancer Survivorship Initiative (NCSI). The activity would build upon the current national Cancer Patient Experience Survey Programme (CPESP) 2010 which focuses on the experience of care of cancer patients.

Section 251 support was sought to enable the legitimate transfer of patient data from the Cancer Registries to Quality Health, and for Quality Health to liaise with cancer centres so that patient questionnaires would be sent to patients under cover of appropriate cancer centre letter headed paper. Support was also required to enable a sample to be identified from the cancer registries. To carry out the activity, Quality Health would require access to name, address, sex, ethnic group, year of birth, NHS number, ICD10 code, speciality code, date of diagnosis, and Trust NACS code for most recent treatment spell.

Outcome

The letter dated 07 December 2010 set out the Committee's rationale and decision for its recommendation of provisional support, subject to a number of clarifications and conditions of approval. A response was subsequently provided providing copies of requested documentation and further explanation around the clarification areas.

In particular, Members debated the response to the information being sent on GP headed paper, and on balance and in this specific instance, agreed that this would not be feasible.

As all aspects have been satisfactorily addressed, this letter provides confirmation of your final approval, and our Register of approved applications will shortly be updated to include this application.

If you have any queries regarding the outcome of this letter please do not hesitate to contact the NIGB Office on 020 7633 7052. Email queries should be sent to eccapplications@nhs.net.

Yours sincerely

Natasha Dunkley
NIGB Approvals Manager

Ethics and Confidentiality Committee
Standard conditions of approval

The support provided under section 251 is subject to the following standard conditions.

The applicant will ensure that:

1. The requested patient identifiable information is only used for the purpose(s) set out in the application.

2. Confidentiality is preserved and that there is no disclosure of information in aggregate or patient level form that may inferentially identify a person, nor will any attempt be made to identify individuals, households or organisations in the data.

3. Requirements of the Statistics and Registration Services Act 2007 are adhered to regarding publication when relevant.

4. All staff with access to patient identifiable information have contractual obligations of confidentiality, enforceable through disciplinary procedures.

5. All staff with access to patient identifiable information have received appropriate ongoing training to ensure they are aware of their responsibilities.

6. Activities are consistent with the Data Protection Act 1998.

7. Audit of data processing by a designated agent of the Secretary of State is facilitated and supported.

8. The wishes of people who have withheld or withdrawn their consent are respected.

9. The NIGB Office is notified of any significant changes which impact on the approval of the application.

10. An annual review to be provided no later than 12 months from date of your final approval letter

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	6
Objectives	3	State specific objectives, including any prespecified hypotheses	6
Methods			
Study design	4	Present key elements of study design early in the paper	7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	7
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	7
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	8-10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	8-10
Bias	9	Describe any efforts to address potential sources of bias	*7-10*
Study size	10	Explain how the study size was arrived at	7
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	10
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	10
		(*b*) Describe any methods used to examine subgroups and interactions	10
		(*c*) Explain how missing data were addressed	12
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	10
		(*e*) Describe any sensitivity analyses	10
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	11
		(b) Give reasons for non-participation at each stage	11
		(c) Consider use of a flow diagram	n/a
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	11
		(b) Indicate number of participants with missing data for each variable of interest	12
Outcome data	15*	Report numbers of outcome events or summary measures	12-16
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	13-15
		(*b*) Report category boundaries when continuous variables were categorized	12-16
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	12-16
Discussion			
Key results	18	Summarise key results with reference to study objectives	17-18
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	17-19
Generalisability	21	Discuss the generalisability (external validity) of the study results	18
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	21

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Patient Reported Outcomes of Cancer Survivors in England 1 to 5 years after Diagnosis: a cross-sectional survey.

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2012-002317.R2
Article Type:	Research
Date Submitted by the Author:	27-Feb-2013
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Primary Subject Heading:	Oncology
Secondary Subject Heading:	Health policy, Public health, Research methods
Keywords:	Adult oncology < ONCOLOGY, Breast tumours < ONCOLOGY, Gastrointestinal tumours < ONCOLOGY, Lymphoma < ONCOLOGY, Urological tumours < ONCOLOGY

Title:

Patient Reported Outcomes of Cancer Survivors in England 1 to 5 years after Diagnosis: a cross-sectional survey.

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Key Words:

Cancer, Survivorship, Quality of Life, Patient Reported Outcomes, EQ5D, FACT

Word Count:

abstract: 304 & main body of paper: 4486

Abstract

Objectives: To determine the feasibility of collecting population based patient reported outcome measures (PROMS) in assessing quality of life (QoL) to inform development of a national PROMS programme for cancer and to begin to describe outcomes in a UK cohort of survivors.

Design: Cross-sectional postal survey of cancer survivors using a population-based sampling approach.

Setting: English National Health Service.

Participants: 4,992 breast, colorectal, prostate and Non-Hodgkin's Lymphoma survivors one to five years from diagnosis.

Primary and Secondary Outcome Measures: Implementation issues, response rates, cancer-specific morbidities utilising items including the EQ5D, tumour-specific sub-scales of the Functional Assessment of Cancer Therapy and Social Difficulties Inventory.

Results:

3,300 (66%) survivors returned completed questionnaires. The majority aged 85+ years did not respond and response rates were lower for those from more deprived area. Response rates did not differ by gender, time since diagnosis or cancer type.

The presence of one or more long term conditions was associated with significantly lower QoL scores. Individuals from most deprived areas reported lower QoL scores and poorer outcomes on other measures, as did those self-reporting recurrent disease or uncertainty about disease status. QoL scores were comparable at all time points for all cancers except NHL. QoL scores were lower than those from the general population in Health Survey for England (2008) and General Practice Patient Survey (2012).

47% of patients reported fear of recurrence whilst 20% reported moderate or severe difficulties with mobility or usual activities. Bowel and urinary problems were common among colorectal and prostate patients. Poor bowel and bladder control were significantly associated with lower QoL.

Conclusions: This method of assessing QoL of cancer survivors is feasible and acceptable to most survivors. Routine collection of national population- based PROMS will enable identification of, and support for, the specific needs of survivors whilst allowing for comparison of outcome by service provider.

Article Summary

Article Focus

To determine the feasibility of routinely collecting population-based patient reported outcomes (PROMS) of cancer survivors to gather information on quality of life and cancer related morbidities that can be used to inform the development of a national PROMS programme for cancer.

Key messages

- Collection of population-based information on quality of life from cohorts of cancer patients who are 1 to 5 years post diagnosis through cancer registries is feasible.
- The best quality of life was reported by those in remission and with no other long term conditions.
- Information obtained by widespread extension of this methodology will enable health economies to compare outcome across provider organisations and facilitate provision of enhanced services to meet the needs of cancer survivors.

Strengths and Limitations

- Findings relate to the largest European survey of survivors of multiple cancer types at clearly defined time points from diagnosis.
- The study design eliminates many of the criticisms which have hindered the collection of population-based cancer patient reported outcome data in the past.
- English cancer registries provide a reliable denominator population from which to identify eligible participants.
- The questionnaires for the four cancer groups were identified as having face and content validity by a panel of health and social care professionals prior to use, following review by consumers and consultation with cancer charities.
- Presence of multiple cancer groups, time points and some missing data may have resulted in a lack of power for certain analyses.

- Selection bias may have arisen through differences in-response rates according to cancer group, deprivation category and age.
- The study excluded those treated in the private sector.

Introduction

1.8 million people are living with and beyond a diagnosis of cancer in England and prevalence is predicted to increase by 3% per annum.[1] Cancer treatments are effectively reducing mortality and extending life, yet there is evidence that physical, psychological and social needs are not being addressed by the health and social care services, with individuals reporting significant unmet needs[2]. There is a lack of robust population-based information from which the prevalence, and impact, of disease and treatment associated morbidity burden can be ascertained and policy for appropriate interventions developed[3]. It has been equally difficult for health economies to compare the quality of health of those following treatment for cancer to those living with other long term conditions (LTC). These deficits have hampered the provision of comprehensive robust services for this growing population[4].

In the United States a number of significant initiatives have been launched to systematically measure health outcomes in cancer survivors using patient reported outcome measures (PROMS) through the National Cancer Institute and American Cancer Society[3 5-6]. In Europe, at least one regional cancer register has started to collect PROMS via approaches made through the treating clinical teams[7-8]. The focus of PROMS work to date has been on refining treatment decision making for individuals and determining methodological approaches to implementation and analysis[5-6 9-11]. These efforts have yet to feed through into major national health system service improvement initiatives. The evaluation of patients' experiences of cancer care in England, through the National Cancer Patient Experience Survey, has resulted in care provider organisations and commissioners being able to identify areas of strengths and weakness in acute cancer care provision[12].

Our objective was to determine the feasibility of routinely collecting population-based PROMS of cancer survivors (via a postal survey of individuals identified from cancer registry information), without introduction from clinicians or researchers known to participants, to gather information on quality of life (QoL) and cancer related morbidities that can be used to inform the development of a national PROMS programme for cancer. Feasibility was assessed for example by evaluating response rates, level of questionnaire completeness and the number of complaints from participants. Findings reported in this paper are a summary of the analyses which are available in comprehensive form from the Department of Health (DH) website (https://www.wp.dh.gov.uk/publications/files/2012/12/9284-TSO-2900701-PROMS.pdf).

Methods

Study design

A cross-sectional postal survey was undertaken of individuals with a diagnosis of breast, colorectal, non-Hodgkin's lymphoma (NHL) or prostate cancer one, two, three and five years earlier. These four time-points were chosen to gain an understanding of whether PROMS varied over time. Patients attending private healthcare centres (estimated to be less than 5% of cases) were excluded as the aims of the study focused on the assessment of PROMS within the National Health Service (NHS) in England.

Cohort Identification and Survey Process

Three cancer registries (Thames Cancer Registry, Eastern Cancer Registry and Information Centre, West Midlands Cancer Intelligence Unit) were chosen as representative examples of the eight cancer registries in England. They provided information on all relevant cancer diagnoses[12] (Supplementary File 1) between 01/02/2010-30/04/2010, 01/02/2009-30/04/2009, 01/02/2008-30/04/2008, and 01/02/2006-30/04/2006. The individual study cohorts for each cancer at time points one, two, three and five years from date of recorded diagnosis were compiled through identification of the 312 cases diagnosed most closely to a specified time-point (First of February for each year). Cases were excluded if: under the age of 16 years, deceased, or not known to have a UK address.

Identified participants were sent a questionnaire by post by the survey provider, *Quality Health*. This was sent under cover of a standard introductory letter with the letter-head of the cancer centre most recently recorded by the cancer registry as having provided treatment. The survey covered patients attending 70 of 160 (43%) acute NHS Trusts delivering cancer care in England during 2011, although we were unable to determine whether these were representative of all patients. Patients consented to taking part in the survey by returning questionnaires and declined by not returning them, or by returning blank questionnaires. . Two reminders were sent to non-responders. Checks for deceased patients were undertaken by the registries at four separate time points in the survey process to ensure attempts were not made to contact deceased individuals.

Details of a dedicated freephone telephone helpline, staffed 24 hours each day, were provided so the queries of any respondents could be resolved.

Questionnaire design and content (Supplementary files 2, 3, 4 and 5)

Questionnaires were developed for each cancer group. Content was identified through literature review, commissioned expert reviews[13-15], consultation with patient groups, cancer charities and expert advisory groups. In this way the views of multi-professional clinicians and service users were captured.

Generic content included:

- Demographic and treatment-related questions adapted from the National Cancer Patient Experience Survey.[12]
- Self-reported response to treatment and disease status
- Amount of physical activity performed each week quantified according to the Chief Medical Officer of England's recommendations[16].
- Presence or absence of long-term conditions (LTCs) other than cancer, using a list widely used in English Department of Health surveys.
- EQ5D: A 5 item generic health-related quality of life measure[17-18] chosen as it is a generic measure of health status widely used to evaluate population health in England[17].
- Social Difficulties Inventory (SDI): A cancer survivor specific measure covering wider QoL domains[19-20,21] including information on the social consequences of cancer.
- Experience of care. Relevant items to these phases of the cancer pathway were taken from the National Cancer Patient Experience Survey Questionnaire.[22]
- Fear of recurrence and dying. These items were generated by the project team and cognitively tested on representative sample goups prior to this pilot survey.

- Individual components on psychological issues and work status identified through the literature as being important to cancer survivors but not covered by other components of the survey[23], [24].

Tumour-specific content included

- Functional Assessment of Cancer Therapy (FACT) tumour specific components (FACT-B, FACT-C , FACT-Lym and FACT-P for breast, colorectal, NHL and prostate cancer respectively)[25].

A detailed description of the qualitative comments provided by respondents are reported in a parallel submission to the BMJ Open.

Cognitive testing was performed on the four site-specific versions of the questionnaire prior to their general use. This was done by sending questionnaires to volunteers (identified through cancer charities and the survey provider) prior to participating in a telephone interview. This style of testing was used to determine the population's ability to complete the questionnaire independently and to follow routing and other instructions in the questionnaire without prompting or help. Appropriate alterations were then made to the questionnaire. The two required changes were omission of a similar item from the FACT-B and FACT-P questionnaires *"I am able to feel like a woman"* and *"I am able to feel like a man"*, because these questions were found to be confusing and unacceptable to volunteers.

Data Handling/Analysis

Age (at time of survey) was categorised as <55, 55-64, 65-74, 75-84, and ≥85 years. Self-reported ethnicity was grouped into white, asian, mixed, black and other. Deprivation category was based on the complete index of multiple deprivation (IMD)[26]. This was derived from the lower super output area (small census area) associated with their place of residence at the time of completing the survey, and used because the survey did not include questions related to income or educational level.

Participants were asked if they had any LTC other than their cancer diagnosis and were asked to tick the appropriate LTCs. This variable was categorised into 'no other', 'one other' and 'two or more LTCs'.

A crosswalk algorithm was used to convert the 5L EQ5D to the 3L version, allowing a weighted health score to be assigned for each individual.[27] United Kingdom population data were used to calculate weighted scores (range -0.5 to 1 [perfect health]). Due to skewness, this outcome variable was categorised and ordered logistic regression undertaken. Three categories representing 'high', 'medium' and 'low' QoL scores were defined for ease of interpretation; these comprised scores equal to 1, less than 1 but greater than or equal to 0.5 and less than 0.5. Odds ratios should be interpreted either as the odds of being in group 2 (medium QoL scores) or group 3 (low QoL scores) compared to group 1 (high QoL scores) *or* the odds of being in group 3 (low QoL scores) compared to group 1 or group 2. Although this was not a standard approach and meant that information and perhaps discriminatory power was lost, our model parameterisation enabled a more natural interpretation of EQ5D QoL data. Furthermore, when comparisons were made with other alternative models, such as tobit regression, findings were very similar.

Cancer-specific questions from FACT[25] were used as explanatory variables in this analysis (FACT total score could not be calculated as only the cancer-specific subscale questions were included). Patient reported treatments were used in the analyses and treatment combinations were categorised for each cancer site with the most common used as the reference group. Given the study design, participants who had survived a year or more and who reported still receiving treatments when they completed the survey were likely to be receiving treatment for advanced or recurrent disease.

Statistical methods

Chi-squared tests were used to compare categorical variables. Descriptive statistics were compared across cancer sites but the statistical models were stratified by cancer site. Variables were entered into the logistic regression model based on their *a priori* clinical and public health importance after agreement by the study investigators. Formal variable selection procedures were not invoked primarily due to statistical problems associated with these data-driven procedures[28] and, secondly, so that findings could be compared consistently across cancer sites and time points. Statistical significance was set at 1% to

minimise the chances of false-positive associations. All analyses were undertaken using STATA v12.1.

Ethics and governance

Approval was given to approach patients without informed consent by the National Information Governance Board (Supplementary File 6) as the study was performed as service evaluation[29].

Results

Participants

Questionnaires were sent to 4992 individuals, 126 (2·5%) of these had moved or died prior to receiving the questionnaire resulting in a final sample size of 4866. 3300 completed questionnaires were received (66% of the study sample). Of the surveys received by participants, the response rate was 68% (3300/4866).

Response rates

Response rate varied significantly between cancer groups (Table 1a): 69·4% in the prostate group compared to 62·3% in the NHL group (p<0.001).

There was significant difference in the age structure of the non-responders vs. responders with a higher proportion of non-responders in the ≥85 years age group (p<0·001).

Response rates differed according to deprivation status (Table 1a) with a response rate of 71·4% in the least deprived category compared to 57·1% in the most deprived category (p<0·001).

No difference in response rates by time since diagnosis, sex or cancer type was found (see https://www.wp.dh.gov.uk/publications/files/2012/12/9284-TSO-2900701-PROMS.pdf for full details).

Demographics of respondents (Table 1b)

Overall there were more males than females. Median age was 69 years (range 36-102). There was significant variation in the distribution of ethnicity by cancer group with higher proportions of non-white ethnic groups with NHL. There was no significant difference by deprivation between cancer groups. Overall more than half of patients reported having a LTC. There were fewer reported LTCs in the breast cohort than in other groups but this did not reach statistical significance.

Missing data

Missing data levels were extremely low, typically less than 5% for most fields. SDI had slightly higher levels of missing data with completeness ranging from 80-85%. For the regression modelling (Tables 3a-3d) which used complete case analysis approach, completeness levels were lower and ranged from 60% (colorectal, prostate) to 83% (breast). There was no evidence that the prevalence of missing data was related to the order of the questions after examining levels of completeness for questions at the beginning compared to the end of the form.

Helpline calls and other contact from survey participants

64 calls were made to the helpline, whilst further information about patient status was received via letters from patients (11) and NHS Trusts (2). The total number of enquiries was 77, representing 0.02% of the study cohort.

Generic PROMS

Responses for the five EQ5D questions demonstrated that a higher percentage of NHL patients reported problems with self-care, mobility and usual activities. Two-thirds of breast cancer patients reported some degree of pain (Supplementary Table 1).

When detailed responses for the five EQ5D questions were summarised by time since diagnosis, there were no significant differences for pain, mobility, usual activities or self-care. However, the percentage reporting no anxiety or depression symptoms increased significantly from 55% at 1 year post-diagnosis to 66% after 5 years (p=0·01) (Supplementary Table 2).

Skewed weighted health scores were obtained from the EQ5D by cancer group (Supplementary Figure 1). The prostate group had significantly higher median (0·88) scores than the other three groups (0·84) (p=0·001). The proportion of the populations reporting high QoL scores ranged from 24·4% for breast to 40·0% for prostate cancer (Table 2). Conversely, the proportion reporting low QoL scores ranged from 8.9% for breast to 13.1% for NHL. For all tumour groups, irrespective of remission status, the percentage of

individuals reporting lower QoL scores increased as the number of other LTCs increased (Supplementary Tables 3-4).

Result by Tumour Type

Multivariable ordered logistic regression (Tables 3a-3d) identified three factors which were consistently associated with lower QoL scores irrespective of tumour type: presence of LTCs, undertaking little physical activity and self-reported disease status.

Breast Cancer (Table 3a)

Increasing number of LTCs, having recurrence of disease or being uncertain of disease status were associated with poorer outcomes across all three measures: The presence of one (OR 1·84, 95%CI 1·25,2·70) or two or more (Odds Ratio (OR) 7·30, 95%Confidence Interval (CI) 4·45,11·93) LTCs was significantly associated with lower QoL scores. Individuals self-reporting recurrent disease (OR 4·70, 95%CI 1·92,11·52) or those uncertain about their disease status (OR 2·51, 95%CI 1·27,4·96) were significantly more likely to report lower QoL scores compared to those self-reporting remission.

Increasing age (apart from those aged 85 years or older) and more days undertaking physical activity were significantly associated with better outcomes in EQ5D, SDI and FACT-B measures: Those aged 65-74 reported significantly higher QoL scores compared to under 55s (OR 0·36, 95%CI 0·22,0·58). Increasing physical activity was associated with higher QoL scores with each additional reported day per week of physical activity reducing the odds of a lower score by 12% (OR 0·88, 95%CI 0·82,0·95).

Individuals from the most deprived areas were significantly more likely to report lower EQ5D derived QoL scores than those from the most affluent areas (OR 3·00, 95%CI 1·64-5·50). Poorer outcomes in FACT-B items were associated with being in the most deprived category.

Colorectal Cancer (Table 3b)

The presence of one (OR 2·09, 95%CI 1·29,3·37) or two or more (OR 4·83, 95%CI 2·85,8·21) LTCs was significantly associated with lower QoL scores. Those who completed the

questionnaire whilst undergoing treatment (OR 7·03, 95%CI 2·44,20·21), experiencing recurrent disease (OR 4·56, 95%CI 1·54,13·49) or who were uncertain about their disease status (OR 2·67, 95%CI 1·23,5·79) had significantly increased odds of reporting lower QoL scores compared to those reporting remission.

Increasing physical activity was significantly associated with a 17% decrease in the odds of a lower QoL score with each additional day per week of physical activity (OR 0·83, 95%CI 0·76,0·90).

23·5% reported urinary leakage, 19·0% difficulty controlling their bowels and 19·2% had a stoma. Individuals experiencing any difficulty controlling their bowels were more than twice as likely to report lower QoL scores (OR 2·30, 95%CI 1·43,3·72). The presence of a stoma or urinary leakage was not significantly associated with QoL.

Greater difficulties with holidays and travel were reported by those with colorectal cancer compared to other cancers. For example, only 51% of colorectal respondents reporting no difficulty compared to 64% with breast or prostate cancer.

Non-Hodgkin's Lymphoma (Table 3c)

The presence of one (OR 2·16, 95%CI 1·44,3·24) or two or more (OR 7·26, 95%CI 4·51,11·69) LTCs was significantly associated with lower QoL scores. Those currently being treated (OR 2·57, 95%CI 1·52,4·33), experiencing a recurrence (OR 3·73, 95%CI 1·68,8·29) or who were not sure about their disease status (OR 3·04, 95%CI 1·58,5·84) had increased odds of reporting lower QoL scores compared to those in remission. These same factors were associated with poorer outcomes on the SDI and FACT-Lym items.

A significant positive association between increasing physical activity and QoL was seen with each additional day of physical activity reducing the odds of lower QoL score by 9% (OR 0·91, 95%CI 0·84,0·98). QoL seemed to improve with time from diagnosis for NHL but the trend was not significant (p=0·100).

Prostate Cancer (Table 3d)

The presence of two or more LTCs (OR 4·28, 95%CI 2·62,7·01) or being in the most deprived category (OR 2·57, 95%CI 1·31,5·04) were significantly associated with lower QoL scores, as well as increased social distress and difficulties identified by FACT-P.

Patients who had surgery only (compared to radiotherapy and hormone treatment) had significantly higher QoL scores (OR 0·39, 95%CI 0·21,0·71) as did those reporting more days of physical activity (OR 0·82, 95%CI 0·75,0·88).

38·5% of prostate patients reported some degree of urinary leakage, 12·9% reported difficulty controlling their bowels and 58·4% reported being unable to have an erection with a further 11% reporting significant difficulty in having or maintaining an erection. The presence of urinary leakage was significantly associated with lower QoL scores (OR 3·52, 5%CI 2·32,5·35). Erectile dysfunction and difficulty controlling bowels were not significantly associated with QoL scores.

Prostate survivors had significantly lower overall social distress scores on the SDI as well as fewer problems in all three sub-scales (everyday living, money matters, self and others) compared to other cancer types.

Fear of recurrence and dying

Almost half (47·3%) of patients reported fear of recurrence and over a quarter (26·8%) reported fear of dying (Supplementary Table 5). Both of these fears decreased significantly with time since diagnosis.

Physical activity

Around one-fifth (21·4%) of participants reported taking 30 minutes or more of physical activity at least five days a week (in line with the Chief Medical Officer's recommendations). This varied by cancer: 16·5% for NHL, 19·0% for breast, 20·2% for colorectal and 29·0% for prostate. Overall 29·8% of patients reported doing no physical activity; this varied by cancer

group with 33·5% of NHL, 31·5% of colorectal and 27·4% of both breast and prostate survivors doing no physical activity.

Discussion

This study represents the largest European survey of survivors of multiple cancer types at clearly defined time points from diagnosis and demonstrates the feasibility of this straightforward method of collecting informative self-reported PROMS data on population-based cohorts of individuals living with and beyond a diagnosis of cancer in England. The process eliminates many of the potential biases that have hindered the collection of population-based cancer PROMS data in the past originating from the use of clinical trial data or acute service provider units for recruitment[30]. English cancer registries, which capture approximately 98-99% of all cancers diagnosed in England[31], provide a reliable denominator population from which to identify eligible participants.

Acceptability and Validity

The relatively high response rate, low level of missing data and low number of calls to the dedicated 24 hour helpline suggest that the methodology is acceptable to the majority of participants. However, the finding of lower participation amongst the elderly or those residing in areas with the greatest socio-economic deprivation would suggest that individuals from these vulnerable groups may need to be assessed by alternative methods. Whilst the questionnaires were identified as having face and content validity by a panel of health and social care professionals prior to use this study does not permit us to comment on the responsiveness or reliability of the instruments. However, the core components of the questionnaires had been identified by independent review as being reliable and appropriate for use in this setting[13-15].

Key results

The QoL of survivors for all four cancers was significantly related to self-reported disease status (remission versus relapse/uncertain), age and presence of LTCs. QoL appeared to either remain constant or improve slightly as time from diagnosis increased. This suggests that some problems experienced by cancer patients persist for long periods.

We have quantified the community prevalence of previously known late morbidities and assessed their impact on QoL. Problems relating to urinary and bowel control have been

shown to be common, with nearly 40% of prostate survivors reporting urinary leakage and 13% difficulty controlling their bowels. Similarly, amongst colorectal survivors nearly a quarter reported urinary leakage and 19% reported difficulty controlling their bowels. These rates are comparable to other studies of cancer patients[32] but exceed those seen in non-cancer populations where the prevalence of urinary incontinence in adult men was 4·5% overall, rising to 16·0% for over 75 year olds[33]. In this study, the presence of "urinary leakage" in prostate survivors and "of difficulty controlling their bowels" in colorectal survivors were significantly associated with lower QoL scores making such symptoms important to address. Erectile dysfunction in prostate survivors, though common, did not significantly impact on QoL. The finding that QoL or physical problems such as difficulty controlling bowels or incontinence do not appear to be less prevalent five years following treatment may suggest individuals are not receiving adequate help or treatment for these conditions. Greater efforts should be made in prevention and early intervention for problems resulting from cancer treatment, and directed at those most at risk of the long–term problems identified from this study.

Comparison with the General Population Data

Most survivors in this study who were in remission and did not report a LTC were found to have a high QoL score. However, even the subgroup in remission with no LTC reported lower QoL scores than the data available from general population studies (Table 4). Some of this difference may be accounted for by age, as the Health Survey for England (2008)[34] and the General Practice Patient Survey (GPPS)[35] cohorts were substantially younger than the reported cancer study cohort. This assumption is supported from the HSE cohort aged over 45 years (median age 63, n=7672) which reported a reduction in QoL scores (good 45%, moderate 46%, poor 9%).

Long-term Conditions

The presence of one or more LTCs, other than their cancer diagnosis, was associated with lower QoL scores in all four cancer groups and mirrors findings from other studies[2 36]. The presence of multi-morbidity and LTCs identifies sub-sets of survivors who may require more active support than others. This needs to be factored into risk stratification models as

health services move away from hospital based cancer follow-up towards a greater focus on self-management.

Physical Activity

The extent to which cancer survivors take physical activity has not previously been reported in England. The findings agree with those from the USA[37], suggesting that prostate survivors are more likely than others to take moderate or vigorous physical activity. We observed an association between higher levels of activity and higher QoL scores, but it is not possible to assess from a cross-sectional survey whether there is a causal relationship.

A smaller percentage of study respondents (21·4%) met the Chief Medical Officer of England's recommendations for physical activity when compared with the HSE(2008) in which 34% of adults met these guidelines[34]. Restricting the HSE data to a similar age profile as the study participants (60-75 years) saw similar levels of physical activity (23%). The HSE data found a trend of decreased physical activity with increasing age, yet, in this study, prostate survivors (the oldest subgroup) reported higher physical activity levels.

Limitations

The presence of multiple cancer groups and time points, along with some missing data (typically <5%), may have resulted in either a lack of power for certain analyses or type I errors (false positive results) due to the number of comparisons. For example, investigating whether the quality of life of those living with recurrent disease differed from those survivors who had been 'cured'. The non-response rate varied significantly by cancer group, deprivation category and age, which could result in selection bias when generalising results. To overcome bias associated with deprivation and age, we propose extension of the pilot study to the largest possible cohorts available nationally; analyses and interpretation of this data will be performed with maximum sensitivity to these areas.

Our study excluded those treated in the private sector (estimated to be under 5% of cancer cases in England[38]). Treatments may also have changed over the 1-5 year period used to select survivors and it is therefore possible the results reflect these changes.

The study relied on self-reporting of long-term conditions, response to treatment and disease status. This information was not independently verified.

We also acknowledge that measures related to the FACT component are primarily intended for use around the time of treatment rather than for survivorship work. Space limitations precluded a more detailed description of results incorporating the FACT and SDI components. However, a comprehensive report including these additional findings has been compiled and can be accessed via the DH website (https://www.wp.dh.gov.uk/publications/files/2012/12/9284-TSO-2900701-PROMS.pdf).

Where next for Cancer PROMS in England?

The use of cancer PROMS has generally been restricted to clinical research, especially clinical trials or small studies. Whilst important work has been undertaken to develop approaches for the measurement of PROMS, they have not been incorporated into routine measurement at a whole health system level. This study demonstrates that population-based survey approaches are feasible and yield acceptable response rates. This approach could provide important insights into where improvement efforts should be targeted to reduce the long-term burden of cancer and its treatments on the growing number of cancer survivors.

Improving QoL in patients with LTC is one of the key goals of English government health policy (forming Domain 2 of the NHS Outcomes Framework)[39]. The approach we report should be scaled up and integrated within routine health outcome assessment on a national basis so that results can be distilled down to hospital/service provider level, as has been done in relation to the experience of acute care of cancer patients[12]. Improvements in quality of survivor care could then be driven by publishing hospital/provider level data. As a result of the findings of this pilot, a national roll-out to all individuals diagnosed 1-3 years earlier with colorectal cancer in England is being performed in January 2013. A similar roll-out to those diagnosed with prostate cancer is planned whilst pilot questionnaires for those with bladder, cervical, endometrial and ovarian cancer are being prepared. To further understand the develomental trajectory of morbidity burden, a longitudinal survey of respondents to the pilot is being undertaken, with a survey 1 year on having been undertaken and consideration for a further data collection point after another 12 months.

Our findings support the on-going international efforts to identify risk factors for poor health-related QoL outcomes following a cancer diagnosis. These include the presence of other LTCs, deprivation and limited physical activity. These, along with the high prevalence of on-going condition-specific problems such as bowel, urinary and erectile dysfunction, warrant attention by cancer services.

Acknowledgements

Dr Nicola Davies, Professor Jane Maher, Dr Mick Peake, Professor Galina Velikova and Dr Penny Wright provided expert advice regarding questionnaire and study design. Thames Cancer Registry, Eastern Cancer Registry and Information Centre, and West Midlands Cancer Intelligence Unit provided information on all eligible cancer survivors. FACIT provided permission to use components of the FACT questionnaires and Penny Wright granted permission to use the Social Difficulties Inventory.

Funding

This survey was funded by the Department of Health, England.

Open source access for BMJ Open was funded through a grant from Macmillan Cancer Support.

Declaration of Competing Interests

All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: financial support for the submitted work from the Department of Health, England: AWG, GH and MR were employed by the Cancer Policy Team, Department of Health, England, whilst the research was carried out; AWG, LKF, RGF and EF, received financial support from Department of Health, England, to carry out the analysis of data reported; JC and MR co-chaired the Department of Health, England, Cancer Patient Experience Advisory Group.

Data Sharing Statement

Statistical code and dataset are available from the corresponding author at the University of Leeds, who will provide a permanent, citable and open access home for the dataset.

Author Contribution Statement

Adam Glaser contributed to the study design, data collection, data analysis, data interpretation and writing of this manuscript.

Lorna Fraser contributed to the data analysis, data interpretation and writing of this manuscript.

Jessica Corner contributed to the study design, data collection, data interpretation and writing of this manuscript.

Richard Feltbower contributed to the data analysis, data interpretation and writing of this manuscript.

Eva Morris contributed to the data analysis, data interpretation and writing of this manuscript.

Greg Hartwell contributed to the study design and data collection.

Mike Richards contributed to the study design, data interpretation, and writing of this manuscript.

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Table 1a Demographic data of responders and non-responders

Characteristic		**Responders (n=3300)**		**Non Responders (n=1692)**		**Total number approached**	**Overall Percentage Responding**
		n	***%***	***n***	***%***		
Cancer Group	**χ2=18.8, p<0·001**						
Breast		854	*25.9*	394	*23.3*	*1248*	*68.4*
Colorectal		802	*24.3*	446	*26.4*	*1248*	*64.3*
NHL		778	*23.6*	470	*27.8*	*1248*	*62.3*
Prostate		866	*26.2*	382	*22.5*	*1248*	*69.4*
Age	**χ2=108, p<0·001**						
under 55		467	*14·2*	282	*16.7*	*749*	*62.3*
55 to 64		692	*21·0*	335	*19.8*	*1027*	*67.4*
65 to 74		1,108	*33·6*	414	*24.5*	*1522*	*72.8*
75 to 84		835	*25·3*	434	*25.6*	*1269*	*65.8*
85+		198	*6·0*	227	*13.4*	*425*	*46.6*
IMD Category	**χ2=55.9, p<0.001**						
1 least deprived		826	*25·0*	331	*19.6*	*1157*	*71.4*
2		812	*24·6*	357	*21.1*	*1169*	*69.5*
3		703	*21·3*	349	*20.7*	*1052*	*66.8*
4		554	*16·8*	352	*20.7*	*906*	*61.1*
5 most deprived		399	*12·1*	300	*17.7*	*699*	*57.1*
Missing		6	*0·2*	*3*	*0.2*	*9*	*66.7*
Time since Diagnosis	**χ2=4.1, p=0·25**						
1 year		848	*25·7*	400	*23.6*	*1248*	*67.9*
2 years		834	*25·3*	414	*24.5*	*1248*	*66.8*
3 years		806	*24·4*	442	*26.1*	*1248*	*64.6*
5 years		812	*24·6*	436	*25.8*	*1248*	*65.1*

Table 1b. Demographic Data by Cancer Group

Characteristic		Breast (n=854)		Colorectal (n=802)		Non Hodgkin's Lymphoma (n=778)		Prostate (n=866)		Total (n=3300)	
		n	%	n	%	n	%	n	%	n	%
Sex	**χ2=1700, p<0·001**										
Male		10	*1·2*	435	*54·2*	419	*53·9*	848	*97·9*	1712	*51·9*
Female		829	*97·0*	348	*43·4*	352	*45·2*	0	*0*	1529	*46·3*
Missing		15	*1·8*	19	*2·4*	7	*0·9*	18	*2·1*	59	*1·8*
Age	**χ2=401, p<0·001**										
under 55		231	*27·0*	57	*7·1*	157	*20·2*	157	*18·1*	467	*14·2*
55 to 64		237	*27·8*	136	*17·0*	173	*22·2*	173	*20·0*	692	*21·0*
65 to 74		224	*26·2*	280	*34·9*	238	*30·6*	238	*27·5*	1,108	*33·6*
75 to 84		122	*14·3*	246	*30·7*	175	*22·5*	175	*20·2*	835	*25·3*
85+		40	*4·7*	83	*10·3*	35	*4·5*	35	*4·0*	198	*6·0*
Ethnicity	**χ2=74·6, p<0·001**										
White		768	*89·9*	740	*92·3*	688	*88·4*	786	*90·8*	2982	*90·4*
Asian		35	*4·1*	19	*2·3*	30	*3·9*	15	*1·7*	99	*3·0*
Black		14	*1·6*	11	*1·4*	21	*2·7*	36	*4·2*	82	*2·5*
Mixed		4	*0·5*	5	*0·6*	6	*0·8*	1	*0·1*	16	*0·5*
Other		4	*0·5*	0	*0*	4	*0·5*	3	*0·3*	11	*0·3*
Missing		29	*3·4*	27	*3·4*	29	*3·7*	25	*2·9*	110	*3·3*
IMD Category	**χ2=4·3, p0·97**										
1 least deprived		211	*24·7*	198	*24·7*	202	*26·0*	215	*24·8*	826	*25·0*
2		210	*24·6*	199	*24·8*	183	*23·5*	220	*25·4*	812	*24·6*
3		184	*21·5*	159	*19·8*	177	*22·7*	183	*21·1*	703	*21·3*
4		141	*16·5*	147	*18·3*	125	*16·1*	141	*16·3*	554	*16·8*
5 most deprived		104	*12·2*	98	*12·2*	91	*11·7*	106	*12·2*	399	*12·1*
Missing		4	*0·5*	1	*0·1*	0	*0*	1	*0·1*	6	*0·2*
Time since Diagnosis	**χ2=5·5, p=0·78**										
1 year		215	*25·2*	202	*25·2*	197	*25·3*	234	*27·0*	848	*25·7*
2 years		212	*24·8*	215	*26·8*	187	*24·0*	220	*25·4*	834	*25·3*
3 years		204	*23·9*	195	*24·3*	207	*26·6*	200	*23·1*	806	*24·4*
5 years		223	*26·1*	190	*23·7*	187	*24·0*	212	*24·5*	812	*24·6*
Other Long Term Health Condition	**χ2=12·1, p=0·06**										
Yes		435	*50·9*	432	*53·9*	435	*55·9*	501	*57·9*	1803	*54·6*
No		353	*41·3*	309	*38·5*	287	*36·9*	299	*34·5*	1248	*37·8*
Don't Know		30	*6·9*	23	*2·9*	33	*4·2*	27	*3·1*	113	*3·4*
Missing		36	*4·2*	38	*4·7*	23	*3·0*	39	*4·5*	136	*4·1*
Disease Status	**χ2=390·0, p<0·001**										
Remission		677	*79·3*	625	*77·9*	526	*67·6*	399	*46·1*	2227	*67·5*
Rx but present		26	*3·0*	32	*4·0*	81	*10·4*	144	*16·6*	283	*8·6*
Not treated		4	*0·5*	6	*0·7*	43	*5·5*	78	*9·0*	131	*4·0*

Recurrence		30	*3·5*	20	*2·5*	30	*3·9*	8	*0.9*	88	*2.6*
Not sure		58	*6·8*	69	*8·6*	53	*6·8*	140	*16·2*	320	*9·7*
Missing		59	*6·9*	50	*6·2*	45	*5·8*	97	*11·2*	251	*7·6*

Table 2. EQ5D outcome category by cancer sub-group

EQ5D Categories	**'High' QoL (Scores=1)**		**Medium QoL (0.5≤Scores<1)**		**Low QoL (Scores<0.5)**		**Missing**	
	n	*%*	n	*%*	n	*%*	n	*%*
Breast	208	*24·4*	514	*60·2*	76	*8·9*	56	*6·6*
Colorectal	255	*31·2*	434	*54·1*	87	*10·8*	26	*3·2*
Non Hodgkins Lymphoma	247	*31·7*	398	*51·2*	102	*13·1*	31	*4·0*
Prostate	347	*40·0*	390	*45·0*	81	*9·4*	48	*5·5*
Total	1057	*32·0*	1736	*52·6*	346	*10·5*	161	*4·9*

Table 3a. Ordered Logistic Regression Model EQ5D in Breast Cancer Patients [n=709, pseudoR^2=0·16 p<0·001]

Characteristic	Odds Ratio*	95% CI		P value
Age (years)				
<55 years	REF			
55-64	0·69	0·45	1·06	0·09
65-74	0·36	0·22	0·58	<0·001
75-84	0·59	0·32	1·08	0·09
85+	1·61	0·57	4·52	0·36
Deprivation				
1 least deprived	REF			
2	1·03	0·66	1·62	0·88
3	1·10	0·68	1·77	0·71
4	0·93	0·55	1·56	0·78
5 most deprived	3·00	1·64	5·50	<0·001
Physical Activity†	0·88	0·82	0·95	<0·001
Number of other LTC (excl BP)				
0	REF			
1	1·84	1·25	2·70	0·002
2+	7·30	4·45	11·93	<0·001
Treatment*				
Radio+Chemo+Surgery+Hormone	REF			
Radio +Chemo+Surgery	0·67	0·38	1·20	0·18
Radio+Surgery	0·51	0·29	0·90	0·02
Radio+Surgery+Hormone	0·56	0·33	0·96	0·04
Surgery only	1·00	0·55	1·84	0·99
Other	0·92	0·53	1·58	0·76
Ethnicity				
White	REF			
Mixed	0·50	0·06	4·29	0·53
Asian	1·96	0·77	5·01	0·16
Black	0·29	0·08	0·98	0·05
Other	2·20	0·17	29·32	0·55
Disease Status				
Remission	REF			
Rx but present	1·49	0·56	3·93	0·43
Not treated	.	.	.	.
Recurrence	4·70	1·92	11·52	0·001
Not sure	2·51	1·27	4·96	0·008
Time since Diagnosis				
1 year	REF			
2 years	1·02	0·64	1·62	0·95
3 years	0·88	0·55	1·41	0·60
5 years	0·93	0·59	1·47	0·76

*Odds of reporting ‘medium’ or ‘low’ QoL EQ5D scores compared to ‘high’ QoL scores where ‘high’, ‘medium’ and ‘low’ QoL was defined as scores=1, 0.5≤scores<1 and scores<0.5 respectively.

†Amount of physical activity performed each week quantified according to the Chief Medical Officer of England’s recommendations[16]

Table 3b. Ordered Logistic Regression Model EQ5D in Colorectal Patients [n=485, pseudoR2=0·18, p<0·001]

Characteristic	Odds Ratio	95% CI		P value
Age (years)				
<55 years	REF			
55-64	1·28	0·59	2·75	0·53
65-74	1·16	0·57	2·35	0·69
75-84	1·23	0·57	2·64	0·59
85+	2·45	0·93	6·41	0·07
Sex				
Male	REF			
Female	1·22	0·81	1·82	0·34
Deprivation				
1 least deprived	REF			
2	0·83	0·48	1·43	0·50
3	0·57	0·33	1·00	0·05
4	0·62	0·34	1·13	0·12
5 most deprived	1·17	0·58	2·34	0·66
Physical Activity†	0·83	0·76	0·90	<0·001
Number of other LTC(excl BP)				
0	REF			
1	2·09	1·29	3·37	<0·001
2+	4·83	2·85	8·21	<0·001
Treatment*				
Surgery only	REF			
Radio+Chemo+Surgery	1·15	0·60	2·21	0·67
Chemo+Surgery	1·35	0·85	2·17	0·21
Other	1·58	0·77	3·22	0·21
Ethnicity				
White	REF			
Mixed	1·72	0·24	12·42	0·59
Asian	1·99	0·46	8·54	0·36
Black	1·14	0·26	4·92	0·86
Other	1·72	0·24	12·42	0·59
Disease Status				
Remission	REF			
Rx but present	7·03	2·44	20·21	<0·001
Not treated	0·16	0·01	2·63	0·20
Recurrence	4·56	1·54	13·49	0·01
Not sure	2·67	1·23	5·79	0·01
Stoma				
No	REF			
Yes	1·32	0·80	2·19	0·27
Difficulty Controlling Bowels				
No	REF			
Yes	2·30	1·43	3·72	<0·001
Leak Urine				
No	REF			
Yes	1·41	0·87	2·30	0·16
Time since Diagnosis				
1 year	REF			
2 years	0·72	0·42	1·22	0·22
3 years	1·03	0·59	1·81	0·92
5 years	0·85	0·49	1·48	0·56

*Odds of reporting ‘medium’ or ‘low’ QoL EQ5D scores compared to ‘high’ QoL scores where ‘high’, ‘medium’ and ‘low’ QoL was defined as scores=1, $0.5 \leq$scores<1 and scores<0.5 respectively.

†Amount of physical activity performed each week quantified according to the Chief Medical Officer of England’s recommendations[16]

Table 3c. Ordered Logistic Regression Model EQ5D in NHL Patients [n=614, pseudoR2=0·15 p<0·001]

Characteristic	Odds Ratio	95% CI		P value
Age (years)				
<55 years	REF			
55-64	0·89	0·55	1·45	0·65
65-74	1·23	0·75	1·99	0·41
75-84	1·60	0·94	2·73	0·08
85+	2·13	0·84	5·39	0·11
Sex				
Male	REF			
Female	1·25	0·89	1·74	0·19
Deprivation				
1 least deprived	REF			
2	1·06	0·67	1·69	0·80
3	1·21	0·75	1·95	0·43
4	1·64	0·97	2·76	0·07
5 most deprived	1·19	0·65	2·21	0·57
Physical Activity†	0·91	0·84	0·98	0·01
Number of other LTC (excluding BP)				
0	REF			
1	2·16	1·44	3·24	<0·001
2+	7·26	4·51	11·69	<0·001
Treatment*				
Chemo only	REF			
Radio+Chemo	0·81	0·47	1·41	0·46
Chemo + Antibody	0·93	0·55	1·59	0·80
Radio+Chemo+Other	1·55	0·87	2·77	0·14
Other	0·96	0·63	1·46	0·86
Ethnicity				
White	REF			
Mixed	2·78	0·28	27·7	0·38
Asian	0·68	0·29	1·59	0·38
Black	0·91	0·33	2·49	0·85
Other	0·61	0·09	4·39	0·62
Disease Status				
Remission	REF			
Rx but present	2·57	1·52	4·33	<0·001
Not treated	0·83	0·17	3·96	0·82
Recurrence	3·73	1·68	8·29	0·001
Not sure	3·04	1·58	5·84	0·001
Time since Diagnosis				
1 year	REF			
2 years	0·62	0·38	0·99	0·05
3 years	0·60	0·38	0·96	0·03
5 years	0·57	0·36	0·90	0·02

*Odds of reporting ‘medium’ or ‘low’ QoL EQ5D scores compared to ‘high’ QoL scores where ‘high’, ‘medium’ and ‘low’ QoL was defined as scores=1, 0.5≤scores<1 and scores<0.5 respectively.

†Amount of physical activity performed each week quantified according to the Chief Medical Officer of England’s recommendations[16]

Table 3d. Ordered Logistic Regression Model EQ5D in Prostate Patients [n=524, pseudoR2=0·22 p<0·001]

Characteristic	Odds Ratio	95% CI		P value
Age (years)				
<55 years	REF			
55-64	1·32	0·41	4·30	0·64
65-74	1·72	0·55	5·38	0·36
75-84	1·32	0·41	4·30	0·64
85+	1·92	0·42	8·78	0·40
Deprivation				
1 least deprived	REF			
2	1·09	0·64	1·85	0·74
3	1·19	0·68	2·08	0·55
4	1·61	0·88	2·95	0·13
5 most deprived	2·57	1·31	5·04	0·01
Physical Activity†	0·82	0·75	0·88	<0·001
Number of other LTC(excl BP)				
0	REF			
1	1·55	0·94	2·54	0·09
2+	4·28	2·62	7·01	<0·001
Treatment*				
Radio+Hormone	REF			
Surgery only	0·39	0·21	0·71	<0·001
Hormone only	1·68	0·85	3·33	0·14
Radio only	0·94	0·53	1·66	0·83
Active surveillance only	1·16	0·47	2·88	0·75
Other	·	·	·	·
Ethnicity				
White	REF			
Mixed	3·82	0·07	203·44	0·51
Asian	3·21	0·56	18·49	0·19
Black	2·54	0·96	6·73	0·06
Other	0·00	0·00	·	0·98
Disease Status				
Remission	REF			
Rx but present	1·75	0·94	3·26	0·08
Not treated	1·06	0·37	3·05	0·91
Recurrence	1·71	0·17	16·91	0·65
Not sure	1·48	0·85	2·58	0·17
Urinary Leakage				
No	REF			
Yes	3·52	2·32	5·35	<0·001
Erectile Dysfunction				
No	REF			
Yes	1·46	0·96	2·23	0·08
Difficulty Controlling Bowels				
No	REF			
Yes	1·62	0·90	2·92	0·10
Time since Diagnosis				
1 year	REF			
2 years	0·83	0·50	1·40	0·49
3 years	0·80	0·47	1·36	0·41
5 years	0·77	0·45	1·33	0·36

*Odds of reporting 'medium' or 'low' QoL EQ5D scores compared to 'high' QoL scores where 'high', 'medium' and 'low' QoL was defined as scores=1, 0.5≤scores<1 and scores<0.5 respectively.

†Amount of physical activity performed each week quantified according to the Chief Medical Officer of England's recommendations[16]

Table 4. Comparison of Quality of Life scores with other population data

	Health Survey for England (HSE 2008)[34]		GP Population Survey (GPPS)[35]	GP Population Survey (GPPS)[35]	This survey	
	All ages	Ages≥ 45 years	All	No LTC	All	In remission with no LTC
Number of respondents	14116	7672	426933	193285	3300	848
Median age	48	63	48	39	69·3	63·2
'High' QOL (Scores=1)	56.0%	45·4%	50·6%	73·8%	32·0%	51·4%
'Medium' QOL (0.5≤Scores <1)	37.7%	45·6%	41·6%	25·2%	52·6%	44·3%
'Low' QOL (Scores <0·5)	6.3%	9·0%	7·8%	0·9%	10·5%	2·1%

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Title:

Patient Reported Outcomes of Cancer Survivors in England 1 to 5 years after Diagnosis: a cross-sectional survey.

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Key Words:

Cancer, Survivorship, Quality of Life, Patient Reported Outcomes, EQ5D, FACT

Word Count:

abstract: 304~~2~~ & main body of paper: 4486~~391~~

Abstract

Objectives: To determine the feasibility of collecting population based patient reported outcome measures (PROMS) in assessing quality of life (QoL) to inform development of a national PROMS programme for cancer and to begin to describe outcomes in a UK cohort of survivors.

Design: Cross-sectional postal survey of cancer survivors using a population-based sampling approach.

Setting: English National Health Service.

Participants: 4,992 breast, colorectal, prostate and Non-Hodgkin's Lymphoma survivors one to five years from diagnosis.

Primary and Secondary Outcome Measures: Implementation issues, response rates, cancer-specific morbidities utilising items including the EQ5D, tumour-specific sub-scales of the Functional Assessment of Cancer Therapy and Social Difficulties Inventory.

Results:

3,300 (66%) survivors returned completed questionnaires. The majority aged 85+ years did not respond and response rates were lower for those from more~~there was an effect of~~ deprived area~~ation on response rates~~. Response rates did not differ by gender, time since diagnosis or cancer type.

The presence of one or more long term conditions was associated with significantly lower QoL scores. Individuals from most deprived areas reported lower QoL scores and poorer outcomes on other measures, as did those self-reporting recurrent disease or uncertainty about disease status. QoL scores were compar~~st~~able at all time points for all cancers except NHL. QoL scores were lower than those from the general population in Health Survey for England (2008) and General Practice Patient Survey (2012).

47% of patients reported fear of recurrence whilst 20% reported moderate or severe difficulties with mobility or usual activities. Bowel and urinary problems were common among colorectal and prostate patients. Poor bowel and bladder control were significantly associated with lower QoL.

Conclusions: This method of assessing QoL of cancer survivors is feasible and acceptable to most survivors. Routine collection of national population- based PROMS will enable identification of, and support for, the specific needs of survivors whilst allowing for comparison of outcome by service provider.

Funding

This survey was funded by the Department of Health, England.

Article Summary

Article Focus

To determine the feasibility of routinely collecting population-based patient reported outcomes (PROMS) of cancer survivors to gather information on quality of life and cancer related morbidities that can be used to inform the development of a national PROMS programme for cancer.

Key messages

- Collection of population-based information on quality of life from cohorts of cancer patients who are 1 to 5 years post diagnosis through cancer registries is feasible.
- The best quality of life was reported by those in remission and with no other long term conditions.
- Information obtained by widespread extension of this methodology will enable health economies to compare outcome across provider organisations and facilitate provision of enhanced services to meet the needs of cancer survivors.

Strengths and Limitations

- Findings relate to the largest European survey of survivors of multiple cancer types at clearly defined time points from diagnosis.
- The study design eliminates many of the criticisms which have hindered the collection of population-based cancer patient reported outcome data in the past.
- English cancer registries provide a reliable denominator population from which to identify eligible participants.
- The questionnaires for the four cancer groups were identified as having face and content validity by a panel of health and social care professionals prior to use, following review by consumers and consultation with cancer charities.
- Presence of multiple cancer groups, time points and some missing data may have resulted in a lack of power for certain analyses.

- Selection bias may have arisen through differences in-response rates according to cancer group, deprivation category and age.
- The study excluded those treated in the private sector.

Introduction

1.8 million people are living with and beyond a diagnosis of cancer in England and prevalence is predicted to increase by 3% per annum.[1] Cancer treatments are effectively reducing mortality and extending life, yet there is evidence that physical, psychological and social needs are not being addressed by the health and social care services, with individuals reporting significant unmet needs[2]. There is a lack of robust population-based information from which the prevalence, and impact, of disease and treatment associated morbidity burden can be ascertained and policy for appropriate interventions developed[3]. It has been equally difficult for health economies to compare the quality of health of those following treatment for cancer to those living with other long term conditions (LTC). These deficits have hampered the provision of comprehensive robust services for this growing population[4].

In the United States a number of significant initiatives have been launched to systematically measure health outcomes in cancer survivors using patient reported outcome measures (PROMS) through the National Cancer Institute and American Cancer Society[3 5-6]. In Europe, at least one regional cancer register has started to collect PROMS via approaches made through the treating clinical teams[7-8] . The focus of PROMS work to date has been on refining treatment decision making for individuals and determining methodological approaches to implementation and analysis[5-6 9-11]. These efforts have yet to feed through into major national health system service improvement initiatives. The evaluation of patients' experiences of cancer care in England, through the National Cancer Patient Experience Survey, has resulted in care provider organisations and commissioners being able to identify areas of strengths and weakness in acute cancer care provision[12].

Our objective was to determine the feasibility of routinely collecting population-based PROMS of cancer survivors (via a postal survey of individuals identified from cancer registry information), without introduction from clinicians or researchers known to participants, to gather information on quality of life (QoL) and cancer related morbidities that can be used to inform the development of a national PROMS programme for cancer. Feasibility was assessed for example by evaluating response rates, level of questionnaire completeness and the number of complaints from participants. Findings reported in this paper are a summary of the analyses which are available in comprehensive form from the Department of Health (DH) website (https://www.wp.dh.gov.uk/publications/files/2012/12/9284-TSO-2900701-PROMS.pdf).

Methods

Study design

A cross-sectional postal survey was undertaken of individuals with a diagnosis of breast, colorectal, non-Hodgkin's lymphoma (NHL) or prostate cancer one, two, three and five years earlier. These four time-points were chosen to gain an understanding of whether PROMS varied over time. Patients attending private healthcare centres (estimated to be less than 5% of cases) were excluded as the aims of the study focused on the assessment of PROMS within the National Health Service (NHS) in England.

Cohort Identification and Survey Process

Three cancer registries (Thames Cancer Registry, Eastern Cancer Registry and Information Centre, West Midlands Cancer Intelligence Unit) were chosen as representative examples of the eight cancer registries in England. They provided information on all relevant cancer diagnoses[12] (Supplementary File 1) between 01/02/2010-30/04/2010, 01/02/2009-30/04/2009, 01/02/2008-30/04/2008, and 01/02/2006-30/04/2006. The individual study cohorts for each cancer at time points one, two, three and five years from date of recorded diagnosis were compiled through identification of the 312 cases diagnosed most closely to a specified time-point (First of February for each year). Cases were excluded if: under the age of 16 years, deceased, or not known to have a UK address.

Identified participants were sent a questionnaire by post by the survey provider, *Quality Health*. This was sent under cover of a standard introductory letter with the letter-head of the cancer centre most recently recorded by the cancer registry as having provided treatment. The survey covered patients attending 70 of 160 (43%) acute NHS Trusts delivering cancer care in England during 2011, although we were unable to determine whether these were representative of all patients. Patients consented to taking part in the survey by returning questionnaires and declined by not returning them, or by returning blank questionnaires. . Two reminders were sent to non-responders. Checks for deceased patients were undertaken by the registries at four separate time points in the survey process to ensure attempts were not made to contact deceased individuals.

Details of a dedicated freephone telephone helpline, staffed 24 hours each day, were provided so the queries of any respondents could be resolved.

Questionnaire design and content (Supplementary files 2, 3, 4 and 5)

Questionnaires were developed for each cancer group. Content was identified through literature review, commissioned expert reviews[13-15], consultation with patient groups, cancer charities and expert advisory groups. In this way the views of multi-professional clinicians and service users were captured.

Generic content included:

- Demographic and treatment-related questions adapted from the National Cancer Patient Experience Survey.[12]
- Self-reported response to treatment and disease status
- Amount of physical activity performed each week quantified according to the Chief Medical Officer of England's recommendations[16].
- Presence or absence of long-term conditions (LTCs) other than cancer, using a list widely used in English Department of Health surveys.
- EQ5D: A 5 item generic health-related quality of life measure[17-18] chosen as it is a generic measure of health status widely used to evaluate population health in England[17].
- Social Difficulties Inventory (SDI): A cancer survivor specific measure covering wider QoL domains[19-20,21] including information on the social consequences of cancer.
- Experience of care. Relevant items to these phases of the cancer pathway were taken from the National Cancer Patient Experience Survey Questionnaire.[22]
- Fear of recurrence and dying. These items were generated by the project team and cognitively tested on representative sample goups prior to this pilot survey.

- Individual components on psychological issues and work status identified through the literature as being important to cancer survivors but not covered by other components of the survey[23], [24].

Tumour-specific content included

- Functional Assessment of Cancer Therapy (FACT) tumour specific components (FACT-B, FACT-C , FACT-Lym and FACT-P for breast, colorectal, NHL and prostate cancer respectively)[25].

A detailed description of the qualitative comments provided by respondents are reported in a parallel submission to the BMJ Open.

Cognitive testing was performed on the four site-specific versions of the questionnaire prior to their general use. This was done by sending questionnaires to volunteers (identified through cancer charities and the survey provider) prior to participating in a telephone interview. This style of testing was used to determine the population's ability to complete the questionnaire independently and to follow routing and other instructions in the questionnaire without prompting or help. Appropriate alterations were then made to the questionnaire. The two required changes were omission of a similar item from the FACT-B and FACT-P questionnaires *"I am able to feel like a woman"* and *"I am able to feel like a man"*, because these questions were found to be confusing and unacceptable to volunteers.

Data Handling/Analysis

Age (at time of survey) was categorised as <55, 55-64, 65-74, 75-84, and ≥85 years. Self-reported ethnicity was grouped into white, asian, mixed, black and other. Deprivation category was based on the complete index of multiple deprivation (IMD)[26]. This was derived from the lower super output area (small census area) associated with their place of residence at the time of completing the survey, and used because the survey did not include questions related to income or educational level.

Participants were asked if they had any LTC other than their cancer diagnosis and were asked to tick the appropriate LTCs. This variable was categorised into 'no other', 'one other' and 'two or more LTCs'.

A crosswalk algorithm was used to convert the 5L EQ5D to the 3L version, allowing a weighted health score to be assigned for each individual.[27] United Kingdom population data were used to calculate weighted scores (range -0.5 to 1 [perfect health]). Due to skewness, this outcome variable was categorised and ordered logistic regression undertaken. Three categories representing 'high', 'medium' and 'low' QoL scores were defined for ease of interpretation; these comprised scores equal to 1, less than 1 but greater than or equal to 0.5 and less than 0.5. Odds ratios should be interpreted either as the odds of being in group 2 (medium QoL scores) or group 3 (low QoL scores) compared to group 1 (high QoL scores) *or* the odds of being in group 3 (low QoL scores) compared to group 1 or group 2. Although this was not a standard approach and meant that information and perhaps discriminatory power was lost, our model parameterisation enabled a more natural interpretation of EQ5D QoL data. Furthermore, when comparisons were made with other alternative models, such as tobit regression, findings were very similar.

Cancer-specific questions from FACT[25] were used as explanatory variables in this analysis (FACT total score could not be calculated as only the cancer-specific subscale questions were included). Patient reported treatments were used in the analyses and treatment combinations were categorised for each cancer site with the most common used as the reference group. Given the study design, participants who had survived a year or more and who reported still receiving treatments when they completed the survey were likely to be receiving treatment for advanced or recurrent disease.

Statistical methods

Chi-squared tests were used to compare categorical variables. Descriptive statistics were compared across cancer sites but the statistical models were stratified by cancer site. Variables were entered into the logistic regression model based on their *a priori* clinical and public health importance after agreement by the study investigators. Formal variable selection procedures were not invoked primarily due to statistical problems associated with these data-driven procedures[28] and, secondly, so that findings could be compared consistently across cancer sites and time points. Statistical significance was set at 1% to

minimise the chances of false-positive associations. All analyses were undertaken using STATA v12.1.

Ethics and governance

Approval was given to approach patients without informed consent by the National Information Governance Board (Supplementary File 6) as the study was performed as service evaluation[29].

Results

Participants

Questionnaires were sent to 4992 individuals, 126 (2·5%) of these had moved or died prior to receiving the questionnaire resulting in a final sample size of 4866. 3300 completed questionnaires were received (66% of the study sample). Of the surveys received by participants, the response rate was 68% (3300/4866).

Response rates

Response rate varied significantly between cancer groups (Table 1a): 69·4% in the prostate group compared to 62·3% in the NHL group (p<0.001).

There was significant difference in the age structure of the non-responders vs. responders with a higher proportion of non-responders in the ≥85 years age group (p<0·001).

Response rates differed according to deprivation status (Table 1a) with a response rate of 71·4% in the least deprived category compared to 57·1% in the most deprived category (p<0·001).

No difference in response rates by time since diagnosis, sex or cancer type was found (see https://www.wp.dh.gov.uk/publications/files/2012/12/9284-TSO-2900701-PROMS.pdf for full details).

Demographics of respondents (Table 1b)

Overall there were more males than females. Median age was 69 years (range 36-102). There was significant variation in the distribution of ethnicity by cancer group with higher proportions of non-white ethnic groups with NHL. There was no significant difference by deprivation between cancer groups. Overall more than half of patients reported having a LTC. There were fewer reported LTCs in the breast cohort than in other groups but this did not reach statistical significance.

Missing data

Missing data levels were extremely low, typically less than 5% for most fields. SDI had slightly higher levels of missing data with completeness ranging from 80-85%. For the regression modelling (Tables 3a-3d) which used complete case analysis approach, completeness levels were lower and ranged from 60% (colorectal, prostate) to 83% (breast). There was no evidence that the prevalence of missing data was related to the order of the questions after examining levels of completeness for questions at the beginning compared to the end of the form.

Helpline calls and other contact from survey participants

64 calls were made to the helpline, whilst further information about patient status was received via letters from patients (11) and NHS Trusts (2). The total number of enquiries was 77, representing 0.02% of the study cohort.

Generic PROMS

Responses for the five EQ5D questions demonstrated that a higher percentage of NHL patients reported problems with self-care, mobility and usual activities. Two-thirds of breast cancer patients reported some degree of pain (Supplementary Table 1).

When detailed responses for the five EQ5D questions were summarised by time since diagnosis, there were no significant differences for pain, mobility, usual activities or self-care. ~~but~~ However, the percentage reporting no anxiety or depression symptoms ~~de~~increased significantly from 55% at 1 year post-diagnosis to 66% after 5 years (p=0·01) (Supplementary Table 2).

Skewed weighted health scores were obtained from the EQ5D by cancer group (Supplementary Figure 1). The prostate group had significantly higher median (0·88) scores than the other three groups (0·84) (p=0·001). The proportion of the populations reporting high QoL scores ranged from 24·4% for breast to 40·0% for prostate cancer (Table 2). Conversely, the proportion reporting low QoL scores ranged from 8.9% for breast to 13.1% for NHL. For all tumour groups, irrespective of remission status, the percentage of

individuals reporting lower QoL scores increased as the number of other LTCs increased (Supplementary Tables 3-4).

Result by Tumour Type

Multivariable ordered logistic regression (Tables 3a-3d) identified three factors which were consistently associated with lower QoL scores irrespective of tumour type: presence of LTCs, undertaking little physical activity and self-reported disease status.

Breast Cancer (Table 3a)

Increasing number of LTCs, having recurrence of disease or being uncertain of disease status were associated with poorer outcomes across all three measures: The presence of one (OR 1·84, 95%CI 1·25,2·70) or two or more (Odds Ratio (OR) 7·30, 95%Confidence Interval (CI) 4·45,11·93) LTCs was significantly associated with lower QoL scores. Individuals self-reporting recurrent disease (OR 4·70, 95%CI 1·92,11·52) or those uncertain about their disease status (OR 2·51, 95%CI 1·27,4·96) were significantly more likely to report lower QoL scores compared to those self-reporting remission.

Increasing age (apart from those aged 85 years or older) and more days undertaking physical activity were significantly associated with better outcomes in EQ5D, SDI and FACT-B measures: Those aged 65-74 reported significantly higher QoL scores compared to under 55s (OR 0·36, 95%CI 0·22,0·58). Increasing physical activity was associated with higher QoL scores with each additional reported day per week of physical activity reducing the odds of a lower score by 12% (OR 0·88, 95%CI 0·82,0·95).

Individuals from the most deprived areas were significantly more likely to report lower EQ5D derived QoL scores than those from the most affluent areas (OR 3·00, 95%CI 1·64-5·50). Poorer outcomes in FACT-B items were associated with being in the most deprived category.

Colorectal Cancer (Table 3b)

The presence of one (OR 2·09, 95%CI 1·29,3·37) or two or more (OR 4·83, 95%CI 2·85,8·21) LTCs was significantly associated with lower QoL scores. Those who completed the

questionnaire whilst undergoing treatment (OR 7·03, 95%CI 2·44,20·21), experiencing recurrent disease (OR 4·56, 95%CI 1·54,13·49) or who were uncertain about their disease status (OR 2·67, 95%CI 1·23,5·79) had significantly increased odds of reporting lower QoL scores compared to those reporting remission.

Increasing physical activity was significantly associated with a 17% decrease in the odds of a lower QoL score with each additional day per week of physical activity (OR 0·83, 95%CI 0·76,0·90).

23·5% reported urinary leakage, 19·0% difficulty controlling their bowels and 19·2% had a stoma. Individuals experiencing any difficulty controlling their bowels were more than twice as likely to report lower QoL scores (OR 2·30, 95%CI 1·43,3·72). The presence of a stoma or urinary leakage was not significantly associated with QoL.

Greater difficulties with holidays and travel were reported by those with colorectal cancer compared to other cancers. For example, only 51% of colorectal respondents reporting no difficulty compared to 64% with breast or prostate cancer.

Non-Hodgkin's Lymphoma (Table 3c)

The presence of one (OR 2·16, 95%CI 1·44,3·24) or two or more (OR 7·26, 95%CI 4·51,11·69) LTCs was significantly associated with lower QoL scores. Those currently being treated (OR 2·57, 95%CI 1·52,4·33), experiencing a recurrence (OR 3·73, 95%CI 1·68,8·29) or who were not sure about their disease status (OR 3·04, 95%CI 1·58,5·84) had increased odds of reporting lower QoL scores compared to those in remission. These same factors were associated with poorer outcomes on the SDI and FACT-Lym items.

A significant positive association between increasing physical activity and QoL was seen with each additional day of physical activity reducing the odds of lower QoL score by 9% (OR 0·91, 95%CI 0·84,0·98). QoL seemed to improve with time from diagnosis for NHL but the trend was not significant (p=0·100).

Prostate Cancer (Table 3d)

The presence of two or more LTCs (OR 4·28, 95%CI 2·62,7·01) or being in the most deprived category (OR 2·57, 95%CI 1·31,5·04) were significantly associated with lower QoL scores, as well as increased social distress and difficulties identified by FACT-P.

Patients who had surgery only (compared to radiotherapy and hormone treatment) had significantly higher QoL scores (OR 0·39, 95%CI 0·21,0·71) as did those reporting more days of physical activity (OR 0·82, 95%CI 0·75,0·88).

38·5% of prostate patients reported some degree of urinary leakage, 12·9% reported difficulty controlling their bowels and 58·4% reported being unable to have an erection with a further 11% reporting significant difficulty in having or maintaining an erection. The presence of urinary leakage was significantly associated with lower QoL scores (OR 3·52, 5%CI 2·32,5·35). Erectile dysfunction and difficulty controlling bowels were not significantly associated with QoL scores.

Prostate survivors had significantly lower overall social distress scores on the SDI as well as fewer problems in all three sub-scales (everyday living, money matters, self and others) compared to other cancer types.

Fear of recurrence and dying

Almost half (47·3%) of patients reported fear of recurrence and over a quarter (26·8%) reported fear of dying (Supplementary Table 5). Both of these fears decreased significantly with time since diagnosis.

Physical activity

Around one-fifth (21·4%) of participants reported taking 30 minutes or more of physical activity at least five days a week (in line with the Chief Medical Officer’s recommendations). This varied by cancer: 16·5% for NHL, 19·0% for breast, 20·2% for colorectal and 29·0% for prostate. Overall 29·8% of patients reported doing no physical activity; this varied by cancer

group with 33·5% of NHL, 31·5% of colorectal and 27·4% of both breast and prostate survivors doing no physical activity.

Discussion

This study represents the largest European survey of survivors of multiple cancer types at clearly defined time points from diagnosis and demonstrates the feasibility of this straightforward method of collecting informative self-reported PROMS data on population-based cohorts of individuals living with and beyond a diagnosis of cancer in England. The process eliminates many of the potential biases that have hindered the collection of population-based cancer PROMS data in the past originating from the use of clinical trial data or acute service provider units for recruitment[30]. English cancer registries, which capture approximately 98-99% of all cancers diagnosed in England[31], provide a reliable denominator population from which to identify eligible participants.

Acceptability and Validity

The relatively high response rate, low level of missing data and low number of calls to the dedicated 24 hour helpline suggest that the methodology is acceptable to the majority of participants. However, the finding of lower participation amongst the elderly or those residing in areas with the greatest socio-economic deprivation would suggest that individuals from these vulnerable groups may need to be assessed by alternative methods. Whilst the questionnaires were identified as having face and content validity by a panel of health and social care professionals prior to use this study does not permit us to comment on the responsiveness or reliability of the instruments. However, the core components of the questionnaires had been identified by independent review as being reliable and appropriate for use in this setting[13-15].

Key results

The QoL of survivors for all four cancers was significantly related to self-reported disease status (remission versus relapse/uncertain), age and presence of LTCs. QoL appeared to either remain constant or improve slightly as time from diagnosis increased. This suggests that some problems experienced by cancer patients persist for long periods.

We have quantified the community prevalence of previously known late morbidities and assessed their impact on QoL. Problems relating to urinary and bowel control have been

shown to be common, with nearly 40% of prostate survivors reporting urinary leakage and 13% difficulty controlling their bowels. Similarly, amongst colorectal survivors nearly a quarter reported urinary leakage and 19% reported difficulty controlling their bowels. These rates are comparable to other studies of cancer patients[32] but exceed those seen in non-cancer populations where the prevalence of urinary incontinence in adult men was 4·5% overall, rising to 16·0% for over 75 year olds[33]. In this study, the presence of "urinary leakage" in prostate survivors and "of difficulty controlling their bowels" in colorectal survivors were significantly associated with lower QoL scores making such symptoms important to address. Erectile dysfunction in prostate survivors, though common, did not significantly impact on QoL. The finding that QoL or physical problems such as difficulty controlling bowels or incontinence do not appear to be less prevalent five years following treatment may suggest individuals are not receiving adequate help or treatment for these conditions. Greater efforts should be made in prevention and early intervention for problems resulting from cancer treatment, and directed at those most at risk of the long–term problems identified from this study.

Comparison with the General Population Data

Most survivors in this study who were in remission and did not report a LTC were found to have a high QoL score. However, even the subgroup in remission with no LTC reported lower QoL scores than the data available from general population studies (Table 4). Some of this difference may be accounted for by age, as the Health Survey for England (2008)[34] and the General Practice Patient Survey (GPPS)[35] cohorts were substantially younger than the reported cancer study cohort. This assumption is supported from the HSE cohort aged over 45 years (median age 63, n=7672) which reported a reduction in QoL scores (good 45%, moderate 46%, poor 9%).

Long-term Conditions

The presence of one or more LTCs, other than their cancer diagnosis, was associated with lower QoL scores in all four cancer groups and mirrors findings from other studies[2 36]. The presence of multi-morbidity and LTCs identifies sub-sets of survivors who may require more active support than others. This needs to be factored into risk stratification models as

health services move away from hospital based cancer follow-up towards a greater focus on self-management.

Physical Activity

The extent to which cancer survivors take physical activity has not previously been reported in England. The findings agree with those from the USA[37], suggesting that prostate survivors are more likely than others to take moderate or vigorous physical activity. We observed an association between higher levels of activity and higher QoL scores, but it is not possible to assess from a cross-sectional survey whether there is a causal relationship.

A smaller percentage of study respondents (21·4%) met the Chief Medical Officer of England's recommendations for physical activity when compared with the HSE(2008) in which 34% of adults met these guidelines[34]. Restricting the HSE data to a similar age profile as the study participants (60-75 years) saw similar levels of physical activity (23%). The HSE data found a trend of decreased physical activity with increasing age, yet, in this study, prostate survivors (the oldest subgroup) reported higher physical activity levels.

Limitations

The presence of multiple cancer groups and time points, along with some missing data (typically <5%), may have resulted in either a lack of power for certain analyses or type I errors (false positive results) due to the number of comparisons. For example, investigating whether the quality of life of those living with recurrent disease differed from those survivors who had been 'cured'. The non-response rate varied significantly by cancer group, deprivation category and age, which could result in selection bias when generalising results. To overcome bias associated with deprivation and age, we propose extension of the pilot study to the largest possible cohorts available nationally; analyses and interpretation of this data will be performed with maximum sensitivity to these areas.

Our study excluded those treated in the private sector (estimated to be under 5% of cancer cases in England[38]). Treatments may also have changed over the 1-5 year period used to select survivors and it is therefore possible the results reflect these changes.

The study relied on self-reporting of long-term conditions, response to treatment and disease status. This~~-~~ information was not independently verified.

~~The highly skewed EQ5D outcome variable was categorised into three levels for multivariable modelling, which is not a standard approach and meant that information and perhaps discriminatory power was lost. However, our model parameterisation enabled a more natural interpretation of EQ5D QoL data and when comparisons were made with other alternative models, such as tobit regression, findings were very similar.~~ We also acknowledge that measures related to the FACT component are primarily intended for use around the time of treatment rather than for survivorship work. Space limitations precluded a more detailed description of results incorporating the FACT and SDI components. However, a comprehensive report including these additional findings has been compiled and can be accessed via the DH website (https://www.wp.dh.gov.uk/publications/files/2012/12/9284-TSO-2900701-PROMS.pdf).

Where next for Cancer PROMS in England?

The use of cancer PROMS has generally been restricted to clinical research, especially clinical trials or small studies. Whilst important work has been undertaken to develop approaches for the measurement of PROMS, they have not been incorporated into routine measurement at a whole health system level. This study demonstrates that population-based survey approaches are feasible and yield acceptable response rates. This approach could provide important insights into where improvement efforts should be targeted to reduce the long-term burden of cancer and its treatments on the growing number of cancer survivors.

Improving QoL in patients with LTC is one of the key goals of English government health policy (forming Domain 2 of the NHS Outcomes Framework)[39]. The approach we report should be scaled up and integrated within routine health outcome assessment on a national basis so that results can be distilled down to hospital/service provider level, as has been done in relation to the experience of acute care of cancer patients[12]. Improvements in quality of survivor care could then be driven by publishing hospital/provider level data. As a result of the findings of this pilot, a national roll-out to all individuals diagnosed 1-3 years earlier with colorectal cancer in England is being performed in January 2013. A similar roll-out to those diagnosed with prostate cancer is planned whilst pilot questionnaires for those with bladder, cervical, endometrial and ovarian cancer are being prepared. To further understand the develomental trajectory of morbidity burden, a longitudinal survey of respondents to the pilot is being undertaken, with a survey 1 year on having been undertaken and consideration for a further data collection point after another 12 months.

Our findings support the on-going international efforts to identify risk factors for poor health-related QoL outcomes following a cancer diagnosis. These include the presence of other LTCs, deprivation and limited physical activity. These, along with the high prevalence of on-going condition-specific problems such as bowel, urinary and erectile dysfunction, warrant attention by cancer services.

Acknowledgements

Dr Nicola Davies, Professor Jane Maher, Dr Mick Peake, Professor Galina Velikova and Dr Penny Wright provided expert advice regarding questionnaire and study design. Thames Cancer Registry, Eastern Cancer Registry and Information Centre, and West Midlands Cancer Intelligence Unit provided information on all eligible cancer survivors. FACIT provided permission to use components of the FACT questionnaires and Penny Wright granted permission to use the Social Difficulties Inventory.

Funding

This survey was funded by the Department of Health, England.

Open source access for BMJ Open was funded through a grant from Macmillan Cancer Support.

Declaration of Competing Interests

All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: financial support for the submitted work from the Department of Health, England: AWG, GH and MR were employed by the Cancer Policy Team, Department of Health, England, whilst the research was carried out; AWG, LKF, RGF and EF, received financial support from Department of Health, England, to carry out the analysis of data reported; JC and MR co-chaired the Department of Health, England, Cancer Patient Experience Advisory Group.

Data Sharing Statement

Statistical code and dataset are available from the corresponding author at the University of Leeds, who will provide a permanent, citable and open access home for the dataset.

Author Contribution Statement

Adam Glaser contributed to the study design, data collection, data analysis, data interpretation and writing of this manuscript.

Lorna Fraser contributed to the data analysis, data interpretation and writing of this manuscript.

Jessica Corner contributed to the study design, data collection, data interpretation and writing of this manuscript.

Richard Feltbower contributed to the data analysis, data interpretation and writing of this manuscript.

Eva Morris contributed to the data analysis, data interpretation and writing of this manuscript.

Greg Hartwell contributed to the study design and data collection.

Mike Richards contributed to the study design, data interpretation, and writing of this manuscript.

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Table 1a Demographic data of responders and non-responders

Characteristic		Responders (n=3300)		Non Responders (n=1692)		Total number approached	Overall Percentage Responding
		n	%	*n*	*%*		
Cancer Group	**χ2=18.8, p<0·001**						
Breast		854	*25.9*	394	*23.3*	*1248*	*68.4*
Colorectal		802	*24.3*	446	*26.4*	*1248*	*64.3*
NHL		778	*23.6*	470	*27.8*	*1248*	*62.3*
Prostate		866	*26.2*	382	*22.5*	*1248*	*69.4*
Age	**χ2=108, p<0·001**						
under 55		467	*14·2*	282	*16.7*	*749*	*62.3*
55 to 64		692	*21·0*	335	*19.8*	*1027*	*67.4*
65 to 74		1,108	*33·6*	414	*24.5*	*1522*	*72.8*
75 to 84		835	*25·3*	434	*25.6*	*1269*	*65.8*
85+		198	*6·0*	227	*13.4*	*425*	*46.6*
IMD Category	**χ2=55.9, p<0.001**						
1 least deprived		826	*25·0*	331	*19.6*	*1157*	*71.4*
2		812	*24·6*	357	*21.1*	*1169*	*69.5*
3		703	*21·3*	349	*20.7*	*1052*	*66.8*
4		554	*16·8*	352	*20.7*	*906*	*61.1*
5 most deprived		399	*12·1*	300	*17.7*	*699*	*57.1*
Missing		6	*0·2*	*3*	*0.2*	*9*	*66.7*
Time since Diagnosis	**χ2=4.1, p=0·25**						
1 year		848	*25·7*	400	*23.6*	*1248*	*67.9*
2 years		834	*25·3*	414	*24.5*	*1248*	*66.8*
3 years		806	*24·4*	442	*26.1*	*1248*	*64.6*
5 years		812	*24·6*	436	*25.8*	*1248*	*65.1*

Table 1b. Demographic Data by Cancer Group

Characteristic		Breast (n=854)		Colorectal (n=802)		Non Hodgkin's Lymphoma (n=778)		Prostate (n=866)		Total (n=3300)	
		n	%	n	%	n	%	n	%	n	%
Sex	χ2=1700, p<0·001										
Male		10	*1·2*	435	*54·2*	419	*53·9*	848	*97·9*	1712	*51·9*
Female		829	*97·0*	348	*43·4*	352	*45·2*	0	*0*	1529	*46·3*
Missing		15	*1·8*	19	*2·4*	7	*0·9*	18	*2·1*	59	*1·8*
Age	χ2=401, p<0·001										
under 55		231	*27·0*	57	*7·1*	157	*20·2*	157	*18·1*	467	*14·2*
55 to 64		237	*27·8*	136	*17·0*	173	*22·2*	173	*20·0*	692	*21·0*
65 to 74		224	*26·2*	280	*34·9*	238	*30·6*	238	*27·5*	1,108	*33·6*
75 to 84		122	*14·3*	246	*30·7*	175	*22·5*	175	*20·2*	835	*25·3*
85+		40	*4·7*	83	*10·3*	35	*4·5*	35	*4·0*	198	*6·0*
Ethnicity	χ2=74·6, p<0·001										
White		768	*89·9*	740	*92·3*	688	*88·4*	786	*90·8*	2982	*90·4*
Asian		35	*4·1*	19	*2·3*	30	*3·9*	15	*1·7*	99	*3·0*
Black		14	*1·6*	11	*1·4*	21	*2·7*	36	*4·2*	82	*2·5*
Mixed		4	*0·5*	5	*0·6*	6	*0·8*	1	*0·1*	16	*0·5*
Other		4	*0·5*	0	*0*	4	*0·5*	3	*0·3*	11	*0·3*
Missing		29	*3·4*	27	*3·4*	29	*3·7*	25	*2·9*	110	*3·3*
IMD Category	χ2=4·3, p0·97										
1 least deprived		211	*24·7*	198	*24·7*	202	*26·0*	215	*24·8*	826	*25·0*
2		210	*24·6*	199	*24·8*	183	*23·5*	220	*25·4*	812	*24·6*
3		184	*21·5*	159	*19·8*	177	*22·7*	183	*21·1*	703	*21·3*
4		141	*16·5*	147	*18·3*	125	*16·1*	141	*16·3*	554	*16·8*
5 most deprived		104	*12·2*	98	*12·2*	91	*11·7*	106	*12·2*	399	*12·1*
Missing		4	*0·5*	1	*0·1*	0	*0*	1	*0·1*	6	*0·2*
Time since Diagnosis	χ2=5·5, p=0·78										
1 year		215	*25·2*	202	*25·2*	197	*25·3*	234	*27·0*	848	*25·7*
2 years		212	*24·8*	215	*26·8*	187	*24·0*	220	*25·4*	834	*25·3*
3 years		204	*23·9*	195	*24·3*	207	*26·6*	200	*23·1*	806	*24·4*
5 years		223	*26·1*	190	*23·7*	187	*24·0*	212	*24·5*	812	*24·6*
Other Long Term Health Condition	χ2=12·1, p=0·06										
Yes		435	*50·9*	432	*53·9*	435	*55·9*	501	*57·9*	1803	*54·6*
No		353	*41·3*	309	*38·5*	287	*36·9*	299	*34·5*	1248	*37·8*
Don't Know		30	*6·9*	23	*2·9*	33	*4·2*	27	*3·1*	113	*3·4*
Missing		36	*4·2*	38	*4·7*	23	*3·0*	39	*4·5*	136	*4·1*
Disease Status	χ2=390·0, p<0·001										
Remission		677	*79·3*	625	*77·9*	526	*67·6*	399	*46·1*	2227	*67·5*
Rx but present		26	*3·0*	32	*4·0*	81	*10·4*	144	*16·6*	283	*8·6*
Not treated		4	*0·5*	6	*0·7*	43	*5·5*	78	*9·0*	131	*4·0*

Recurrence		30	*3·5*	20	*2·5*	30	*3·9*	8	*0.9*	88	*2.6*
Not sure		58	*6·8*	69	*8·6*	53	*6·8*	140	*16·2*	320	*9·7*
Missing		59	*6·9*	50	*6·2*	45	*5·8*	97	*11·2*	251	*7·6*

Table 2. EQ5D outcome category by cancer sub-group

EQ5D Categories	'High' QoL (Scores=1)		Medium QoL (0.5≤Scores<1)		Low QoL (Scores<0.5)		Missing	
	n	%	n	%	n	%	n	%
Breast	208	*24·4*	514	*60·2*	76	*8·9*	56	*6·6*
Colorectal	255	*31·2*	434	*54·1*	87	*10·8*	26	*3·2*
Non Hodgkins Lymphoma	247	*31·7*	398	*51·2*	102	*13·1*	31	*4·0*
Prostate	347	*40·0*	390	*45·0*	81	*9·4*	48	*5·5*
Total	1057	*32·0*	1736	*52·6*	346	*10·5*	161	*4·9*

Table 3a. Ordered Logistic Regression Model EQ5D in Breast Cancer Patients [n=709, pseudoR^2=0·16 p<0·001]

Characteristic		Odds Ratio*	95% CI		P value
Age (years)					
	<55 years	REF			
	55-64	0·69	0·45	1·06	0·09
	65-74	0·36	0·22	0·58	<0·001
	75-84	0·59	0·32	1·08	0·09
	85+	1·61	0·57	4·52	0·36
Deprivation					
	1 least deprived	REF			
	2	1·03	0·66	1·62	0·88
	3	1·10	0·68	1·77	0·71
	4	0·93	0·55	1·56	0·78
	5 most deprived	3·00	1·64	5·50	<0·001
Physical Activity†		0·88	0·82	0·95	<0·001
Number of other LTC (excl BP)					
	0	REF			
	1	1·84	1·25	2·70	0·002
	2+	7·30	4·45	11·93	<0·001
Treatment*					
	Radio+Chemo+Surgery+Hormone	REF			
	Radio +Chemo+Surgery	0·67	0·38	1·20	0·18
	Radio+Surgery	0·51	0·29	0·90	0·02
	Radio+Surgery+Hormone	0·56	0·33	0·96	0·04
	Surgery only	1·00	0·55	1·84	0·99
	Other	0·92	0·53	1·58	0·76
Ethnicity					
	White	REF			
	Mixed	0·50	0·06	4·29	0·53
	Asian	1·96	0·77	5·01	0·16
	Black	0·29	0·08	0·98	0·05
	Other	2·20	0·17	29·32	0·55
Disease Status					
	Remission	REF			
	Rx but present	1·49	0·56	3·93	0·43
	Not Treated	·	·	·	·
	Recurrence	4·70	1·92	11·52	0·001
	Not sure	2·51	1·27	4·96	0·008
Time since Diagnosis					
	1 year	REF			
	2 years	1·02	0·64	1·62	0·95
	3 years	0·88	0·55	1·41	0·60
	5 years	0·93	0·59	1·47	0·76

*Odds of reporting 'medium' or 'low' QoL EQ5D scores compared to 'high' QoL scores where 'high', 'medium' and 'low' QoL was defined as scores=1, 0.5≤scores<1 and scores<0.5 respectively.

†Amount of physical activity performed each week quantified according to the Chief Medical Officer of England's recommendations[16]

Table 3b. Ordered Logistic Regression Model EQ5D in Colorectal Patients [n=485, pseudoR2=0·18, p<0·001]

Characteristic	**Odds Ratio**	**95% CI**		**P value**
Age (years)				
<55 years	REF			
55-64	1·28	0·59	2·75	0·53
65-74	1·16	0·57	2·35	0·69
75-84	1·23	0·57	2·64	0·59
85+	2·45	0·93	6·41	0·07
Sex				
Male	REF			
Female	1·22	0·81	1·82	0·34
Deprivation				
1 least deprived	REF			
2	0·83	0·48	1·43	0·50
3	0·57	0·33	1·00	0·05
4	0·62	0·34	1·13	0·12
5 most deprived	1·17	0·58	2·34	0·66
Physical Activity†	0·83	0·76	0·90	<0·001
Number of other LTC(excl BP)				
0	REF			
1	2·09	1·29	3·37	<0·001
2+	4·83	2·85	8·21	<0·001
Treatment*				
Surgery only	REF			
Radio+Chemo+Surgery	1·15	0·60	2·21	0·67
Chemo+Surgery	1·35	0·85	2·17	0·21
Other	1·58	0·77	3·22	0·21
Ethnicity				
White	REF			
Mixed	1·72	0·24	12·42	0·59
Asian	1·99	0·46	8·54	0·36
Black	1·14	0·26	4·92	0·86
Other	1·72	0·24	12·42	0·59
Disease Status				
Remission	REF			
Rx but present	7·03	2·44	20·21	<0·001
Not treated	0·16	0·01	2·63	0·20
Recurrence	4·56	1·54	13·49	0·01
Not sure	2·67	1·23	5·79	0·01
Stoma				
No	REF			
Yes	1·32	0·80	2·19	0·27
Difficulty Controlling Bowels				
No	REF			
Yes	2·30	1·43	3·72	<0·001
Leak Urine				
No	REF			
Yes	1·41	0·87	2·30	0·16
Time since Diagnosis				
1 year	REF			
2 years	0·72	0·42	1·22	0·22
3 years	1·03	0·59	1·81	0·92
5 years	0·85	0·49	1·48	0·56

*Odds of reporting ‘medium’ or ‘low’ QoL EQ5D scores compared to ‘high’ QoL scores where ‘high’, ‘medium’ and ‘low’ QoL was defined as scores=1, 0.5≤scores<1 and scores<0.5 respectively.

†Amount of physical activity performed each week quantified according to the Chief Medical Officer of England’s recommendations[16]

Table 3c. Ordered Logistic Regression Model EQ5D in NHL Patients [n=614, pseudoR2=0·15 p<0·001]

Characteristic	Odds Ratio	95% CI		P value
Age (years)				
<55 years	REF			
55-64	0·89	0·55	1·45	0·65
65-74	1·23	0·75	1·99	0·41
75-84	1·60	0·94	2·73	0·08
85+	2·13	0·84	5·39	0·11
Sex				
Male	REF			
Female	1·25	0·89	1·74	0·19
Deprivation				
1 least deprived	REF			
2	1·06	0·67	1·69	0·80
3	1·21	0·75	1·95	0·43
4	1·64	0·97	2·76	0·07
5 most deprived	1·19	0·65	2·21	0·57
Physical Activity†	0·91	0·84	0·98	0·01
Number of other LTC (excluding BP)				
0	REF			
1	2·16	1·44	3·24	<0·001
2+	7·26	4·51	11·69	<0·001
Treatment*				
Chemo only	REF			
Radio+Chemo	0·81	0·47	1·41	0·46
Chemo + Antibody	0·93	0·55	1·59	0·80
Radio+Chemo+Other	1·55	0·87	2·77	0·14
Other	0·96	0·63	1·46	0·86
Ethnicity				
White	REF			
Mixed	2·78	0·28	27·7	0·38
Asian	0·68	0·29	1·59	0·38
Black	0·91	0·33	2·49	0·85
Other	0·61	0·09	4·39	0·62
Disease Status				
Remission	REF			
Rx but present	2·57	1·52	4·33	<0·001
Not treated	0·83	0·17	3·96	0·82
Recurrence	3·73	1·68	8·29	0·001
Not sure	3·04	1·58	5·84	0·001
Time since Diagnosis				
1 year	REF			
2 years	0·62	0·38	0·99	0·05
3 years	0·60	0·38	0·96	0·03
5 years	0·57	0·36	0·90	0·02

*Odds of reporting ‘medium’ or ‘low’ QoL EQ5D scores compared to ‘high’ QoL scores where ‘high’, ‘medium’ and ‘low’ QoL was defined as scores=1, 0.5≤scores<1 and scores<0.5 respectively.

†Amount of physical activity performed each week quantified according to the Chief Medical Officer of England’s recommendations[16]

Table 3d. Ordered Logistic Regression Model EQ5D in Prostate Patients [n=524, pseudoR2=0·22 p<0·001]

Characteristic	Odds Ratio	95% CI		P value
Age (years)				
<55 years	REF			
55-64	1·32	0·41	4·30	0·64
65-74	1·72	0·55	5·38	0·36
75-84	1·32	0·41	4·30	0·64
85+	1·92	0·42	8·78	0·40
Deprivation				
1 least deprived	REF			
2	1·09	0·64	1·85	0·74
3	1·19	0·68	2·08	0·55
4	1·61	0·88	2·95	0·13
5 most deprived	2·57	1·31	5·04	0·01
Physical Activity†	0·82	0·75	0·88	<0·001
Number of other LTC(excl BP)				
0	REF			
1	1·55	0·94	2·54	0·09
2+	4·28	2·62	7·01	<0·001
Treatment*				
Radio+Hormone	REF			
Surgery only	0·39	0·21	0·71	<0·001
Hormone only	1·68	0·85	3·33	0·14
Radio only	0·94	0·53	1·66	0·83
Active surveillance only	1·16	0·47	2·88	0·75
Other	·	·	·	·
Ethnicity				
White	REF			
Mixed	3·82	0·07	203·44	0·51
Asian	3·21	0·56	18·49	0·19
Black	2·54	0·96	6·73	0·06
Other	0·00	0·00	·	0·98
Disease Status				
Remission	REF			
Rx but present	1·75	0·94	3·26	0·08
Not treated	1·06	0·37	3·05	0·91
Recurrence	1·71	0·17	16·91	0·65
Not sure	1·48	0·85	2·58	0·17
Urinary Leakage				
No	REF			
Yes	3·52	2·32	5·35	<0·001
Erectile Dysfunction				
No	REF			
Yes	1·46	0·96	2·23	0·08
Difficulty Controlling Bowels				
No	REF			
Yes	1·62	0·90	2·92	0·10
Time since Diagnosis				
1 year	REF			
2 years	0·83	0·50	1·40	0·49
3 years	0·80	0·47	1·36	0·41
5 years	0·77	0·45	1·33	0·36

*Odds of reporting ‘medium’ or ‘low’ QoL EQ5D scores compared to ‘high’ QoL scores where ‘high’, ‘medium’ and ‘low’ QoL was defined as scores=1, $0.5 \leq$scores<1 and scores<0.5 respectively.

†Amount of physical activity performed each week quantified according to the Chief Medical Officer of England’s recommendations[16]

Table 4. Comparison of Quality of Life scores with other population data

	Health Survey for England (HSE 2008)[34]		GP Population Survey (GPPS)[35]	GP Population Survey (GPPS)[35]	This survey	
	All ages	Ages≥ 45 years	All	No LTC	All	In remission with no LTC
Number of respondents	14116	7672	426933	193285	3300	848
Median age	48	63	48	39	69·3	63·2
'High' QOL (Scores=1)	56.0%	45·4%	50·6%	73·8%	32·0%	51·4%
'Medium' QOL (0.5≤Scores <1)	37.7%	45·6%	41·6%	25·2%	52·6%	44·3%
'Low' QOL (Scores <0·5)	6.3%	9·0%	7·8%	0·9%	10·5%	2·1%

Supplementary Table 1. Quality of Life Dimension Results (EQ5D) by Cancer Sub group

EQ5D dimension		**Breast (n=854)**		**Colorectal (n=802)**		**Non Hodgkin's Lymphoma (n=778)**		**Prostate (n=866)**		**Total (n=3300)**	
		n	***%***	**n**	***%***	**n**	***%***	**n**	***%***	**n**	***%***
Mobility χ2=51·3, p<0·001	No Problems	567	*66·4*	442	*55·1*	427	*54·9*	535	*61·8*	1971	*59·7*
	Slight Problems	105	*12·3*	159	*19·8*	140	*18·0*	131	*15·1*	535	*16·2*
	Moderate Problems	107	*12·5*	120	*15·0*	120	*15·4*	97	*11·2*	444	*13·5*
	Severe Problems	46	*5·4*	57	*7·1*	71	*9·1*	69	*8·0*	243	*7·4*
	Cannot walk	8	*0·9*	13	*1·6*	6	*0·8*	4	*0·4*	31	*0·9*
	Missing	21	*2·5*	11	*1·4*	14	*1·8*	30	*3·5*	76	*2·3*
Self Care χ2=30·4, p=0·002	No Problems	716	*83·8*	651	*81·2*	611	*78·5*	704	*81·3*	2682	*81·3*
	Slight Problems	47	*5·5*	67	*8·4*	66	*8·5*	78	*9·0*	258	*7·8*
	Moderate Problems	45	*5·3*	46	*5·7*	71	*9·1*	44	*5·1*	206	*6·2*
	Severe Problems	12	*1·4*	18	*2·2*	12	*1·5*	9	*1·0*	51	*1·5*
	Cannot wash/dress	6	*0·7*	9	*1·1*	4	*0·5*	4	*0·5*	23	*0·7*
	Missing	28	*3·3*	11	*1·4*	14	*1·8*	27	*3·1*	80	*2·4*
Usual Activities χ2=34·5, p<0·001	No Problems	513	*60·1*	429	*53·5*	411	*52·8*	533	*61·5*	1886	*57·2*
	Slight Problems	162	*19·0*	173	*21·6*	156	*20·1*	145	*16·7*	636	*19·3*
	Moderate Problems	111	*13·0*	113	*14·1*	127	*16·3*	104	*12·1*	455	*13·7*
	Severe Problems	31	*3·6*	48	*6·0*	49	*6·3*	43	*5·0*	171	*5·2*
	Cannot do usual activities	14	*1·6*	24	*3·0*	26	*3·3*	15	*1·7*	79	*2·4*
	Missing	23	*2·7*	15	*1·8*	9	*1·2*	26	*3·0*	73	*2·2*
Pain χ2=134·3, p<0·001	No Pain	329	*38·5*	429	*53·5*	408	*52·4*	526	*60·7*	1692	*51·3*
	Slight Pain	341	*39·9*	220	*27·4*	180	*23·1*	169	*19·5*	910	*27·6*
	Moderate Pain	113	*13·2*	92	*11·5*	120	*15·4*	101	*11·7*	426	*12·9*
	Severe Pain	39	*4·6*	35	*4·4*	51	*6·6*	38	*4·4*	163	*4·9*
	Extreme Pain	5	*0·6*	9	*1·1*	10	*1·3*	3	*0·3*	27	*0·8*
	Missing	27	*3·2*	17	*2·1*	9	*1·2*	29	*3·3*	82	*2·5*
Anxiety/ depression χ2=37·1, p<0·001	No anxiety/depression	475	*55·6*	504	*62·8*	464	*59·6*	566	*65·4*	2009	*60·9*
	Slight anxiety/depression	241	*28·2*	196	*24·4*	186	*23·9*	183	*21·1*	806	*24·4*
	Moderate anxiety/depression	78	*9·1*	78	*9·7*	83	*10·7*	76	*8·8*	315	*9·5*
	Severe anxiety/depression	21	*2·5*	6	*0·8*	21	*2·7*	8	*0·9*	56	*1·7*
	Extreme anxiety/depression	10	*1·2*	4	*0·5*	8	*1·0*	4	*0·5*	26	*0·8*
	Missing	29	*3·4*	14	*1·8*	16	*2·1*	29	*3·3*	88	*2·7*

Supplementary Table 2 Quality of Life Dimension Results (EQ5D) by time since diagnosis of cancer

		1 year (n=848)		2 years (n=834)		3 years (n=806)		5 years (n=812)		Total (n=3300)	
		N	%	N	%	N	%	N	%	N	%
Mobility	No Problems	521	*61.4*	501	*60.1*	486	*60.3*	463	*57.0*	1971	*59.7*
χ2=21.1, p=0.05	Slight Problems	150	*17.7*	123	*14.7*	127	*15.8*	135	*16.6*	535	*16.2*
	Moderate Problems	93	*11.0*	116	*13.9*	104	*12.9*	131	*13.1*	444	*13.5*
	Severe Problems	62	*7.3*	62	*7.4*	56	*6.9*	63	*7.8*	243	*7.4*
	Cannot walk	2	*0.2*	8	*9.6*	13	*1.6*	8	*1.0*	31	*0.9*
	Missing	20	*2.4*	24	*2.9*	20	*2.5*	12	*1.5*	76	*2.3*
Self Care	No Problems	696	*82.1*	674	*80.8*	659	*81.8*	653	*80.4*	2682	*81.3*
χ2=10.2, p=0.59	Slight Problems	59	*6.9*	65	*7.8*	61	*7.6*	73	*9.0*	258	*7.8*
	Moderate Problems	57	*6.7*	56	*6.7*	42	*5.2*	51	*6.3*	206	*6.2*
	Severe Problems	12	*1.4*	12	*1.4*	14	*1.7*	13	*1.6*	51	*1.5*
	Cannot wash/dress	3	*0.4*	4	*0.5*	10	*1.2*	6	*0.7*	23	*0.7*
	Missing	21	*2.5*	23	*2.8*	20	*2.5*	16	*2.0*	80	*2.4*
Usual Activities	No Problems	465	*54.8*	474	*56.8*	465	*57.7*	482	*59.4*	1886	*57.2*
χ2=13.9, p=0.31	Slight Problems	181	*21.3*	157	*18.8*	161	*20.0*	137	*16.9*	636	*19.3*
	Moderate Problems	131	*15.4*	112	*13.4*	95	*11.8*	117	*14.4*	455	*13.7*
	Severe Problems	35	*4.1*	45	*5.4*	44	*5.5*	47	*5.8*	171	*5.2*
	Cannot do usual activities	18	*2.1*	19	*2.3*	23	*2.8*	19	*2.3*	79	*2.4*
	Missing	18	*2.1*	27	*3.2*	18	*2.2*	10	*1.2*	73	*2.2*
Pain	No Pain	421	*49.6*	412	*49.4*	435	*54.0*	424	*52.2*	1692	*51.3*
χ2=18.0, p=0.12	Slight Pain	262	*30.9*	237	*28.4*	198	*24.6*	213	*26.2*	910	*27.6*
	Moderate Pain	101	*11.9*	112	*13.4*	105	*13.0*	108	*13.3*	426	*12.9*
	Severe Pain	34	*4.0*	44	*5.3*	38	*4.7*	47	*5.8*	163	*4.9*
	Extreme Pain	7	*0.8*	6	*0.7*	11	*1.4*	3	*0.4*	27	*0.8*
	Missing	23	*2.7*	23	*2.8*	19	*2.4*	17	*2.1*	82	*2.5*
Anxiety/depression	No anxiety/depression	466	*55.0*	505	*60.6*	499	*61.9*	539	*66.4*	2009	*60.9*
χ2=25.8, p=0.01	Slight anxiety/depression	244	*28.8*	195	*23.4*	196	*24.3*	171	*21.1*	806	*24.4*
	Moderate anxiety/depression	88	*10.4*	86	*10.3*	68	*8.4*	73	*9.0*	315	*9.5*
	Severe anxiety/depression	20	*2.4*	13	*1.5*	13	*1.6*	10	*1.2*	56	*1.7*
	Extreme anxiety/depression	6	*0.7*	8	*1.0*	6	*0.7*	6	*0.7*	26	*0.8*
	Missing	24	*2.8*	27	*3.2*	24	*3.0*	13	*1.6*	88	*2.7*

Supplementary Table 3. EQ5D outcome category by the number of Long Term Conditions (LTC) in patients in remission

EQ5D Categories	High QoL (Scores=1)		Medium QoL (0.5≤Scores<1)		Low QoL (Scores<0.5)		Missing		Total
	n	%	n	%	n	%	n	%	
No LTC	436	51·4	376	44·3	18	2·1	18	2·1	848
1 LTC	250	36·2	378	54·7	40	5·8	23	3·3	691
≥2 LTC	129	18·8	419	60·9	119	17·3	21	3·1	688
Total	815	36·6	1,173	52·7	177	7·9	62	2·8	2,227

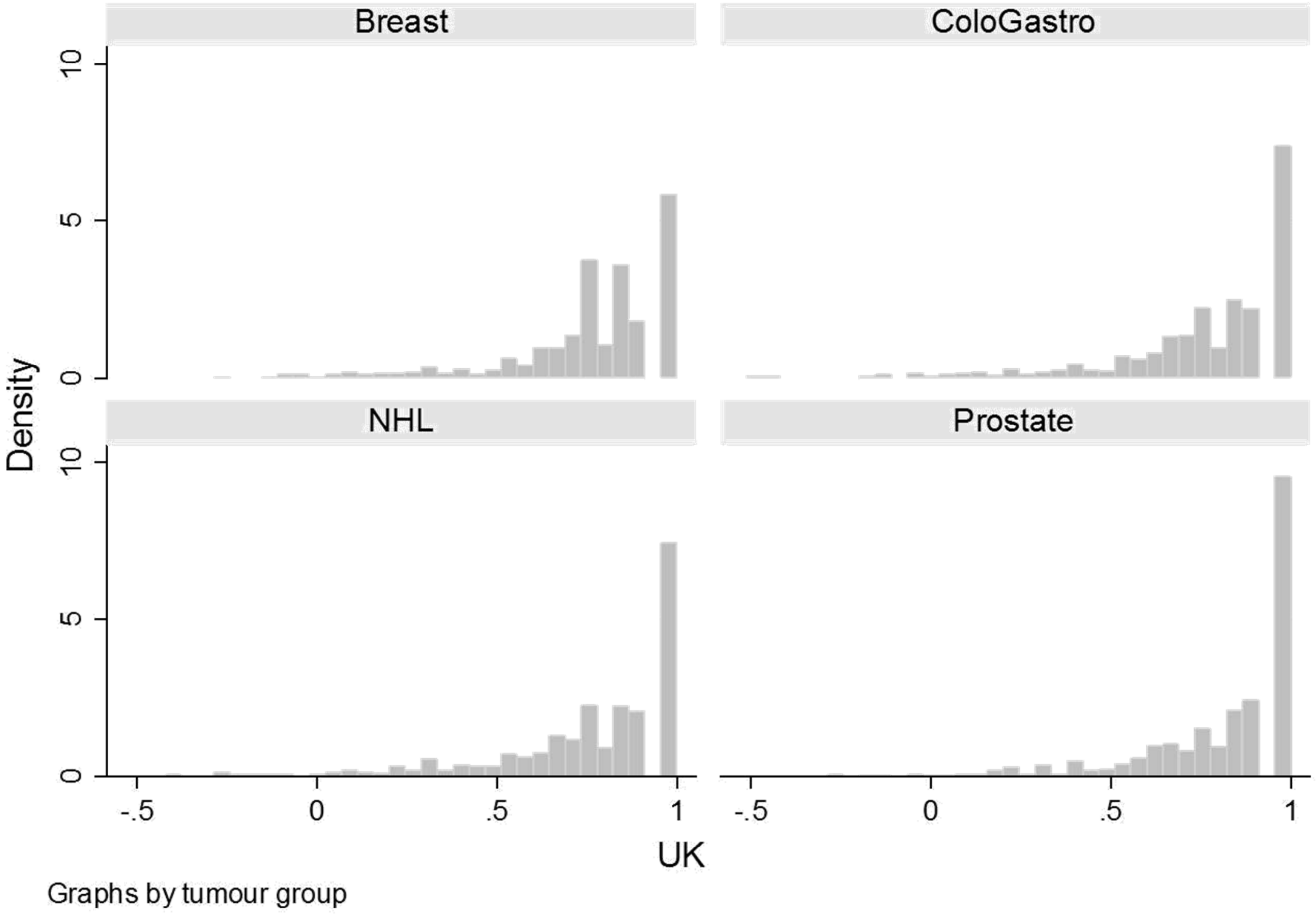
Supplementary Table 4. EQ5D outcome category by the number of Long Term Conditions (LTC) in patients not in remission

EQ5D Categories	High QoL (Scores=1)		Medium QoL (0.5≤Scores<1)		Low QoL (Scores<0.5)		Missing		Total
	n	%	n	%	n	%	n	%	
No LTC	79	33·9	130	55·8	15	6·4	9	3·9	233
1 LTC	64	23·1	175	63·2	25	9·0	13	4·7	277
≥2 LTC	37	11·9	166	53·2	94	30·1	15	4·8	312
Total	180	21·9	471	57·3	134	16·3	37	4·5	822

Supplementary Table 5. Fear of Dying and Recurrence of Disease by Time since Diagnosis

Fear of Dying	Yes%		No		Missing		Total
	n	%	n	%	n	%	
1 year ago	256	*30·2*	542	*63·9*	50	*5·9*	848
2 years ago	233	*27·9*	543	*65·1*	58	*7·0*	834
3 years ago	214	*26·6*	531	*65·9*	61	*7·6*	806
5 years ago	180	*22·2*	583	*71·8*	49	*6·0*	812
Total	883	*26·8*	2,199	*66·6*	218	*6·6*	3,300
Fear of Recurrence	n	%	n	%	n	%	
1 year ago	437	*51·5*	369	*43·5*	42	*5·0*	848
2 years ago	403	*48·3*	398	*47·7*	33	*4·0*	834
3 years ago	376	*46·7*	384	*47·6*	46	*5·7*	806
5 years ago	345	*42·5*	427	*52·6*	40	*4·9*	812
Total	1,561	*47·3*	1,578	*47·8*	161	*4·9*	3,300

Supplementary Figure 1. Distribution of EQ5D summary scores by cancer sub-type



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Supplementary File 1	**ICD10 Codes included in the Study**
Breast Cancer	ICD10 Codes C50 & D05
Colorectal/Lower G.I.	ICD10 Codes C18, C19, C20, and C21
Non-Hodgkin's Lymphoma	ICD10 Codes C82, C83, C84 & C85
Prostate	ICD10 Code C61

Living with and beyond Breast Cancer

This questionnaire is about your health and quality of life since being diagnosed with your cancer. Its purpose is to provide information which can help the NHS monitor and improve the quality of health services for future patients.

Who should complete the questionnaire?
The questions should be answered by the person named in the letter enclosed with this questionnaire. If that person needs help to complete the questionnaire, the answers should be given from their point of view – not the point of view of the person who is helping.

Completing the questionnaire
For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please **do not** write your name or address anywhere on the questionnaire.

IMPORTANT INFORMATION

To make sure the information we collect is useful, we need to collect some personal details from you and to access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the quality of life for people who are living with and beyond cancer. These statistics will be used to compare the differences in quality of life for people treated for different types of cancer by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:

- Your personal details and relevant health information can be held and used by an organisation contracted to the Department of Health to analyse the data
- Other information about you held by the Patient Demographics Service, the Secondary Users Service, Cancer Registries and other NHS databases can be held and used by an organisation contracted to the Department of Health to analyse the data
- Your personal details can be used to send you related follow-up questionnaires in the future

Your personal information will be handled securely and anonymised after analysis and before any publication.

Your personal information will not be released by the Department of Health or third party organisations working on its behalf unless required by law or where there is a clear overriding public interest.

You can withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

If you have any queries about the questionnaire,
please call the FREEPHONE helpline number **on 0800 783 1775**

Taking part in this survey is voluntary
Published reports will not contain any personal details

YOUR HEALTH TODAY

The questions in this section are all about your health and how you feel on the day you complete this questionnaire.

1. What treatments have you received for your breast cancer? **(Tick all that apply)**

1 ☐ Radiotherapy

2 ☐ Chemotherapy (excluding hormone treatment)

3 ☐ Hormone treatment

4 ☐ Surgery

2. How long is it since you completed your **initial treatment** for breast cancer? *Treatment includes any chemotherapy, radiotherapy, or surgery for your breast cancer. When answering this question please do not include hormone treatments such as Tamoxifen.*

1 ☐ I am still having my initial treatment

2 ☐ It is less than 3 months since my initial treatment

3 ☐ It is between 3 and 12 months since my initial treatment

4 ☐ It is between 1 and 5 years since my initial treatment

5 ☐ It is more than 5 years since my initial treatment

6 ☐ Don't know / can't remember

3. How has your breast cancer responded to treatment?

1 ☐ My breast cancer has responded fully to treatment (I am in remission)

2 ☐ My breast cancer has been treated but is still present

3 ☐ My breast cancer has not been treated at all

4 ☐ My breast cancer has come back after it was originally treated

5 ☐ I am not certain what is happening with my breast cancer

4. If you have had breast surgery, do any of the following apply to you? **(Tick all that apply)**

1 ☐ I have had a lumpectomy

2 ☐ I have had a mastectomy

3 ☐ I have had breast reconstruction

4 ☐ I am awaiting or considering breast reconstruction

5 ☐ None of these apply to me

YOUR HEALTH TODAY

Under each heading, please tick the ONE box that best describes your health TODAY.

5. MOBILITY

I have no problems in walking about ☐1
I have slight problems in walking about ☐2
I have moderate problems in walking about ☐3
I have severe problems in walking about ☐4
I am unable to walk about ☐5

6. SELF CARE

I have no problems washing or dressing myself ☐1
I have slight problems washing or dressing myself ☐2
I have moderate problems washing or dressing myself ☐3
I have severe problems washing or dressing myself ☐4
I am unable to wash or dress myself ☐5

7. USUAL ACTIVITIES *(work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ☐1
I have slight problems doing my usual activities ☐2
I have moderate problems doing my usual activities ☐3
I have severe problems doing my usual activities ☐4
I am unable to do my usual activities ☐5

8. PAIN / DISCOMFORT

I have no pain or discomfort ☐1
I have slight pain or discomfort ☐2
I have moderate pain or discomfort ☐3
I have severe pain or discomfort ☐4
I have extreme pain or discomfort ☐5

9. ANXIETY / DEPRESSION

I am not anxious or depressed ☐1
I am slightly anxious or depressed ☐2
I am moderately anxious or depressed ☐3
I am severely anxious or depressed ☐4
I am extremely anxious or depressed ☐5

YOUR HEALTH AND WELLBEING IN THE LAST 7 DAYS

The questions in this section are about your health and how you have felt in the past 7 days.

Please mark one box per line to give your response.

	During the past 7 days:	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
10.	I have been short of breath	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
11.	I am self conscious about the way I dress	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
12.	One or both of my arms are swollen or tender	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
13.	I feel sexually attractive	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
14.	I am bothered by hair loss	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
15.	I worry that other members of my family might someday get the same illness I have	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
16.	I worry about the effect of stress on my illness	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
17.	I am bothered by a change in weight	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
18.	I have certain parts of my body where I experience pain	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

19. In the **past week**, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your heart rate? *This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that is part of your job.*

None	**I day**	**2 days**	**3 days**	**4 days**	**5 days**	**6 days**	**7 days**
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These might be to do with things like their family life, social activities, finances and work.

Please tick the response that best describes your answer.

	During the past month:	**No difficulty**	**A little**	**Quite a bit**	**Very much**	**Does not apply**
20.	Have you had any difficulty in maintaining your independence?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
21.	Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
22.	Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
23.	Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
24.	Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
25.	Have you had any difficulty with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
26.	Have you had any financial difficulties?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
27.	Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
28.	Have you had any difficulty concerning your work? (or education if you are a student)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
29.	Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

	During the past month:	No difficulty	A little	Quite a bit	Very much	Does not apply
30.	Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
31.	Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
32.	Have you had any difficulty concerning sexual matters?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
33.	Have you had any difficulty concerning plans to have a family?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
34.	Have you had any difficulty concerning your appearance or body image?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
35.	Have you felt isolated?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
36.	Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
37.	Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
38.	Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
39.	Have you had any difficulty with your plans to travel or take a holiday?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
40.	Have you had any difficulty with any other area of your everyday life?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Please tick the response that best describes your answer.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply to me
41. I have fears about my cancer spreading	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	6 ☐
42. I have fears about my cancer coming back	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	6 ☐
43. I have fears about death and dying	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
44. I experience memory loss	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
45. I have trouble sleeping	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
46. I have trouble concentrating	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
47. I always feel tired	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
48. I experience mood swings	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
49. I am often irritable	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	

OVERALL SUPPORT AND CARE

50. Do you have an up-to-date written care plan? *A care plan is a document that sets out your needs and goals for caring for your cancer.*

1 ☐ Yes, definitely
2 ☐ Yes, I think so
3 ☐ No
4 ☐ I do not need a care plan
5 ☐ Don't know

51. Do you have a named nurse who you can contact if you have a worry about your cancer care? *A named nurse is sometimes known as a Clinical Nurse Specialist or Specialist Cancer Nurse.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know

52. Do you know who to contact if you have a concern about any aspect of living with or after cancer?

1 ☐ Yes, definitely
2 ☐ Yes, I think so
3 ☐ No

53. Do you think that hospital staff did everything they could to support you following your cancer treatment?

1 ☐ Yes, all of the time
2 ☐ Only some of the time
3 ☐ Never
4 ☐ I did not need any support

54. Do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?

1 ☐ Yes, all of the time
2 ☐ Only some of the time
3 ☐ Never
4 ☐ My general practice is not involved
5 ☐ I do not need any support

55. Following your initial cancer treatment have you been given enough care and help from health and social services (for example, district nurses, home helps or occupational therapists)?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not need help from health or social services
5 ☐ Don't know / can't remember

56. Would it have been helpful to have had more advice or information on any of the following issues: **(Tick all that apply)**

1 ☐ Diet and lifestyle
2 ☐ Physical activity and exercise
3 ☐ Financial help or benefits
4 ☐ Free prescriptions
5 ☐ Returning to or staying in work
6 ☐ Information / advice for family / friends / carer
7 ☐ The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)
8 ☐ The psychological or emotional aspects of living with and after cancer
9 ☐ I have all the information and advice I need

ABOUT YOU

If you are helping someone to complete this questionnaire, please make sure this information is the patient's and not your own.

57. What **year** were you born?

(Please write in) e.g. | 1 | 9 | 4 | 4 |

| Y | Y | Y | Y |

58. Are you male or female?

1 ☐ Male
2 ☐ Female

59. Which of the following best describes your sexual orientation?

1 ☐ Heterosexual / straight (opposite sex)
2 ☐ Bisexual (both sexes)
3 ☐ Lesbian (same sex)
4 ☐ Other
5 ☐ Prefer not to answer

60. Which statement best describes your living arrangements?

1 ☐ I live with partner/spouse/family/friends
2 ☐ I live alone
3 ☐ I live in a nursing home, hospital or other long term care home
4 ☐ Other

61. Do you have a long standing health condition? *Please include anything* ***other than your cancer*** *that has troubled you over a period of time or that could affect you over a period of time.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know / can't say

62. Which, if any, of the following conditions do you have? **(Tick all that apply)**

1 ☐ Alzheimer's disease or dementia
2 ☐ Angina
3 ☐ Arthritis
4 ☐ Asthma or other chronic chest problem
5 ☐ Blindness or visual impairment
6 ☐ Deafness or hearing impairment
7 ☐ Diabetes
8 ☐ Epilepsy
9 ☐ Heart condition
10 ☐ High blood pressure
11 ☐ Kidney disease
12 ☐ Learning difficulty
13 ☐ Liver disease
14 ☐ Long term back problems
15 ☐ Long-standing mental health problem
16 ☐ Long-standing neurological problem
17 ☐ Another long-standing condition
18 ☐ I do not have any of these conditions

63. What was your employment status ***before you were diagnosed with cancer***?

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

64. What is your employment status currently? *If on maternity or sick leave answer in relation to your **usual** employment status*

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

65. If you are currently employed at the moment, are you:

1 ☐ Not working at all
2 ☐ Working less hours than usual
3 ☐ Working your usual hours
4 ☐ Working more hours than usual
5 ☐ This question does not apply to me

66. To which of these ethnic groups would you say you belong? **(Tick ONE only)**

a. WHITE

1 ☐ British
2 ☐ Irish
3 ☐ Any other White background (Please write in box)

☐

b. MIXED

4 ☐ White and Black Caribbean
5 ☐ White and Black African
6 ☐ White and Asian
7 ☐ Any other Mixed background (Please write in box)

☐

c. ASIAN OR ASIAN BRITISH

8 ☐ Indian
9 ☐ Pakistani
10 ☐ Bangladeshi
11 ☐ Any other Asian background (Please write in box)

☐

d. BLACK OR BLACK BRITISH

12 ☐ Caribbean
13 ☐ African
14 ☐ Any other Black background (Please write in box)

☐

e. CHINESE OR OTHER ETHNIC GROUP

15 ☐ Chinese
16 ☐ Any other ethnic group (Please write in box)

☐

COMMENTS

If you have anything else you would like to tell us about living with and beyond cancer, please do so here:

Questions 5-9 are EQ- 5D-5L. UK (English) v.2 © 2009 EuroQol Group. EQ-5D™ is a trade mark of the EuroQol Group.

Questions 10 – 18 are from FACIT copyright 1987, 1997 by David Cella, PhD

Questions 20 – 40 are from the Social Difficulties Inventory. Originators of the Social Difficulties Inventory: Wright, E.P., Cull, A. and Selby, P.

Living with and beyond Colorectal / Gastro Intestinal Cancer

This questionnaire is about your health and quality of life since being diagnosed with your cancer. Its purpose is to provide information which can help the NHS monitor and improve the quality of health services for future patients.

Who should complete the questionnaire?

The questions should be answered by the person named in the letter enclosed with this questionnaire. If that person needs help to complete the questionnaire, the answers should be given from their point of view – not the point of view of the person who is helping.

Completing the questionnaire

For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please **do not** write your name or address anywhere on the questionnaire.

IMPORTANT INFORMATION

To make sure the information we collect is useful, we need to collect some personal details from you and to access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the quality of life for people who are living with and beyond cancer. These statistics will be used to compare the differences in quality of life for people treated for different types of cancer by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:

- Your personal details and relevant health information can be held and used by an organisation contracted to the Department of Health to analyse the data
- Other information about you held by the Patient Demographics Service, the Secondary Users Service, Cancer Registries and other NHS databases can be held and used by an organisation contracted to the Department of Health to analyse the data
- Your personal details can be used to send you related follow-up questionnaires in the future

Your personal information will be handled securely and anonymised after analysis and before any publication.

Your personal information will not be released by the Department of Health or third party organisations working on its behalf unless required by law or where there is a clear overriding public interest.

You can withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

If you have any queries about the questionnaire,
please call the FREEPHONE helpline number **on 0800 783 1775**

Taking part in this survey is voluntary
Published reports will not contain any personal details

YOUR HEALTH TODAY

The questions in this section are all about your health and how you feel on the day you complete this questionnaire.

1. What treatments have you received for your colorectal / GI cancer? **(Tick all that apply)**

1 ☐ Radiotherapy
2 ☐ Chemotherapy
3 ☐ Surgery

2. How long is it since you completed your **initial treatment** for colorectal / GI cancer? *Treatment includes any chemotherapy, radiotherapy, or surgery for your colorectal / GI cancer.*

1 ☐ I am still having my initial treatment
2 ☐ It is less than 3 months since my initial treatment
3 ☐ It is between 3 and 12 months since my initial treatment
4 ☐ It is between 1 and 5 years since my initial treatment
5 ☐ It is more than 5 years since my initial treatment
6 ☐ Don't know / can't remember

3. How has your colorectal / GI cancer responded to treatment?

1 ☐ My colorectal / GI cancer has responded fully to treatment (I am in remission)
2 ☐ My colorectal / GI cancer has been treated but is still present
3 ☐ My colorectal / GI cancer has not been treated at all
4 ☐ My colorectal / GI cancer has come back after it was originally treated
5 ☐ I am not certain what is happening with my colorectal / GI cancer

4. If you have a stoma (e.g. colostomy) is it:

1 ☐ Still present
2 ☐ Reversed
3 ☐ This does not apply to me

YOUR HEALTH TODAY

Under each heading, please tick the ONE box that best describes your health TODAY.

5. MOBILITY

I have no problems in walking about ☐1
I have slight problems in walking about ☐2
I have moderate problems in walking about ☐3
I have severe problems in walking about ☐4
I am unable to walk about ☐5

6. SELF CARE

I have no problems washing or dressing myself ☐1
I have slight problems washing or dressing myself ☐2
I have moderate problems washing or dressing myself ☐3
I have severe problems washing or dressing myself ☐4
I am unable to wash or dress myself ☐5

7. USUAL ACTIVITIES *(work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ☐1
I have slight problems doing my usual activities ☐2
I have moderate problems doing my usual activities ☐3
I have severe problems doing my usual activities ☐4
I am unable to do my usual activities ☐5

8. PAIN / DISCOMFORT

I have no pain or discomfort ☐1
I have slight pain or discomfort ☐2
I have moderate pain or discomfort ☐3
I have severe pain or discomfort ☐4
I have extreme pain or discomfort ☐5

9. ANXIETY / DEPRESSION

I am not anxious or depressed ☐1
I am slightly anxious or depressed ☐2
I am moderately anxious or depressed ☐3
I am severely anxious or depressed ☐4
I am extremely anxious or depressed ☐5

YOUR HEALTH AND WELL BEING IN THE LAST 7 DAYS

The questions in this section are about your health and how you have felt in the past <u>7 days</u>.

Please mark one box per line to give your response.

	During the past 7 days:	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
10.	I have swelling or cramps in my stomach area	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
11.	I am losing weight	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
12.	I have control of my bowels	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
13.	I can digest my food well	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
14.	I have diarrhoea	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
15.	I have a good appetite	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
16.	I like the appearance of my body	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
17.	I have difficulty urinating	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
18.	I urinate more frequently than usual	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
19.	I leak urine	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

20. Do you have an ostomy appliance / stoma? 1 ☐ No 2 ☐ Yes

	If yes, please answer the next two items:	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
21.	I am embarrassed by my ostomy appliance / stoma	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
22.	Caring for my ostomy appliance / stoma is difficult	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

23. Do you have any difficulty in controlling your bowels (e.g. any accidents)? 1 ☐ No 2 ☐ Yes

		Monthly	**Weekly**	**Daily**	**Constantly**	**It varies**
24.	If yes, how often do you have difficulties?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

25. In the **past week**, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your heart rate? *This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that is part of your job.*

None	**I day**	**2 days**	**3 days**	**4 days**	**5 days**	**6 days**	**7 days**
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These might be to do with things like their family life, social activities, finances and work.

Please tick the response that best describes your answer.

During the past month:	**No difficulty**	**A little**	**Quite a bit**	**Very much**	**Does not apply**
26. Have you had any difficulty in maintaining your independence?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
27. Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
28. Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
29. Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
30. Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
31. Have you had any difficulty with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
32. Have you had any financial difficulties?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
33. Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
34. Have you had any difficulty concerning your work? (or education if you are a student)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
35. Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

During the past month:	**No difficulty**	**A little**	**Quite a bit**	**Very much**	**Does not apply**
36. Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
37. Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
38. Have you had any difficulty concerning sexual matters?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
39. Have you had any difficulty concerning plans to have a family?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
40. Have you had any difficulty concerning your appearance or body image?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
41. Have you felt isolated?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
42. Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
43. Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
44. Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
45. Have you had any difficulty with your plans to travel or take a holiday?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
46. Have you had any difficulty with any other area of your everyday life?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Please tick the response that best describes your answer.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply to me
47. I have fears about my cancer spreading	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
48. I have fears about my cancer coming back	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
49. I have fears about death and dying	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
50. I experience memory loss	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
51. I have trouble sleeping	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
52. I have trouble concentrating	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
53. I always feel tired	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
54. I experience mood swings	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
55. I am often irritable	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	

OVERALL SUPPORT AND CARE

56. Do you have an up-to-date written care plan? *A care plan is a document that sets out your needs and goals for caring for your cancer.*

1 ☐ Yes, definitely

2 ☐ Yes, I think so

3 ☐ No

4 ☐ I do not need a care plan

5 ☐ Don't know

57. Do you have a named nurse who you can contact if you have a worry about your cancer care? *A named nurse is sometimes known as a Clinical Nurse Specialist or Specialist Cancer Nurse.*

1 ☐ Yes

2 ☐ No

3 ☐ Don't know

58. Do you know who to contact if you have a concern about any aspect of living with or after cancer?

1 ☐ Yes, definitely

2 ☐ Yes, I think so

3 ☐ No

59. Do you think that hospital staff did everything they could to support you following your cancer treatment?

1 ☐ Yes, all of the time

2 ☐ Only some of the time

3 ☐ Never

4 ☐ I did not need any support

60. Do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?

1 ☐ Yes, all of the time

2 ☐ Only some of the time

3 ☐ Never

4 ☐ My general practice is not involved

5 ☐ I do not need any support

61. Following your initial cancer treatment have you been given enough care and help from health and social services (for example, district nurses, home helps or occupational therapists)?

1 ☐ Yes, definitely

2 ☐ Yes, to some extent

3 ☐ No

4 ☐ I did not need help from health or social services

5 ☐ Don't know / can't remember

62. Would it have been helpful to have had more advice or information on any of the following issues: **(Tick all that apply)**

1 ☐ Diet and lifestyle

2 ☐ Physical activity and exercise

3 ☐ Financial help or benefits

4 ☐ Free prescriptions

5 ☐ Returning to or staying in work

6 ☐ Information / advice for family / friends / carer

7 ☐ The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)

8 ☐ The psychological or emotional aspects of living with and after cancer

9 ☐ I have all the information and advice I need

ABOUT YOU

If you are helping someone to complete this questionnaire, please make sure this information is the patient's and not your own.

63. What **year** were you born?

(Please write in) e.g. | 1 | 9 | 4 | 4 |

Y	Y	Y	Y

64. Are you male or female?

1 ☐ Male
2 ☐ Female

65. Which of the following best describes your sexual orientation?

1 ☐ Heterosexual / straight (opposite sex)
2 ☐ Bisexual (both sexes)
3 ☐ Gay or lesbian (same sex)
4 ☐ Other
5 ☐ Prefer not to answer

66. Which statement best describes your living arrangements?

1 ☐ I live with partner/spouse/family/friends
2 ☐ I live alone
3 ☐ I live in a nursing home, hospital or other long term care home
4 ☐ Other

67. Do you have a long standing health condition? *Please include anything **other than your cancer** that has troubled you over a period of time or that could affect you over a period of time.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know / can't say

68. Which, if any, of the following conditions do you have? **(Tick all that apply)**

1 ☐ Alzheimer's disease or dementia
2 ☐ Angina
3 ☐ Arthritis
4 ☐ Asthma or other chronic chest problem
5 ☐ Blindness or visual impairment
6 ☐ Deafness or hearing impairment
7 ☐ Diabetes
8 ☐ Epilepsy
9 ☐ Heart condition
10 ☐ High blood pressure
11 ☐ Kidney disease
12 ☐ Learning difficulty
13 ☐ Liver disease
14 ☐ Long term back problems
15 ☐ Long-standing mental health problem
16 ☐ Long-standing neurological problem
17 ☐ Another long-standing condition
18 ☐ I do not have any of these conditions

69. What was your employment status ***before you were diagnosed with cancer***?

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

70. What is your employment status currently? *If on maternity or sick leave answer in relation to your **usual** employment status.*

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

71. If you are currently employed at the moment, are you:

1 ☐ Not working at all
2 ☐ Working less hours than usual
3 ☐ Working your usual hours
4 ☐ Working more hours than usual
5 ☐ This question does not apply to me

72. To which of these ethnic groups would you say you belong? **(Tick ONE only)**

a. WHITE

1 ☐ British
2 ☐ Irish
3 ☐ Any other White background (Please write in box)

b. MIXED

4 ☐ White and Black Caribbean
5 ☐ White and Black African
6 ☐ White and Asian
7 ☐ Any other Mixed background (Please write in box)

c. ASIAN OR ASIAN BRITISH

8 ☐ Indian
9 ☐ Pakistani
10 ☐ Bangladeshi
11 ☐ Any other Asian background (Please write in box)

d. BLACK OR BLACK BRITISH

12 ☐ Caribbean
13 ☐ African
14 ☐ Any other Black background (Please write in box)

e. CHINESE OR OTHER ETHNIC GROUP

15 ☐ Chinese
16 ☐ Any other ethnic group (Please write in box)

COMMENTS

If you have anything else you would like to tell us about living with and beyond cancer, please do so here:

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Questions 10 – 18 and 20 - 22 are taken from FACIT copyright 1987, 1997 by David Cella, PhD

Questions 26 – 46 are taken from the Social Difficulties Inventory. Originators of the Social Difficulties Inventory: Wright, E.P., Cull, A. and Selby, P.

Living with and beyond Non Hodgkin's Lymphoma

This questionnaire is about your health and quality of life since being diagnosed with your cancer. Its purpose is to provide information which can help the NHS monitor and improve the quality of health services for future patients.

Who should complete the questionnaire?
The questions should be answered by the person named in the letter enclosed with this questionnaire. If that person needs help to complete the questionnaire, the answers should be given from their point of view – not the point of view of the person who is helping.

Completing the questionnaire
For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please **do not** write your name or address anywhere on the questionnaire.

IMPORTANT INFORMATION

To make sure the information we collect is useful, we need to collect some personal details from you and to access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the quality of life for people who are living with and beyond cancer. These statistics will be used to compare the differences in quality of life for people treated for different types of cancer by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:

- Your personal details and relevant health information can be held and used by an organisation contracted to the Department of Health to analyse the data
- Other information about you held by the Patient Demographics Service, the Secondary Users Service, Cancer Registries and other NHS databases can be held and used by an organisation contracted to the Department of Health to analyse the data
- Your personal details can be used to send you related follow-up questionnaires in the future

Your personal information will be handled securely and anonymised after analysis and before any publication.

Your personal information will not be released by the Department of Health or third party organisations working on its behalf unless required by law or where there is a clear overriding public interest.

You can withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

If you have any queries about the questionnaire,
please call the FREEPHONE helpline number **on 0800 783 1775**

Taking part in this survey is voluntary
Published reports will not contain any personal details

YOUR HEALTH TODAY

The questions in this section are all about your health and how you feel on the day you complete this questionnaire.

1. What treatments have you received for your Non Hodgkin's Lymphoma (NHL)? **(Tick all that apply)**

1 ☐ Radiotherapy
2 ☐ Chemotherapy
3 ☐ Surgery
4 ☐ Antibody therapy (including Rituximab)
5 ☐ Stem cell transplant

2. How long is it since you completed your **initial treatment** for NHL? *Treatment includes any chemotherapy, radiotherapy, or surgery for your NHL. When answering this question please do not include antibody (Rituximab) treatment which you may have been given as a maintenance treatment following chemotherapy.*

1 ☐ I am still having my initial treatment
2 ☐ It is less than 3 months since my initial treatment
3 ☐ It is between 3 and 12 months since my initial treatment
4 ☐ It is between 1 and 5 years since my initial treatment
5 ☐ It is more than 5 years since my initial treatment
6 ☐ Don't know / can't remember

3. How has your NHL responded to treatment?

1 ☐ My NHL has responded fully to treatment (I am in remission)
2 ☐ My NHL has been treated but is still present
3 ☐ My NHL has not been treated at all
4 ☐ My NHL has come back after it was originally treated
5 ☐ I am not certain what is happening with my NHL

YOUR HEALTH TODAY

Under each heading, please tick the ONE box that best describes your health TODAY.

4. MOBILITY

I have no problems in walking about ☐1
I have slight problems in walking about ☐2
I have moderate problems in walking about ☐3
I have severe problems in walking about ☐4
I am unable to walk about ☐5

5. SELF CARE

I have no problems washing or dressing myself ☐1
I have slight problems washing or dressing myself ☐2
I have moderate problems washing or dressing myself ☐3
I have severe problems washing or dressing myself ☐4
I am unable to wash or dress myself ☐5

6. USUAL ACTIVITIES *(work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ☐1
I have slight problems doing my usual activities ☐2
I have moderate problems doing my usual activities ☐3
I have severe problems doing my usual activities ☐4
I am unable to do my usual activities ☐5

7. PAIN / DISCOMFORT

I have no pain or discomfort ☐1
I have slight pain or discomfort ☐2
I have moderate pain or discomfort ☐3
I have severe pain or discomfort ☐4
I have extreme pain or discomfort ☐5

8. ANXIETY / DEPRESSION

I am not anxious or depressed ☐1
I am slightly anxious or depressed ☐2
I am moderately anxious or depressed ☐3
I am severely anxious or depressed ☐4
I am extremely anxious or depressed ☐5

YOUR HEALTH AND WELL BEING IN THE LAST 7 DAYS

The questions in this section are about your health and how you have felt in the past 7 days.

Please mark one box per line to give your response.

	During the past 7 days:	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
9.	I have certain parts of my body where I experience pain	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
10.	I am bothered by lumps or swelling in certain parts of my body (e.g. neck, armpits, or groin)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
11.	I am bothered by fevers (episodes of high body temperature)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
12.	I have night sweats	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
13.	I am bothered by itching	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
14.	I have trouble sleeping at night	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
15.	I get tired easily	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
16.	I am losing weight	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
17.	I have a loss of appetite	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
18.	I have trouble concentrating	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
19.	I worry about getting infections	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
20.	I worry that I might get new symptoms of my illness	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
21.	I feel isolated from others because of my illness or treatment	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
22.	I have emotional ups and downs	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
23.	Because of my illness, I have difficulty planning for the future	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

24. In the **past week**, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your heart rate? *This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that is part of your job.*

None	**I day**	**2 days**	**3 days**	**4 days**	**5 days**	**6 days**	**7 days**
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These might be to do with things like their family life, social activities, finances and work.

Please tick the response that best describes your answer.

	During the past month:	**No difficulty**	**A little**	**Quite a bit**	**Very much**	**Does not apply**
25.	Have you had any difficulty in maintaining your independence?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
26.	Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
27.	Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
28.	Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
29.	Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
30.	Have you had any difficulty with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
31.	Have you had any financial difficulties?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
32.	Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
33.	Have you had any difficulty concerning your work? (or education if you are a student)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
34.	Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

During the past month:	No difficulty	A little	Quite a bit	Very much	Does not apply
35. Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
36. Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
37. Have you had any difficulty concerning sexual matters?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
38. Have you had any difficulty concerning plans to have a family?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
39. Have you had any difficulty concerning your appearance or body image?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
40. Have you felt isolated?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
41. Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
42. Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
43. Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
44. Have you had any difficulty with your plans to travel or take a holiday?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
45. Have you had any difficulty with any other area of your everyday life?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Please tick the response that best describes your answer.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply to me
46. I have fears about my cancer spreading	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
47. I have fears about my cancer coming back	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
48. I have fears about death and dying	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
49. I experience memory loss	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
50. I have trouble sleeping	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
51. I have trouble concentrating	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
52. I always feel tired	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
53. I experience mood swings	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
54. I am often irritable	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	

OVERALL SUPPORT AND CARE

55. Do you have an up-to-date written care plan? *A care plan is a document that sets out your needs and goals for caring for your cancer.*

1 ☐ Yes, definitely
2 ☐ Yes, I think so
3 ☐ No
4 ☐ I do not need a care plan
5 ☐ Don't know

56. Do you have a named nurse who you can contact if you have a worry about your cancer care? *A named nurse is sometimes known as a Clinical Nurse Specialist or Specialist Cancer Nurse.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know

57. Do you know who to contact if you have a concern about any aspect of living with or after cancer?

1 ☐ Yes, definitely
2 ☐ Yes, I think so
3 ☐ No

58. Do you think that hospital staff did everything they could to support you following your cancer treatment?

1 ☐ Yes, all of the time
2 ☐ Only some of the time
3 ☐ Never
4 ☐ I did not need any support

59. Do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?

1 ☐ Yes, all of the time
2 ☐ Only some of the time
3 ☐ Never
4 ☐ My general practice is not involved
5 ☐ I do not need any support

60. Following your initial cancer treatment have you been given enough care and help from health and social services (for example, district nurses, home helps or occupational therapists)?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not need help from health or social services
5 ☐ Don't know / can't remember

61. Would it have been helpful to have had more advice or information on any of the following issues: **(Tick all that apply)**

1 ☐ Diet and lifestyle
2 ☐ Physical activity and exercise
3 ☐ Financial help or benefits
4 ☐ Free prescriptions
5 ☐ Returning to or staying in work
6 ☐ Information / advice for family / friends / carer
7 ☐ The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)
8 ☐ The psychological or emotional aspects of living with and after cancer
9 ☐ I have all the information and advice I need

ABOUT YOU

If you are helping someone to complete this questionnaire, please make sure this information is the patient's and not your own.

62. What **year** were you born?

(Please write in) e.g.

1	9	4	4

Y	Y	Y	Y

63. Are you male or female?

1 ☐ Male
2 ☐ Female

64. Which of the following best describes your sexual orientation?

1 ☐ Heterosexual / straight (opposite sex)
2 ☐ Bisexual (both sexes)
3 ☐ Gay or lesbian (same sex)
4 ☐ Other
5 ☐ Prefer not to answer

65. Which statement best describes your living arrangements?

1 ☐ I live with partner / spouse / family / friends
2 ☐ I live alone
3 ☐ I live in a nursing home, hospital or other long term care home
4 ☐ Other

66. Do you have a long standing health condition? *Please include anything **other than your cancer** that has troubled you over a period of time or that could affect you over a period of time.*

1 ☐ Yes
2 ☐ No
3 ☐ Don't know / can't say

67. Which, if any, of the following conditions do you have? **(Tick all that apply)**

1 ☐ Alzheimer's disease or dementia
2 ☐ Angina
3 ☐ Arthritis
4 ☐ Asthma or other chronic chest problem
5 ☐ Blindness or visual impairment
6 ☐ Deafness or hearing impairment
7 ☐ Diabetes
8 ☐ Epilepsy
9 ☐ Heart condition
10 ☐ High blood pressure
11 ☐ Kidney disease
12 ☐ Learning difficulty
13 ☐ Liver disease
14 ☐ Long term back problems
15 ☐ Long-standing mental health problem
16 ☐ Long-standing neurological problem
17 ☐ Another long-standing condition
18 ☐ I do not have any of these conditions

68. What was your employment status ***before you were diagnosed with cancer***?

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

69. What is your employment status currently? *If on maternity or sick leave answer in relation to your* ***usual*** *employment status.*

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

70. If you are currently employed at the moment, are you:

1 ☐ Not working at all
2 ☐ Working less hours than usual
3 ☐ Working your usual hours
4 ☐ Working more hours than usual
5 ☐ This question does not apply to me

71. To which of these ethnic groups would you say you belong? **(Tick ONE only)**

a. WHITE

1 ☐ British
2 ☐ Irish
3 ☐ Any other White background (Please write in box)

b. MIXED

4 ☐ White and Black Caribbean
5 ☐ White and Black African
6 ☐ White and Asian
7 ☐ Any other Mixed background (Please write in box)

c. ASIAN OR ASIAN BRITISH

8 ☐ Indian
9 ☐ Pakistani
10 ☐ Bangladeshi
11 ☐ Any other Asian background (Please write in box)

d. BLACK OR BLACK BRITISH

12 ☐ Caribbean
13 ☐ African
14 ☐ Any other Black background (Please write in box)

e. CHINESE OR OTHER ETHNIC GROUP

15 ☐ Chinese
16 ☐ Any other ethnic group (Please write in box)

COMMENTS

If you have anything else you would like to tell us about living with and beyond cancer, please do so here:

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Questions 25 – 45 are from the Social Difficulties Inventory. Originators of the Social Difficulties Inventory: Wright, E.P., Cull, A. and Selby, P.

NHS

Living with and beyond Prostate Cancer

This questionnaire is about your health and quality of life since being diagnosed with your cancer. Its purpose is to provide information which can help the NHS monitor and improve the quality of health services for future patients.

Who should complete the questionnaire?
The questions should be answered by the person named in the letter enclosed with this questionnaire. If that person needs help to complete the questionnaire, the answers should be given from their point of view – not the point of view of the person who is helping.

Completing the questionnaire
For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please **do not** write your name or address anywhere on the questionnaire.

IMPORTANT INFORMATION

To make sure the information we collect is useful, we need to collect some personal details from you and to access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the quality of life for people who are living with and beyond cancer. These statistics will be used to compare the differences in quality of life for people treated for different types of cancer by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:

- Your personal details and relevant health information can be held and used by an organisation contracted to the Department of Health to analyse the data
- Other information about you held by the Patient Demographics Service, the Secondary Users Service, Cancer Registries and other NHS databases can be held and used by an organisation contracted to the Department of Health to analyse the data
- Your personal details can be used to send you related follow-up questionnaires in the future

Your personal information will be handled securely and anonymised after analysis and before any publication.

Your personal information will not be released by the Department of Health or third party organisations working on its behalf unless required by law or where there is a clear overriding public interest.

You can withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

If you have any queries about the questionnaire,
please call the FREEPHONE helpline number **on 0800 783 1775**

Taking part in this survey is voluntary
Published reports will not contain any personal details

YOUR HEALTH TODAY

The questions in this section are all about your health and how you feel on the day you complete this questionnaire.

1. What treatments have you received for your prostate cancer? **(Tick all that apply)**

1 ☐ Radiotherapy (including brachytherapy) (with or without planned hormonal treatment)
2 ☐ Surgery
3 ☐ Hormone treatment
4 ☐ Chemotherapy (not including hormones)
5 ☐ HIFU
6 ☐ Cryotherapy
7 ☐ Active Surveillance (close monitoring but no current intervention)

2. How long is it since you completed your **initial treatment** for prostate cancer? *Treatment includes any chemotherapy, radiotherapy, or surgery for your prostate cancer. When answering this question please do not include hormone treatments.*

1 ☐ I am still having my initial treatment
2 ☐ It is less than 3 months since my initial treatment
3 ☐ It is between 3 and 12 months since my initial treatment
4 ☐ It is between 1 and 5 years since my initial treatment
5 ☐ It is more than 5 years since my initial treatment
6 ☐ Don't know / can't remember

3. How has your prostate cancer responded to treatment?

1 ☐ My prostate cancer has responded fully to treatment (I am in remission)
2 ☐ My prostate cancer has been treated but is still present
3 ☐ My prostate cancer has not been treated at all
4 ☐ My prostate cancer has come back after it was originally treated
5 ☐ I am not certain what is happening with my prostate cancer

YOUR HEALTH TODAY

Under each heading, please tick the ONE box that best describes your health TODAY.

4. MOBILITY

I have no problems in walking about	☐1
I have slight problems in walking about	☐2
I have moderate problems in walking about	☐3
I have severe problems in walking about	☐4
I am unable to walk about	☐5

5. SELF CARE

I have no problems washing or dressing myself	☐1
I have slight problems washing or dressing myself	☐2
I have moderate problems washing or dressing myself	☐3
I have severe problems washing or dressing myself	☐4
I am unable to wash or dress myself	☐5

6. USUAL ACTIVITIES *(work, study, housework, family or leisure activities)*

I have no problems doing my usual activities	☐1
I have slight problems doing my usual activities	☐2
I have moderate problems doing my usual activities	☐3
I have severe problems doing my usual activities	☐4
I am unable to do my usual activities	☐5

7. PAIN / DISCOMFORT

I have no pain or discomfort	☐1
I have slight pain or discomfort	☐2
I have moderate pain or discomfort	☐3
I have severe pain or discomfort	☐4
I have extreme pain or discomfort	☐5

8. ANXIETY / DEPRESSION

I am not anxious or depressed	☐1
I am slightly anxious or depressed	☐2
I am moderately anxious or depressed	☐3
I am severely anxious or depressed	☐4
I am extremely anxious or depressed	☐5

YOUR HEALTH AND WELLBEING IN THE LAST 7 DAYS

The questions in this section are about your health and how you have felt in the past 7 days.

Please mark one box per line to give your response.

	During the past 7 days:	Not at all	A little bit	Some-what	Quite a bit	Very much
9.	I am losing weight	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
10.	I have a good appetite	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
11.	I have aches and pains that bother me	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
12.	I have certain parts of my body where I experience pain	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
13.	My pain keeps me from doing things I want to do	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
14.	I am satisfied with my present comfort level	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
15.	I have trouble moving my bowels	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
16.	I have difficulty urinating	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
17.	I urinate more frequently than usual	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
18.	My problems with urinating limit my activities	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
19.	I am able to have and maintain an erection	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
20.	I leak urine	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

21. Do you have any difficulty in controlling your bowels (e.g. any accidents)? 1 ☐ No 2 ☐ Yes

		Monthly	Weekly	Daily	Constantly	It varies
22.	If yes, how often do you have difficulties?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

23. In the **past week**, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your heart rate? *This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that is part of your job.*

None	I day	2 days	3 days	4 days	5 days	6 days	7 days
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These might be to do with things like their family life, social activities, finances and work.

Please tick the response that best describes your answer.

During the past month:	**No difficulty**	**A little**	**Quite a bit**	**Very much**	**Does not apply**
24. Have you had any difficulty in maintaining your independence?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
25. Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
26. Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
27. Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
28. Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
29. Have you had any difficulty with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
30. Have you had any financial difficulties?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
31. Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
32. Have you had any difficulty concerning your work? (or education if you are a student)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
33. Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

During the past month:	**No difficulty**	**A little**	**Quite a bit**	**Very much**	**Does not apply**
34. Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
35. Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
36. Have you had any difficulty concerning sexual matters?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
37. Have you had any difficulty concerning plans to have a family?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
38. Have you had any difficulty concerning your appearance or body image?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
39. Have you felt isolated?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
40. Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
41. Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
42. Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
43. Have you had any difficulty with your plans to travel or take a holiday?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
44. Have you had any difficulty with any other area of your everyday life?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

YOUR HEALTH AND WELL BEING IN THE LAST MONTH

The questions in this section are about your health and how you have felt during the past month.

Please tick the response that best describes your answer.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply to me
45. I have fears about my cancer spreading	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	6 ☐
46. I have fears about my cancer coming back	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	6 ☐
47. I have fears about death and dying	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
48. I experience memory loss	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
49. I have trouble sleeping	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
50. I have trouble concentrating	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
51. I always feel tired	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
52. I experience mood swings	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	
53. I am often irritable	1 ☐	2 ☐	3 ☐	5 ☐	5 ☐	

OVERALL SUPPORT AND CARE

54. Do you have an up-to-date written care plan? *A care plan is a document that sets out your needs and goals for caring for your cancer.*

- 1 ☐ Yes, definitely
- 2 ☐ Yes, I think so
- 3 ☐ No
- 4 ☐ I do not need a care plan
- 5 ☐ Don’t know

55. Do you have a named nurse who you can contact if you have a worry about your cancer care? *A named nurse is sometimes known as a Clinical Nurse Specialist or Specialist Cancer Nurse.*

- 1 ☐ Yes
- 2 ☐ No
- 3 ☐ Don’t know

56. Do you know who to contact if you have a concern about any aspect of living with or after cancer?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, I think so
- 3 ☐ No

57. Do you think that hospital staff did everything they could to support you following your cancer treatment?

- 1 ☐ Yes, all of the time
- 2 ☐ Only some of the time
- 3 ☐ Never
- 4 ☐ I did not need any support

58. Do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?

- 1 ☐ Yes, all of the time
- 2 ☐ Only some of the time
- 3 ☐ Never
- 4 ☐ My general practice is not involved
- 5 ☐ I do not need any support

59. Following your initial cancer treatment have you been given enough care and help from health and social services (for example, district nurses, home helps or occupational therapists)?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ I did not need help from health or social services
- 5 ☐ Don’t know / can’t remember

60. Would it have been helpful to have had more advice or information on any of the following issues: **(Tick all that apply)**

- 1 ☐ Diet and lifestyle
- 2 ☐ Physical activity and exercise
- 3 ☐ Financial help or benefits
- 4 ☐ Free prescriptions
- 5 ☐ Returning to or staying in work
- 6 ☐ Information / advice for family / friends / carer
- 7 ☐ The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)
- 8 ☐ The psychological or emotional aspects of living with and after cancer
- 9 ☐ I have all the information and advice I need

ABOUT YOU

If you are helping someone to complete this questionnaire, please make sure this information is the patient's and not your own.

61. What **year** were you born?

(Please write in) e.g. | 1 | 9 | 4 | 4 |

Y	Y	Y	Y

62. Are you male or female?

1 ☐ Male

2 ☐ Female

63. Which of the following best describes your sexual orientation?

1 ☐ Heterosexual / straight (opposite sex)

2 ☐ Bisexual (both sexes)

3 ☐ Gay (same sex)

4 ☐ Other

5 ☐ Prefer not to answer

64. Which statement best describes your living arrangements?

1 ☐ I live with partner/spouse/family/friends

2 ☐ I live alone

3 ☐ I live in a nursing home, hospital or other long term care home

4 ☐ Other

65. Do you have a long standing health condition? *Please include anything* ***other than your cancer*** *that has troubled you over a period of time or that could affect you over a period of time.*

1 ☐ Yes

2 ☐ No

3 ☐ Don't know / can't say

66. Which, if any, of the following conditions do you have? **(Tick all that apply)**

1 ☐ Alzheimer's disease or dementia

2 ☐ Angina

3 ☐ Arthritis

4 ☐ Asthma or other chronic chest problem

5 ☐ Blindness or visual impairment

6 ☐ Deafness or hearing impairment

7 ☐ Diabetes

8 ☐ Epilepsy

9 ☐ Heart condition

10 ☐ High blood pressure

11 ☐ Kidney disease

12 ☐ Learning difficulty

13 ☐ Liver disease

14 ☐ Long term back problems

15 ☐ Long-standing mental health problem

16 ☐ Long-standing neurological problem

17 ☐ Another long-standing condition

18 ☐ I do not have any of these conditions

67. What was your employment status ***before you were diagnosed with cancer***?

1 ☐ Full time employment

2 ☐ Part time employment

3 ☐ Homemaker

4 ☐ Student (in education)

5 ☐ Retired

6 ☐ Unemployed – and seeking work

7 ☐ Unemployed – unable to work for health reasons

8 ☐ Other

68. What is your employment status currently? *If on maternity or sick leave answer in relation to your **usual** employment status.*

1 ☐ Full time employment

2 ☐ Part time employment

3 ☐ Homemaker

4 ☐ Student (in education)

5 ☐ Retired

6 ☐ Unemployed – and seeking work

7 ☐ Unemployed – unable to work for health reasons

8 ☐ Other

69. If you are currently employed at the moment, are you:

1 ☐ Not working at all

2 ☐ Working less hours than usual

3 ☐ Working your usual hours

4 ☐ Working more hours than usual

5 ☐ This question does not apply to me

70. To which of these ethnic groups would you say you belong? **(Tick ONE only)**

a. WHITE

1 ☐ British

2 ☐ Irish

3 ☐ Any other White background (Please write in box)

b. MIXED

4 ☐ White and Black Caribbean

5 ☐ White and Black African

6 ☐ White and Asian

7 ☐ Any other Mixed background (Please write in box)

c. ASIAN OR ASIAN BRITISH

8 ☐ Indian

9 ☐ Pakistani

10 ☐ Bangladeshi

11 ☐ Any other Asian background (Please write in box)

d. BLACK OR BLACK BRITISH

12 ☐ Caribbean

13 ☐ African

14 ☐ Any other Black background (Please write in box)

e. CHINESE OR OTHER ETHNIC GROUP

15 ☐ Chinese

16 ☐ Any other ethnic group (Please write in box)

COMMENTS

If you have anything else you would like to tell us about living with and beyond cancer, please do so here:

Questions 4-8 are EQ -5D-5L. UK (English) v.2 © 2009 EuroQol Group. EQ-5D™ is a trade mark of the EuroQol Group.

Questions 9 – 20 are taken from FACIT copyright 1987, 1997 by David Cella, PhD

Questions 24 – 44 are taken from the Social Difficulties Inventory. Originators of the Social Difficulties Inventory: Wright, E.P., Cull, A. and Selby, P.

NIGB
Ethics and Confidentiality Committee

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Tel: (020) 7633 7052
Email: eccapplications@nhs.net

Simon Phillips
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133 -155 Waterloo Road
London
SE1 8UG

18 May 2011

Dear Simon

8-05 (b)/2010 National Cancer Survivorship Initiative – patient reported outcome survey of cancer survivors

Thank you for your application for support under section 251 of the NHS Act 2006 to process patient identifiable information without consent. This application was considered by the Ethics and Confidentiality Committee at its meeting on 01 December 2010.

Context

This application from the Department of Health (acting as sponsor) and Quality Health (the implementation provider) sought support to cover the pilot phase of a proposed national survey of cancer survivors, which is intended to last up until 30 June 2011.

Update: due to slippages in timetables, it has been noted that following notification on 17 May 2011, that the survey will be completed by September 2011.

The purpose of this activity was to aim to improve understanding of quality of life outcomes for cancer survivors and was intended to support the DH National Cancer Survivorship Initiative (NCSI). The activity would build upon the current national Cancer Patient Experience Survey Programme (CPESP) 2010 which focuses on the experience of care of cancer patients.

Section 251 support was sought to enable the legitimate transfer of patient data from the Cancer Registries to Quality Health, and for Quality Health to liaise with cancer centres so that patient questionnaires would be sent to patients under cover of appropriate cancer centre letter headed paper. Support was also required to enable a sample to be identified from the cancer registries. To carry out the activity, Quality Health would require access to name, address, sex, ethnic group, year of birth, NHS number, ICD10 code, speciality code, date of diagnosis, and Trust NACS code for most recent treatment spell.

Outcome

NIGB
Ethics and Confidentiality Committee

The letter dated 07 December 2010 set out the Committee's rationale and decision for its recommendation of provisional support, subject to a number of clarifications and conditions of approval. A response was subsequently provided providing copies of requested documentation and further explanation around the clarification areas.

In particular, Members debated the response to the information being sent on GP headed paper, and on balance and in this specific instance, agreed that this would not be feasible.

As all aspects have been satisfactorily addressed, this letter provides confirmation of your final approval, and our Register of approved applications will shortly be updated to include this application.

If you have any queries regarding the outcome of this letter please do not hesitate to contact the NIGB Office on 020 7633 7052. Email queries should be sent to eccapplications@nhs.net.

Yours sincerely

Natasha Dunkley
NIGB Approvals Manager

NIGB
Ethics and Confidentiality Committee

Ethics and Confidentiality Committee
Standard conditions of approval

The support provided under section 251 is subject to the following standard conditions.

The applicant will ensure that:

1. The requested patient identifiable information is only used for the purpose(s) set out in the application.
2. Confidentiality is preserved and that there is no disclosure of information in aggregate or patient level form that may inferentially identify a person, nor will any attempt be made to identify individuals, households or organisations in the data.
3. Requirements of the Statistics and Registration Services Act 2007 are adhered to regarding publication when relevant.
4. All staff with access to patient identifiable information have contractual obligations of confidentiality, enforceable through disciplinary procedures.
5. All staff with access to patient identifiable information have received appropriate ongoing training to ensure they are aware of their responsibilities.
6. Activities are consistent with the Data Protection Act 1998.
7. Audit of data processing by a designated agent of the Secretary of State is facilitated and supported.
8. The wishes of people who have withheld or withdrawn their consent are respected.
9. The NIGB Office is notified of any significant changes which impact on the approval of the application.
10. An annual review to be provided no later than 12 months from date of your final approval letter

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

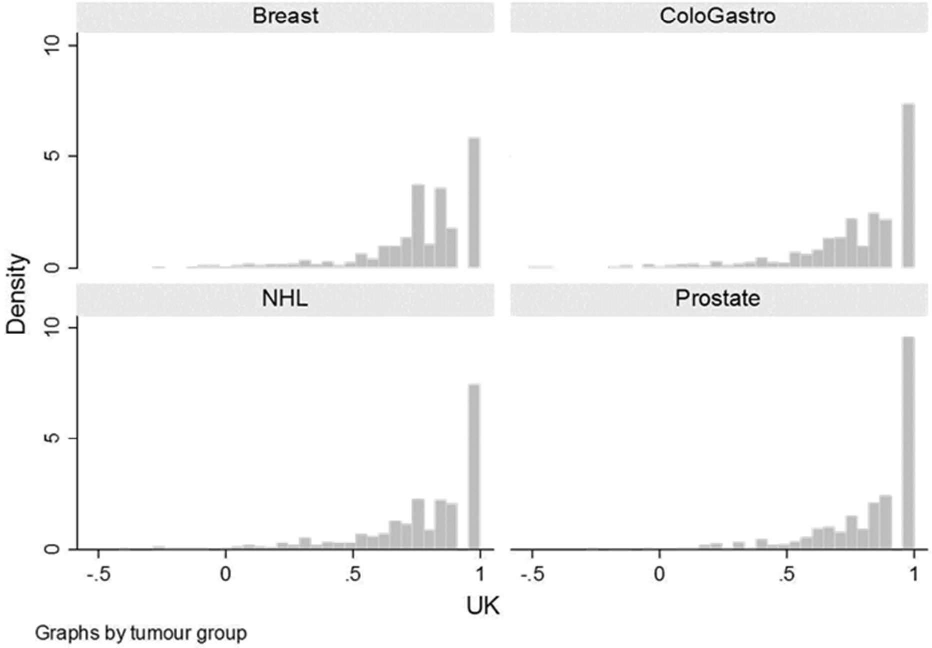
Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	6
Objectives	3	State specific objectives, including any prespecified hypotheses	6
Methods			
Study design	4	Present key elements of study design early in the paper	7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	7
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	7
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	8-10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	8-10
Bias	9	Describe any efforts to address potential sources of bias	*7-10*
Study size	10	Explain how the study size was arrived at	7
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	10
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	10
		(*b*) Describe any methods used to examine subgroups and interactions	10
		(*c*) Explain how missing data were addressed	12
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	10
		(*e*) Describe any sensitivity analyses	10
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	11
		(b) Give reasons for non-participation at each stage	11
		(c) Consider use of a flow diagram	n/a
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	11
		(b) Indicate number of participants with missing data for each variable of interest	12
Outcome data	15*	Report numbers of outcome events or summary measures	12-16
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	13-15
		(*b*) Report category boundaries when continuous variables were categorized	12-16
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	12-16
Discussion			
Key results	18	Summarise key results with reference to study objectives	17-18
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	17-19
Generalisability	21	Discuss the generalisability (external validity) of the study results	18
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	21

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Supplementary Figure 1. Distribution of EQ5D summary scores by cancer sub-type



Supplementary Table 1. Quality of Life Dimension Results (EQ5D) by Cancer Sub group

EQ5D dimension		**Breast (n=854)**		**Colorectal (n=802)**		**Non Hodgkin's Lymphoma (n=778)**		**Prostate (n=866)**		**Total (n=3300)**	
		n	***%***	**n**	***%***	**n**	***%***	**n**	***%***	**n**	***%***
Mobility **χ2=51·3, p<0·001**	No Problems	567	*66·4*	442	*55·1*	427	*54·9*	535	*61·8*	1971	*59·7*
	Slight Problems	105	*12·3*	159	*19·8*	140	*18·0*	131	*15·1*	535	*16·2*
	Moderate Problems	107	*12·5*	120	*15·0*	120	*15·4*	97	*11·2*	444	*13·5*
	Severe Problems	46	*5·4*	57	*7·1*	71	*9·1*	69	*8·0*	243	*7·4*
	Cannot walk	8	*0·9*	13	*1·6*	6	*0·8*	4	*0·4*	31	*0·9*
	Missing	21	*2·5*	11	*1·4*	14	*1·8*	30	*3·5*	76	*2·3*
Self Care **χ2=30·4, p=0·002**	No Problems	716	*83·8*	651	*81·2*	611	*78·5*	704	*81·3*	2682	*81·3*
	Slight Problems	47	*5·5*	67	*8·4*	66	*8·5*	78	*9·0*	258	*7·8*
	Moderate Problems	45	*5·3*	46	*5·7*	71	*9·1*	44	*5·1*	206	*6·2*
	Severe Problems	12	*1·4*	18	*2·2*	12	*1·5*	9	*1·0*	51	*1·5*
	Cannot wash/dress	6	*0·7*	9	*1·1*	4	*0·5*	4	*0·5*	23	*0·7*
	Missing	28	*3·3*	11	*1·4*	14	*1·8*	27	*3·1*	80	*2·4*
Usual Activities **χ2=34·5, p<0·001**	No Problems	513	*60·1*	429	*53·5*	411	*52·8*	533	*61·5*	1886	*57·2*
	Slight Problems	162	*19·0*	173	*21·6*	156	*20·1*	145	*16·7*	636	*19·3*
	Moderate Problems	111	*13·0*	113	*14·1*	127	*16·3*	104	*12·1*	455	*13·7*
	Severe Problems	31	*3·6*	48	*6·0*	49	*6·3*	43	*5·0*	171	*5·2*
	Cannot do usual activities	14	*1·6*	24	*3·0*	26	*3·3*	15	*1·7*	79	*2·4*
	Missing	23	*2·7*	15	*1·8*	9	*1·2*	26	*3·0*	73	*2·2*
Pain **χ2=134·3, p<0·001**	No Pain	329	*38·5*	429	*53·5*	408	*52·4*	526	*60·7*	1692	*51·3*
	Slight Pain	341	*39·9*	220	*27·4*	180	*23·1*	169	*19·5*	910	*27·6*
	Moderate Pain	113	*13·2*	92	*11·5*	120	*15·4*	101	*11·7*	426	*12·9*
	Severe Pain	39	*4·6*	35	*4·4*	51	*6·6*	38	*4·4*	163	*4·9*
	Extreme Pain	5	*0·6*	9	*1·1*	10	*1·3*	3	*0·3*	27	*0·8*
	Missing	27	*3·2*	17	*2·1*	9	*1·2*	29	*3·3*	82	*2·5*
Anxiety/ depression **χ2=37·1, p<0·001**	No anxiety/depression	475	*55·6*	504	*62·8*	464	*59·6*	566	*65·4*	2009	*60·9*
	Slight anxiety/depression	241	*28·2*	196	*24·4*	186	*23·9*	183	*21·1*	806	*24·4*
	Moderate anxiety/depression	78	*9·1*	78	*9·7*	83	*10·7*	76	*8·8*	315	*9·5*
	Severe anxiety/depression	21	*2·5*	6	*0·8*	21	*2·7*	8	*0·9*	56	*1·7*
	Extreme anxiety/depression	10	*1·2*	4	*0·5*	8	*1·0*	4	*0·5*	26	*0·8*
	Missing	29	*3·4*	14	*1·8*	16	*2·1*	29	*3·3*	88	*2·7*

Supplementary Table 2 Quality of Life Dimension Results (EQ5D) by time since diagnosis of cancer

		1 year (n=848)		2 years (n=834)		3 years (n=806)		5 years (n=812)		Total (n=3300)	
		N	%	N	%	N	%	N	%	N	%
Mobility	No Problems	521	*61.4*	501	*60.1*	486	*60.3*	463	*57.0*	1971	*59.7*
χ2=21.1, p=0.05	Slight Problems	150	*17.7*	123	*14.7*	127	*15.8*	135	*16.6*	535	*16.2*
	Moderate Problems	93	*11.0*	116	*13.9*	104	*12.9*	131	*13.1*	444	*13.5*
	Severe Problems	62	*7.3*	62	*7.4*	56	*6.9*	63	*7.8*	243	*7.4*
	Cannot walk	2	*0.2*	8	*9.6*	13	*1.6*	8	*1.0*	31	*0.9*
	Missing	20	*2.4*	24	*2.9*	20	*2.5*	12	*1.5*	76	*2.3*
Self Care	No Problems	696	*82.1*	674	*80.8*	659	*81.8*	653	*80.4*	2682	*81.3*
χ2=10.2, p=0.59	Slight Problems	59	*6.9*	65	*7.8*	61	*7.6*	73	*9.0*	258	*7.8*
	Moderate Problems	57	*6.7*	56	*6.7*	42	*5.2*	51	*6.3*	206	*6.2*
	Severe Problems	12	*1.4*	12	*1.4*	14	*1.7*	13	*1.6*	51	*1.5*
	Cannot wash/dress	3	*0.4*	4	*0.5*	10	*1.2*	6	*0.7*	23	*0.7*
	Missing	21	*2.5*	23	*2.8*	20	*2.5*	16	*2.0*	80	*2.4*
Usual Activities	No Problems	465	*54.8*	474	*56.8*	465	*57.7*	482	*59.4*	1886	*57.2*
χ2=13.9, p=0.31	Slight Problems	181	*21.3*	157	*18.8*	161	*20.0*	137	*16.9*	636	*19.3*
	Moderate Problems	131	*15.4*	112	*13.4*	95	*11.8*	117	*14.4*	455	*13.7*
	Severe Problems	35	*4.1*	45	*5.4*	44	*5.5*	47	*5.8*	171	*5.2*
	Cannot do usual activities	18	*2.1*	19	*2.3*	23	*2.8*	19	*2.3*	79	*2.4*
	Missing	18	*2.1*	27	*3.2*	18	*2.2*	10	*1.2*	73	*2.2*
Pain	No Pain	421	*49.6*	412	*49.4*	435	*54.0*	424	*52.2*	1692	*51.3*
χ2=18.0, p=0.12	Slight Pain	262	*30.9*	237	*28.4*	198	*24.6*	213	*26.2*	910	*27.6*
	Moderate Pain	101	*11.9*	112	*13.4*	105	*13.0*	108	*13.3*	426	*12.9*
	Severe Pain	34	*4.0*	44	*5.3*	38	*4.7*	47	*5.8*	163	*4.9*
	Extreme Pain	7	*0.8*	6	*0.7*	11	*1.4*	3	*0.4*	27	*0.8*
	Missing	23	*2.7*	23	*2.8*	19	*2.4*	17	*2.1*	82	*2.5*
Anxiety/depression	No anxiety/depression	466	*55.0*	505	*60.6*	499	*61.9*	539	*66.4*	2009	*60.9*
χ2=25.8, p=0.01	Slight anxiety/depression	244	*28.8*	195	*23.4*	196	*24.3*	171	*21.1*	806	*24.4*
	Moderate anxiety/depression	88	*10.4*	86	*10.3*	68	*8.4*	73	*9.0*	315	*9.5*
	Severe anxiety/depression	20	*2.4*	13	*1.5*	13	*1.6*	10	*1.2*	56	*1.7*
	Extreme anxiety/depression	6	*0.7*	8	*1.0*	6	*0.7*	6	*0.7*	26	*0.8*
	Missing	24	*2.8*	27	*3.2*	24	*3.0*	13	*1.6*	88	*2.7*

Supplementary Table 3. EQ5D outcome category by the number of Long Term Conditions (LTC) in patients in remission

EQ5D Categories	**High QoL (Scores=1)**		**Medium QoL (0.5≤Scores<1)**		**Low QoL (Scores<0.5)**		**Missing**		**Total**
	n	%	n	%	n	%	n	%	
No LTC	436	51·4	376	44·3	18	2·1	18	2·1	848
1 LTC	250	36·2	378	54·7	40	5·8	23	3·3	691
≥2 LTC	129	18·8	419	60·9	119	17·3	21	3·1	688
Total	815	36·6	1,173	52·7	177	7·9	62	2·8	2,227

Supplementary Table 4. EQ5D outcome category by the number of Long Term Conditions (LTC) in patients not in remission

EQ5D Categories	**High QoL (Scores=1)**		**Medium QoL (0.5≤Scores<1)**		**Low QoL (Scores<0.5)**		**Missing**		**Total**
	n	%	n	%	n	%	n	%	
No LTC	79	33·9	130	55·8	15	6·4	9	3·9	233
1 LTC	64	23·1	175	63·2	25	9·0	13	4·7	277
≥2 LTC	37	11·9	166	53·2	94	30·1	15	4·8	312
Total	180	21·9	471	57·3	134	16·3	37	4·5	822

Supplementary Table 5. Fear of Dying and Recurrence of Disease by Time since Diagnosis

Fear of Dying	Yes%		No		Missing		Total
	n	%	n	%	n	%	
1 year ago	256	*30·2*	542	*63·9*	50	*5·9*	848
2 years ago	233	*27·9*	543	*65·1*	58	*7·0*	834
3 years ago	214	*26·6*	531	*65·9*	61	*7·6*	806
5 years ago	180	*22·2*	583	*71·8*	49	*6·0*	812
Total	883	*26·8*	2,199	*66·6*	218	*6·6*	3,300
Fear of Recurrence	n	%	n	%	n	%	
1 year ago	437	*51·5*	369	*43·5*	42	*5·0*	848
2 years ago	403	*48·3*	398	*47·7*	33	*4·0*	834
3 years ago	376	*46·7*	384	*47·6*	46	*5·7*	806
5 years ago	345	*42·5*	427	*52·6*	40	*4·9*	812
Total	1,561	*47·3*	1,578	*47·8*	161	*4·9*	3,300