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Quality of Life of Colorectal Cancer Survivors in England

Report on a national survey of colorectal cancer survivors using Patient Reported Outcome Measures (PROMs)

March 2015

NHS England Publications Gateway Reference 02777

NHS England Equalities Statement

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of this methodology and the consequent report, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it;

- Given regard to the need to reduce inequalities between patients in access to, and outcomes from, healthcare services and in securing that services are provided in an integrated way where this may reduce health inequalities."

NHS England and this report

As stated above promoting equality and addressing health inequalities are at the heart of NHS England's values. We seek, at all times, to reduce inequalities between patients in the way they access and receive healthcare services.

The information in this report was compiled using a whole population approach to sampling, and therefore included all groups, and did not exclude any potentially vulnerable or disadvantaged individuals.

Analysis of the resulting data found that the proportion of those who responded to the survey from a 'non-white' background were markedly lower than those from a 'white' background. This is a concern and something we will look to address in future research programmes of this kind ; as part of this process we will conduct further analysis of the colorectal cancer survivor data to understand if there are factors that might have contributed to this.

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Description	**This is the first national PROM survey of cancer survivors, in England. It asks about quality of life issues for those who are living 12 – 36 months, at least, beyond bowel cancer treatment. The report, and the data toolkit, in particular, will allow provider Trusts, Clinical Commissioning Groups and Strategic Clinical Networks to look at the answers to the questions in the survey from the users of those services, within their duty.**
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Foreword

The publication of this report represents an important milestone in the evaluation of quality of life for people living with and beyond colorectal cancer in England as it is the first national whole population cancer survey using Patient Reported Outcome Measures (PROMs).

Current estimates indicate 240,000 people in the UK are living with or beyond a diagnosis of colorectal cancer, and this number is expected to double to 630,000 by 2040. Whilst an increase in survival rates is clearly a great accomplishment, there are unintended negative consequences associated with this. As a result of having colorectal cancer, and undergoing the associated treatments such as radiotherapy, chemotherapy and surgery, the quality of life of those affected by it can potentially be significantly reduced.

There were 21,802 individual responses to the survey which was carried out in 2013 and sent to people diagnosed with colorectal cancer during 2010 and 2011 who survived between 12 and 36 months post-diagnosis.

Respondents described different parts of their journey from a diagnosis of colorectal cancer to treatment and through to their experiences of aftercare. Respondents often related challenges they experienced to their quality of life to a greater or lesser extent. These 'frequently occurring challenges' include: The emotional impact of cancer and treatment; On-going social and financial problems that made life difficult; Long-term and age-related illnesses that could exacerbate, or be exacerbated by, problems associated with cancer treatment; Unpleasant physical side-effects of treatment.

The information in this report will be of vital importance to:

- describe the quality of survival of people with colorectal cancer
- identify consequences of survival and impact on function
- identify factors that impact on outcome, including treatment
- compare outcomes by service provider organisations
- support enhanced commissioning & delivery of care
- enable provision of appropriate health & social care
- use in clinical trials & supportive care research

This report also provides an exciting opportunity to share information to support development and commissioning of robust living with and beyond cancer services across the health economy.

I hope this report challenges health and social care commissioners and providers to address the issues identified in this survey.

Mr Sean Duffy

National Clinical Director for Cancer: NHS England

Executive summary

Methodology

- Individuals alive 12-36 months after a diagnosis of colorectal cancer were identified via the National Cancer Registration Service and were sent a questionnaire in January 2013.
- Of 34,467 individuals approached, 21,802 returned a fully or partially completed questionnaire (63% response rate). The data presented here is based on the responses to those questionnaires.

Demographics

- 62% of respondents had colon cancer, 7% had recto-sigmoid cancer and had 31% rectal cancer. 55-64 and 65-74 year olds were most likely to respond. White people and those living in the least deprived areas were more likely to respond.
- 20% reported no other long term condition (LTC), 30% had one other, 20% two others and 23% three or more other LTCs.

Health status measured with EQ-5D

- 35% of all colorectal respondents reported no problems on the EQ-5D (no issues identified across the 5 domains of EQ-5D – pain/discomfort, self-care, usual activities, mobility, anxiety/depression). Those with colon cancer were more likely to report this ‘perfect’ health state (37%) compared to those with rectosigmoid cancer (36%) and rectal cancer (29%). Males with colorectal cancer were more likely to report ‘perfect’ health than females, with the difference being most marked for those with colon cancer.
- 65-74 year olds were the most likely to report ‘perfect’ health, with those aged over 85 years and under 55 years least likely to report this health state. Those with concurrent LTCs, those with recurrent or residual disease and those with a stoma were much less likely to report ‘perfect’ health.
- EQ-5D data could be age- and sex- matched against the general population using the Health Survey for England 2011 (HSE 2011) for 4,615 individuals. 31% of the colorectal survey respondents reported being in ‘perfect’ health, whilst 40% of HSE 2011 respondents were in this health state. The largest discrepancy was reported by the colorectal cohort aged under 55 years (27% colorectal cohort and 50% HSE 2011) with the next largest discrepancy being for those aged 55-64 years with colorectal cancer (34% vs 40%). Those aged 65 years and over with colorectal cancer reported similar levels of ‘perfect’ health compared to the general population.

- Mobility and usual activities were the EQ-5D domains most likely to have been affected in individuals following a colorectal cancer diagnosis (compared to the general population).

Stoma

- 12-36 months from a diagnosis of colorectal cancer, 21% of individuals reported the presence of a stoma (10% colon, 20% rectosigmoid, 43% rectum). 20% of those with a stoma were embarrassed quite a bit or very embarrassed - individuals with rectal cancer living with a stoma were less embarrassed by it. They equally had less difficulty caring for it (9% rectum, 15% rectosigmoid, 13% colon).
- The presence of a stoma significantly reduced the proportion of individuals reporting 'perfect' health (19%) on the EQ-5D, whilst those who reported a reversal of stoma had almost the same level of 'perfect' health (35%) as those known to have never had a stoma (40%). The presence of a stoma was associated with the reporting of higher levels of social distress on the Social distress Inventory (SDI), whilst those who reported having had a stoma reversed showed little difference with those who had never had a stoma.

Bowel, urine and sexual issues

- 22% of those without a stoma reported they had little or no control of their bowels. 7% reported a significant issue with diarrhoea.
- 20% reported having little or no appetite and 20% reported being unable to digest food well.
- No difficulties with urinating were reported by the majority: Overall 4% reported difficulty urinating with 13% reporting urinating more frequently than normal and 5% reporting leaking urine. These problems were slightly more common in the rectal group.
- 25% of respondents reported difficulties with sexual matters with those diagnosed with rectal tumours being most affected (rectal tumours 38%, rectosigmoid 24%, colonic tumours 18%).
- 40% of respondents were unhappy with their appearance whilst 35% were happy.

Social functioning

- 15% respondents reported significant social distress (18% rectal, 15% rectosigmoid, 14% colon). Issues with 'everyday living' (19%) and 'self and others' (18%) were more common than 'money matters' (16%). Social distress was most marked for the under 55 years and 85+years age groups, no gender effect was identified.
- Deprivation was linked to the levels of social distress experienced 12-36 months after a diagnosis of colorectal cancer, with increasing deprivation being associated with a greater incidence of reported social distress.

- High social distress scores were more likely in those reporting either recurrent (35%) or residual but treated disease (35%) as opposed to those reporting to be in remission (11%). The presence of increasing numbers of additional LTCs was linked to increasing numbers reporting high levels of social distress.
- Difficulties with travel plans were reported by 22% of respondents, again this was most marked following a diagnosis of a rectal tumour (rectum 26%, rectosigmoid 21%, colon 19%).
- 40% experienced trouble sleeping and 40% reported feeling tired. 30% reported memory loss whilst 29% experienced mood swings, 29% reported irritability and 28% had difficulty concentrating.

Fear of cancer spreading, recurring or death

- Over half the respondents (56%) had fears of their cancer returning, 46% had fears of their cancer spreading and 30% experienced fears about death and dying.

Health and social care support

- Over three quarters of people reported being supported well all the time by their hospital with a further 14% some of the time. 6% reported not needing support whilst 2% felt never supported.
- 55% reported being supported by their GP at all times with a further 14% some of the time. 9% felt they never needed support whilst 14% reported never receiving support.
- Health and Social Service support was reported to be appropriate by 36% with a further 18% reporting support to a certain extent. 10% reported not receiving appropriate support whilst 36% felt they did not need help.

Lifestyle

- 35% of respondents reported doing 30 minutes of exercise on no days each week, 44% did between 1 and 4 days each week, 21% did the recommended 5 or more days each week.
- Around 6% of respondents described themselves as smokers, nearly 40% as ex-smokers and over 50% as non-smokers. A slightly higher proportion of people with rectal tumours self-reported as smokers or ex-smokers. Of those respondents who had rectal tumours and classed themselves as ex-smokers, a slightly higher proportion quit 1-2 years ago and a slightly lower proportion quit more than 5 years ago compared with tumours of the colon and rectosigmoid tumours.

Respondents' comments

- An open-ended free-text question was placed at the end of the PROMS questionnaire. A quarter of the survey respondents (n= 5,634, 25.8%) chose to answer to this question.

- The majority of comments were positive, with respondents expressing gratitude and praising individual healthcare professionals, departments, hospitals or the NHS as a whole. However, alongside these very positive comments there were also many less favourable.
- Respondents described different parts of their journey from a diagnosis of colorectal cancer to treatment and through to their experiences of aftercare. Respondents often related challenges they experienced to their quality of life to a greater or lesser extent. These 'frequently occurring challenges' include: The emotional impact of cancer and treatment; On-going social and financial problems that made life difficult; Long-term and age-related illnesses that could exacerbate, or be exacerbated by, problems associated with cancer treatment; Unpleasant physical side-effects of treatment.

Introduction

Aims of the study

Around 40,000 individuals are diagnosed with colorectal cancer each year in the UK[1]. Mortality from colorectal cancer has reduced as a result of both advances in medicine and technology, and potentially through earlier identification and treatment of colorectal cancer through better screening[2]. This has led to an increase in the number of people living in the UK that have survived colorectal cancer. Current estimates indicate 240,000 people are living in the UK with or beyond a diagnosis of colorectal cancer, and this number is expected to double to 630,000 by 2040[3]. Whilst an increase in survival rates is clearly a great accomplishment, there are unintended negative consequences associated with this[4]. As a result of having colorectal cancer, and undergoing the associated treatments such as radiotherapy, chemotherapy and surgery, the quality of life of survivors can potentially be significantly reduced.

The study aimed to explore the extent to which health-related quality of life is affected by the disease, and sought to identify key areas where more can be done to improve the quality of survival after colorectal cancer. These effects are explored through the analysis of survey questions answered by survivors of colorectal cancer relating to their health-related quality of life and their experience of care by the NHS.

Context of the study

The process of collecting patient reported outcome measures (PROMs) using questionnaires is a method that has recently been adopted by the NHS. PROMs data have been collected on four elective procedures nationally since April 2009[5] and are becoming increasingly important forming part of the NHS Outcomes Framework for Domain 3 around helping people to recover from episodes of ill health or following injury[6].

More specifically for colorectal cancer, the feasibility of collecting PROMs data was tested through a pilot study in July 2011[7] which confirmed the value of collecting PROMs data on four different cancer tumour types (breast, prostate, colorectal and non-Hodgkin's lymphoma). The results highlighted a range of quality of life issues experienced by cancer survivors.

This study was commissioned by the Department of Health as a follow-on from the pilot study. In January 2013 surveys were sent to people diagnosed with colorectal cancer during 2010 and 2011 who survived between 12 and 36 months post-diagnosis. This report describes how the study was undertaken and presents a high level analysis and interpretation of the results. Accompanying this report are two excel based tools which should be used alongside this report to provide more detailed information. The National Reporting Tool explores the national findings by respondent characteristics and tumour type and includes information on the free text comments provided. The NHS Trust, CCG and SCN level data toolkit enables the results from each Strategic Clinical Network (SCN), Clinical Commissioning Group (CCG) and Hospital NHS Trust to be visualised. This tool includes the responses to each question in the survey. Additionally a set of peer-reviewed journal articles will be produced using the survey data.

Methodology

Study design

The cohort of individuals to be approached was identified via the National Cancer Registration Service (NCRS) using the following criteria:

- The person was over 16 years old
- The person had survived 12-36 months since their diagnosis of colorectal cancer in 2010 or 2011
- The person had received treatment in the NHS in England

Colorectal cancer was defined as those patients who had cancer of the colon, cancer of the recto-sigmoid junction or cancer of the rectum as per the International Classification of Diseases register (ICD-10[8] codes C18-C20). We estimate that >97%of the eligible cases were identified.

Every effort was made to ensure that no deceased persons received the survey. The questionnaire was sent out to people with a covering letter outlining the study and up to 2 reminders were sent to those who did not respond. A phone line was provided to assist in completing the questionnaire should anyone have any queries. Consent to take part in the survey was through the return of a fully or partially completed survey. Individuals who declined to consent either did not return the survey or returned the questionnaire blank.

The questionnaire comprised of 76 questions with an additional comments box. The questions were divided into a number of different sections outlined below.

- **General questions** - a range of questions asking about the type of treatment the person had, the length of time since their treatment, how well their cancer had responded to treatment and whether they had a stoma or not.
- **Outcome questions** - a set of questions using three different instruments (described below) to assess how the patient felt about the impact of the cancer physically and emotionally.
- **Overall support and care** - a number of questions about the care the person received in primary care (GP/community care) and secondary care (hospital), as well as questions around access to information and support, and more general questions about lifestyle (smoking and exercise).
- **About you** - demographic questions were included to enable the results to be considered alongside factors such as age, sex, deprivation, ethnicity, and presence of long term conditions.

- **Comments** - a free text box was available for patient's to make any additional comments on any aspects of living with cancer not touched on elsewhere in the survey or to provide further views and explanations.

Questionnaire instruments

The outcome questions in the survey were made up of three instruments: the EQ-5D, FACT items and SDI. These instruments are summarised below in brief.

EQ-5D (Euroqol 5 level)

This is a generic health-related quality of life measure. The instrument includes 5 different dimensions covering: Mobility, Self-care, Usual activities, Pain/discomfort and Anxiety/depression. The individual is asked to select from 5 different options to describe how they feel ranging from 'no problems' to 'extreme' problems (questions 5-9 in the survey).

FACT items (Functional Assessment of Cancer Therapy)

Questions specific to cancer were taken from a larger survey instrument to understand more about the physical and emotional impact on quality of life. The individual responded to a set of statements on a scale from 'not at all' (no issues) to 'very much' (major problems) (questions 10-22 in the survey).

SDI (Social Difficulties Inventory)

This instrument is designed to look at the impact of cancer on issues such as family life, social activities, finances and work. The respondent is asked to rate their level of difficulty on a number of questions ranging from 'no difficulty' to 'very much' (questions 26-46 in the survey).

Additional questions were also included in the survey asking the person to assess the extent to which they agree with a set of statements around moods and feelings, and questions related to the respondents' views on their healthcare experience and lifestyle. These were used to capture any additional important health related quality of life issues not covered by the instruments.

Handling quantitative data

This section looks at how the quantitative data was handled prior to analysis. As the eligible participants were identified via the NCRS, additional cancer registration data were available.

Therefore, some of the information is taken from the questionnaire responses and some from the cancer registry.

Age, sex and Duke's stage of disease at diagnosis were taken from the cancer registry data. Age was categorised as <55, 55-64, 65-74, 75-84, and ≥85 years. Deprivation quintiles were derived, based on the 2010 index of multiple deprivation (IMD[9]), using postcode of residence at the time the individual completed the survey.

Self-reported ethnicity was grouped into white and non-white; this could not be broken down further due to the small numbers of respondents from minority ethnic groups. Participants were asked if they had any long term conditions (LTC) other than their cancer diagnosis and were asked to tick the appropriate LTCs within a given list (question 72 of the Colorectal PROMS survey). This variable was categorised into 'no other LTC', 'one other LTC', 'two other LTCs', and 'three or more LTCs'. Information on disease status (remission, treated but still present, no treatment, recurrence, not certain), treatments (surgery, radiotherapy and chemotherapy) and stoma status (present, reversed, no stoma) were derived from self-reports captured by the questionnaire.

EQ-5D

The 5-level version of EQ-5D10 records the respondents' self-assessed problems on each of five domains. These data may be summarised as a single index score using a standard algorithm; scores range from -0.5 to 1, where 1 is the maximum score for an individual reporting no problems on any of the domains. Due to the highly skewed distribution of the scores (median=0.84, IQR=0.71-1.0), this outcome variable was categorised as 'perfect' (a score of 1) or 'less than perfect' health (a score <1). It should be noted that 'perfect' health here is defined exclusively in terms of the dimensions specified by the EQ-5D descriptive classification and that it remains possible for patients to experience health problems on otherwise non-defined/unobserved dimensions

FACT items and other condition specific

Bowel cancer specific questions from FACT items[11] were examined separately (the FACT total score could not be calculated as only the certain relevant questions were included). The five possible responses were grouped into three categories for ease of presentation: Not at all/A little, Somewhat, Quite a bit/Very much. The analysis of questions relating to bowel function was limited those without a stoma, as it was felt that individuals with a stoma present could interpret the questions in a variety of different ways.

SDI

The Social Difficulties Inventory[12] (SDI) contains 21 questions, 16 of which form the main outcome measure (SD-16). The SD-16 scores were examined, along with the scores on the three subscales that form the SD-16: 'Everyday living', 'Money matters' and 'Self and other'. Higher scores on the SD-16 and subscales indicate a more negative impact on quality of life. Scores of more than 10 on the SD-16 suggest that there is a significant negative effect on the individual's ability to cope and intervention may be required. These individuals are classed as being in 'social distress'. The levels of 'social distress' responses were examined on a range of characteristics. The subscale scores and the responses to five questions that do not form part of the wider SD-16 were examined separately.

Health Survey England

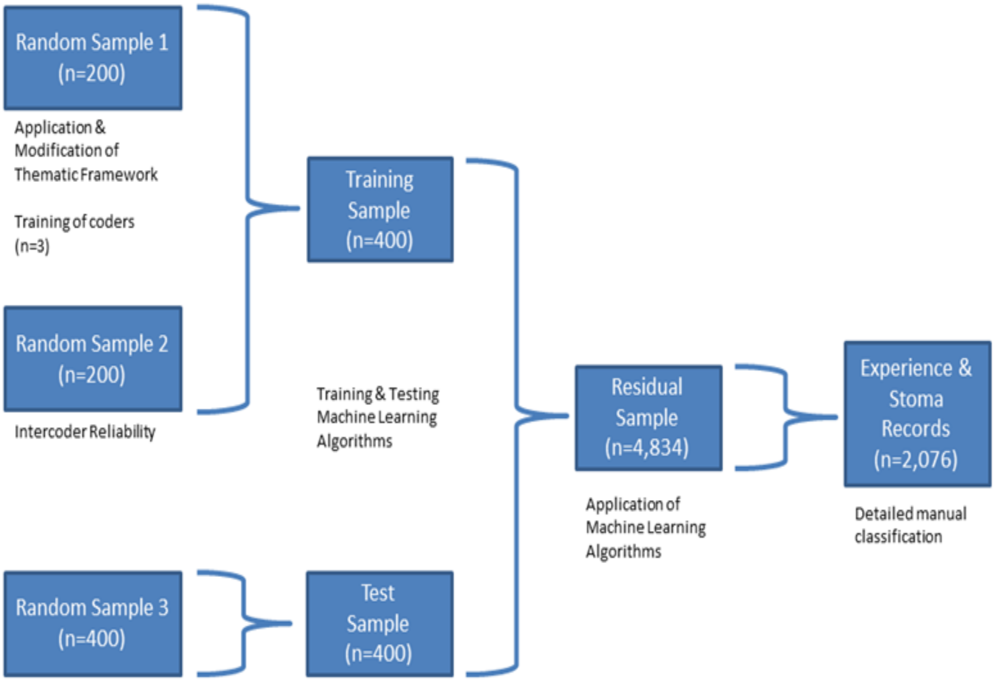
In order to make some comparisons of the health-related quality of life (HRQL) of colorectal survivors with the general population, the Health Survey for England 2011 (HSE 2011)[13] was used. This is a large household survey (8,610 individuals aged over 16) which measures HRQL using EQ-5D allowing direct comparison. The colorectal PROMS and HSE datasets were age and sex matched, creating a comparable sample of 4615 individuals with EQ-5D responses on all five domains (this lower number reflects the very different age profiles of the two surveys).

Handling qualitative data

The 5,634 free text comments provided by individuals at the end of the questionnaire were analysed to explore their content through applying text mining methods to identify comments relevant to specific topics of interest (e.g. positive/negative experience). Based on substantive work to describe the experience of living with and beyond cancer in a thematic framework[14] and methodological work around search strategy development for systematic reviews[15-16], the thematic framework was applied to patient comments and used to manually classify a random sample of comments. This manually coded sample was then used to apply supervised machine learning algorithms in order to automatically identify comments of specific topics of interest (e.g. positive/negative experience, stoma). These were then analysed to develop a tentative model that explained how different elements of care described by respondents determined whether their experiences were either positive or negative (Figure 25 in results section).

To analyse responses to the free-text comments box at the end of the questionnaire, text mining techniques were used to identify comments specific to perceptions of service quality experienced by respondents. Text mining combines methods from natural language processing, information retrieval and machine learning to explore research questions in the social sciences[17]. This analysis consisted of three linked steps.

Figure 1 – Development and Implementation of qualitative analysis



1. Application of the thematic framework of the experience of living with and beyond cancer[18-19.] Agreement of raters (AR, KH, RW) for the main categories of interest (Cohen's Kappa) ranged from substantial (0.64) to excellent (0.87).
2. Training and testing a set of machine learning algorithms (MLA) in order to be able to identify comments including certain codes (e.g. positive experience) in the remaining data set.
3. Application of trained MLA's to the remaining yet unclassified comments (n=4,834) retrieving 2,076 comments related to positive or negative experience of care. A detailed manual coding was then conducted on these comments.

Data limitations

The information presented in this report and the associated toolkits must be interpreted with consideration of the issues highlighted below. Ideally, we would have liked to present variation in health outcomes by service provider comparisons, however, due to these issues we did not feel that such comparisons would be robust or meaningful.

1) Case ascertainment

The survey captured data on those who survived between one and three years from the diagnosis of colorectal cancer. But, survival rates are known to vary significantly across the country. Those who die rapidly are likely to have more advanced disease and more co-morbidities than those who survive and, as demonstrated by this survey these individuals are more likely to report lower health-related quality of life (HRQL). The incomplete case ascertainment of the survey prevents, therefore, organisational comparisons.

2) Respondent bias

There are significant differences in the characteristics of those who did and did not respond to the survey. The elderly, those living in more socio-economically deprived areas and those with more advanced disease were less likely to respond. Evidence suggests these individuals have lower HRQL. Their failure to respond means their outcomes could not be included in comparative analyses and so makes any organisational comparisons inaccurate.

3) Lack of control data

No information was available from respondents on their health related quality of life prior to being diagnosed with their cancer. Equally, there was no information available for non-cancer controls of an age, sex and socio-economic status matched population at organisational level. The characteristics of populations managed by different NHS organisations are known to be significantly different. Insufficient information was, therefore, available to enable assessment of the underlying HRQL of populations and so determine the true impact of the disease and its management between NHS organisations

4) Distribution of EQ-5D scores

The main HRQL outcome used in the survey was EQ-5D. The results of this score display a highly skewed distribution. Modelling this is methodologically difficult and requires the development of appropriate methods to produce robust provider comparisons.

Results

Response rates and response bias

The NCRS identified 35,213 individuals with a diagnosis of colorectal cancer in 2010 or 2011. Of these, 746 (2.1%) were removed as the individual had died leaving a final sample of 34,467. Of these, 21,802 individuals returned partially or fully completed questionnaires giving a response rate of 63.3%. The characteristics of responders and non-responders were compared to see whether certain characteristics seemed to influence the likelihood of a person completing the survey. This is important as response bias may influence the outcomes. Below are the key findings on response rates (see table 1 for details).

1) **Age -** The 55-64 and 65-74 age groups had the highest response rates (both 67.7%) and the 85+ had the lowest response rate (49.0%)

2) **Sex** - More males than females were surveyed (56.8% versus 43.2%). The response rate was slightly higher for males than females (64.8% in males and 61.3% in females)

3) **Ethnicity** - 71.9% of people approached were white, and 3.1% non-white. The response rate was higher for white (64.9%) compared to non-white (44.7%)

4) **Stage of disease** - Response rates were higher for individuals diagnosed with early stage disease (Dukes A, 68.9%) compared to those with later stage disease (Dukes D, 59.2%)

5) **Deprivation** - Individuals living in more deprived areas were less likely to respond (52.1% compared to 70.2% living in the least deprived areas

The key findings from the response rates suggest that those over 85, those from a non-white ethnic group and people living in more deprived areas were significantly less likely to respond to the survey.

Characteristics of respondents

The characteristics of the survey respondents were examined overall and split by tumour type (see table 2 for details).

1) **Tumour type** - Individuals with colon tumours accounted for 62% of respondents, 7% were rectosigmoid and 31% were rectum tumours

2) **Age -** Individuals with colon tumours tended to be slightly older - a lower proportion were under 55 years old (29% were under 55 compared to 37% for rectosigmoid and 40% for rectum), and a higher proportion were over 75 years old (35% for colon tumours compared to 27% for rectosigmoid and 25% for rectum).

3) **Sex** - A higher proportion of respondents were male (58% compared to 42% overall). This pattern was reflected across all tumour types, particularly for rectosigmoid and rectum where the proportion of males was much higher than females.

4) **Deprivation** - Around 50% of respondents were from the least and second least deprived areas, therefore far fewer people were from the remaining deprivation quintiles, with less that 12% overall being from the most deprived quintile.

5) **Disease status** - Over three-quarters of respondents for each tumour type reported that they were in remission, 5% said the cancer was still present and 3% said it had returned and 10 % did not respond. The split across tumour types was fairly even.

6) **Stoma status** - 10% individuals with colon tumours reporting having a stoma and 7% said their stoma had been reversed. For rectosigmoid the proportions were 21% with a stoma and 23% reversed, and for rectum tumours 42% said they had a stoma and 31% said their stoma had been reversed.

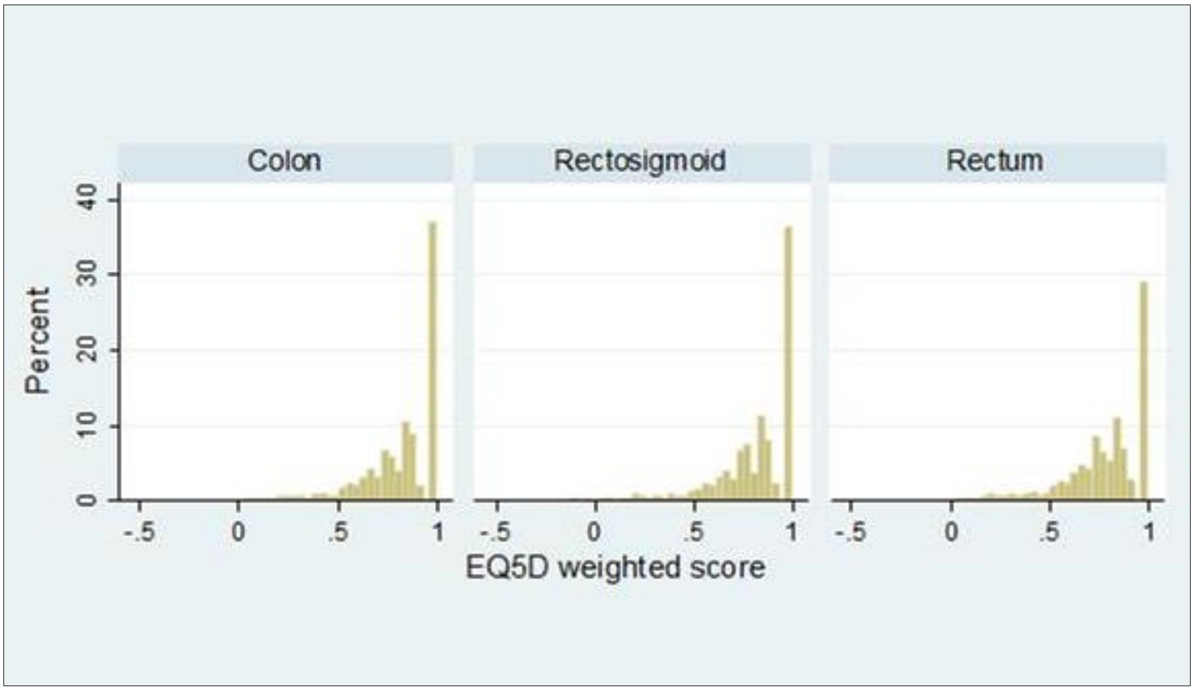
7) **Treatment type** - 51% of colon patients reported having surgery only, with another 39% reporting that they had surgery combined with chemotherapy and/or radiotherapy treatment. For rectum patients 30% had surgery only, and 59% had surgery with chemotherapy and/or radiotherapy.

8) **Long term conditions** - The split by number of long term conditions was consistent across all three tumour sites, with around 20% of people reporting that they had no other long term conditions, nearly one third reporting that they had one other long term condition, and around 40% stating they had 2 or more long term conditions.

Generic PROMs - EQ-5D

The concept of 'perfect' health using the EQ-5D was explored by tumour type and patient characteristic. The EQ-5D was analysed in this way due to the skewed distribution of the utility scores. 'perfect' health overall for the EQ-5D was defined as a response of 'no problem' on any of the five domains.

Figure 2 - Distribution of EQ-5D utility scores



Combining the three tumour types, over one third (35%) of all colorectal respondents reported 'perfect' health (no problems on any of the EQ-5D domains). Looking at the separate tumour types, colon and rectosigmoid cancer patients were more likely to report 'perfect' health (37% and 36% respectively) compared with rectal cancer respondents (29%).

There were slight differences between tumour types in relation to age, sex, deprivation and treatment, but the largest effects were seen in relation to disease status and number of long term conditions. The scores for all tumour types for 'perfect' health are presented below by each characteristic. For the breakdown of 'perfect' health by tumour type for each characteristic see the national tool.

Figure 3 - Proportion of respondents in 'perfect' health by age group

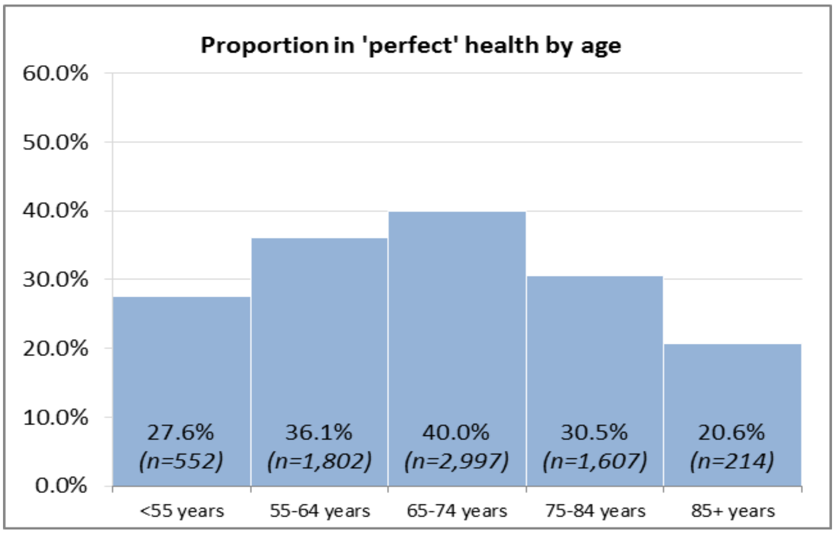


Figure 4 - Proportion of respondents in 'perfect' health by gender

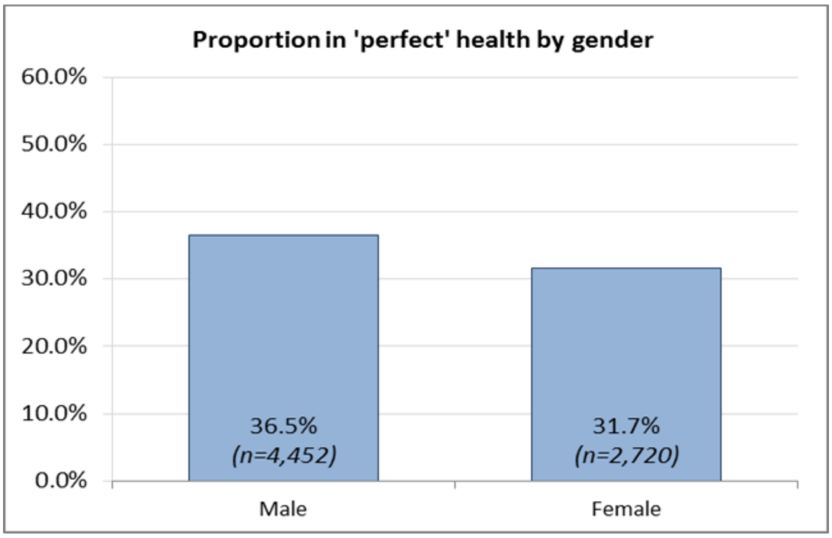


Figure 5 - Proportion of respondents in 'perfect' health by deprivation quintile

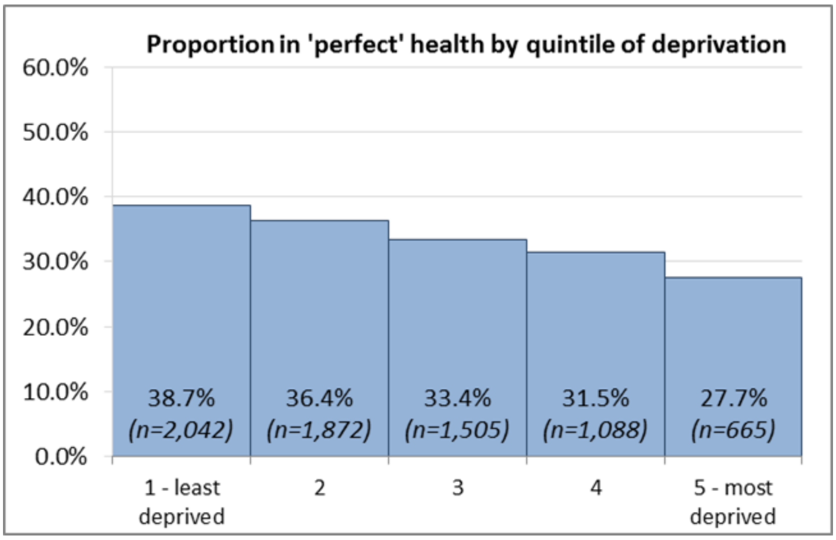


Figure 6 - Proportion of respondents in 'perfect' health by disease status

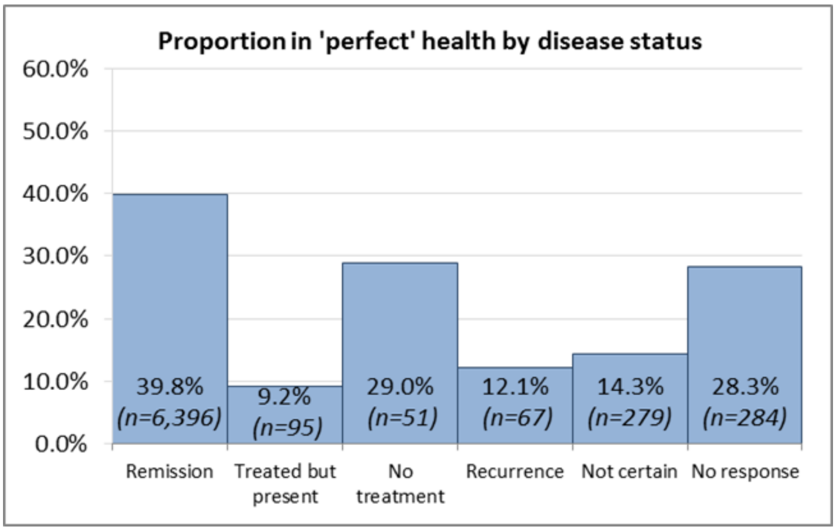
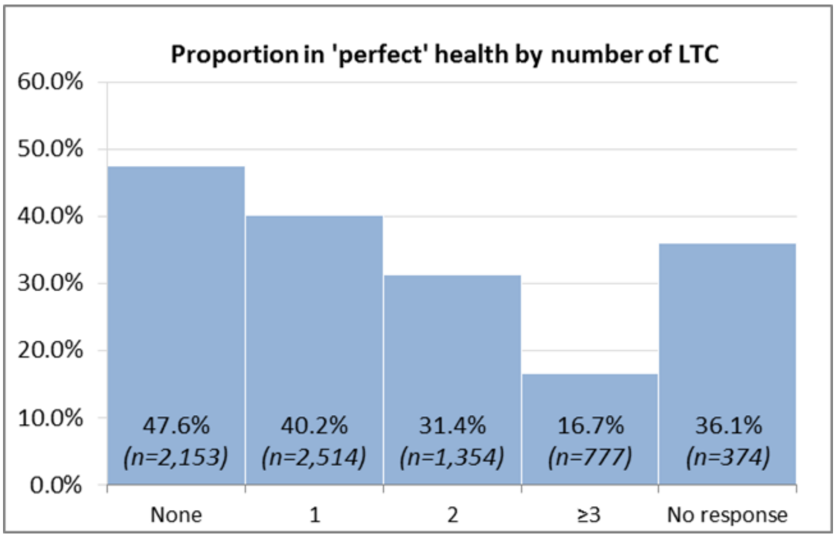


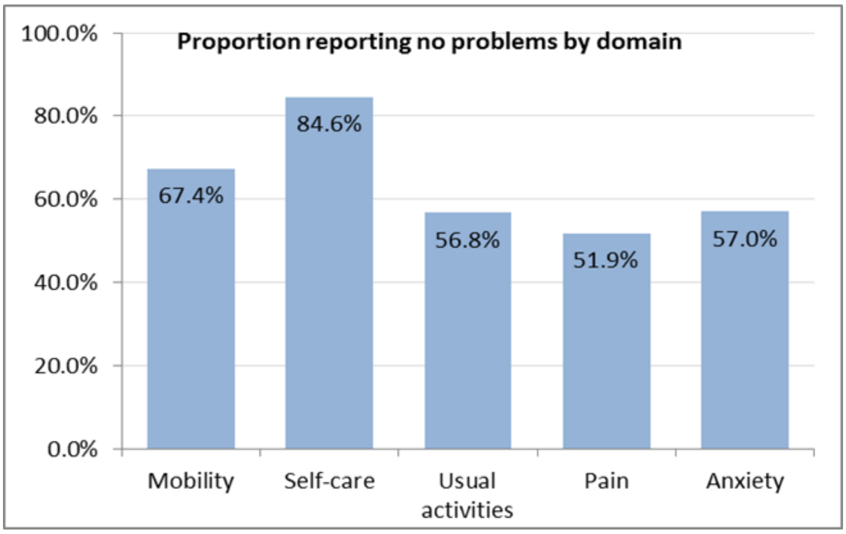
Figure 7 - Proportion of respondents in 'perfect' health by number of long term conditions



Across the five EQ-5D domains, the highest proportion of respondents reported no problems with the 'self-care' domain (84.6%) (figure 8). The domain with the lowest proportion of respondents reporting no problems was for pain and discomfort with 51.9% of respondents reporting 'no problems' on this domain.

By tumour type, respondents with rectal tumours had slightly worse outcomes on the EQ-5D domains compared with other tumour types on the 'usual activities' and 'pain/discomfort' domains.

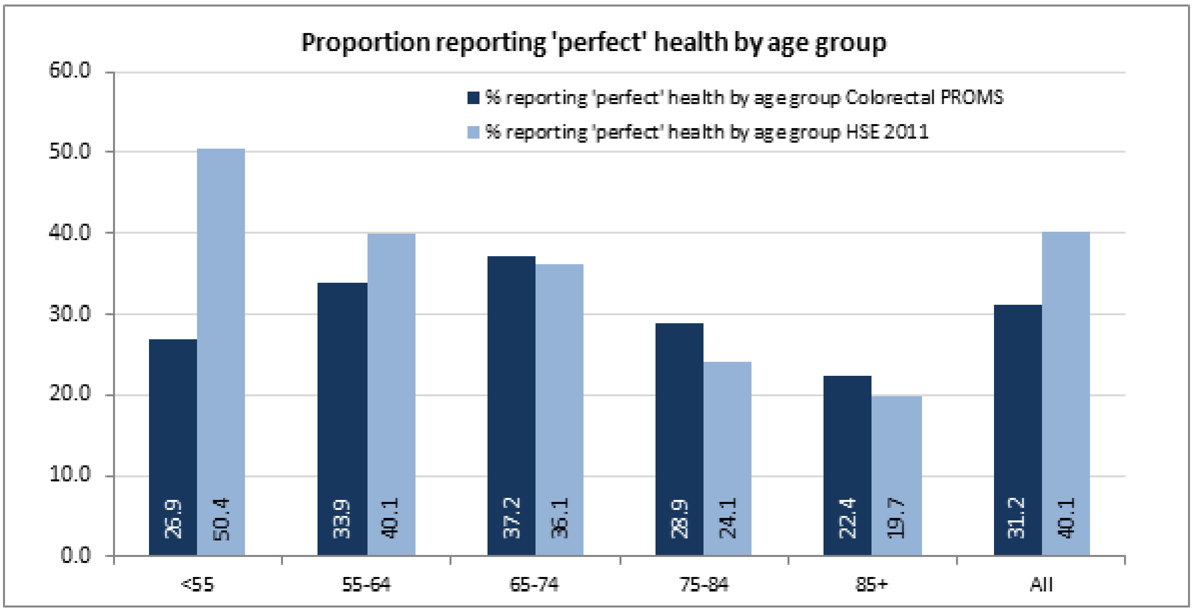
Figure 8- Proportion of respondents reporting no problems by EQ-5D domain



Comparison with Health Survey for England 2011

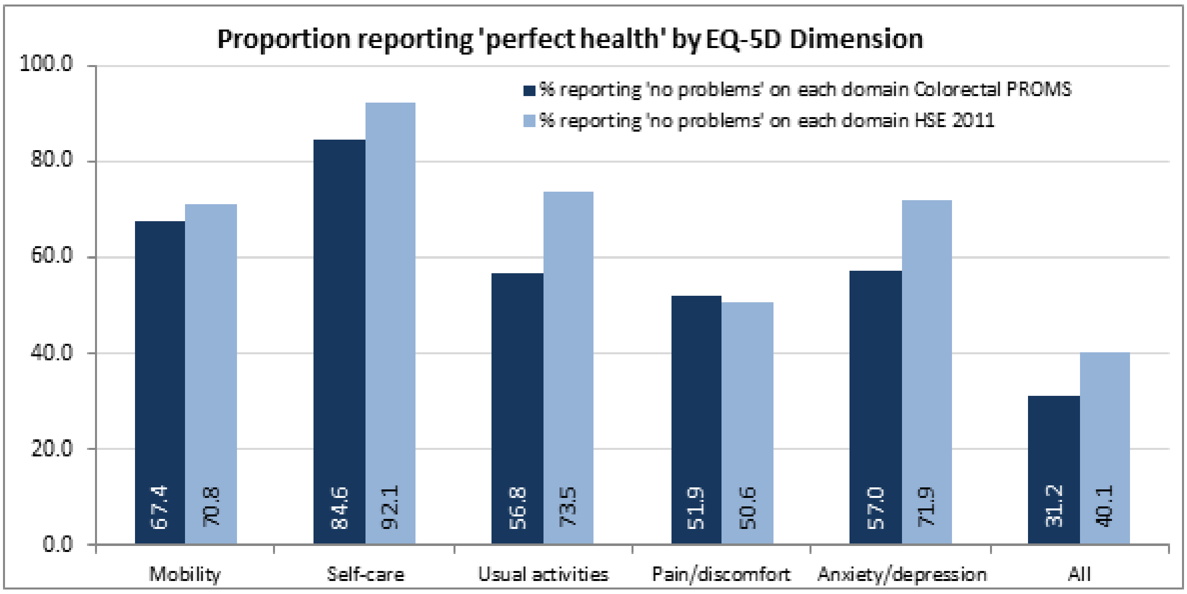
The outcomes for 4,615 colorectal cancer survivors were compared with an age and sex matched sample of people from the Health Survey for England (HSE) 2011. As the EQ-5D measure was used in both the PROMs survey and the HSE 2011, levels of 'perfect health' could be compared. Levels of 'perfect' health were found to be lower in colorectal cancer survivors compared to the general population (31.2% versus 40.1%). This difference was largest in the under 55 age group, where only 27% of colorectal cancer survivors (compared 50% of the general population) reported 'perfect' health.

Figure 9 - Comparison of 'perfect' health by age group for colorectal cancer survivors and HSE



The proportion of people in ‘perfect’ health was also compared across the 2 groups by each of the EQ-5D domains. Apart from the pain/discomfort domain which was similar across both groups, lower proportions of colorectal cancer survivors reported that they were in ‘perfect’ health on each of the other four domains. The difference was particularly significant for usual activities (57% v 73%) and anxiety/depression (57% v 72%).

Figure 10- Comparison of ‘perfect’ health by EQ-5D dimension for colorectal cancer survivors and HSE

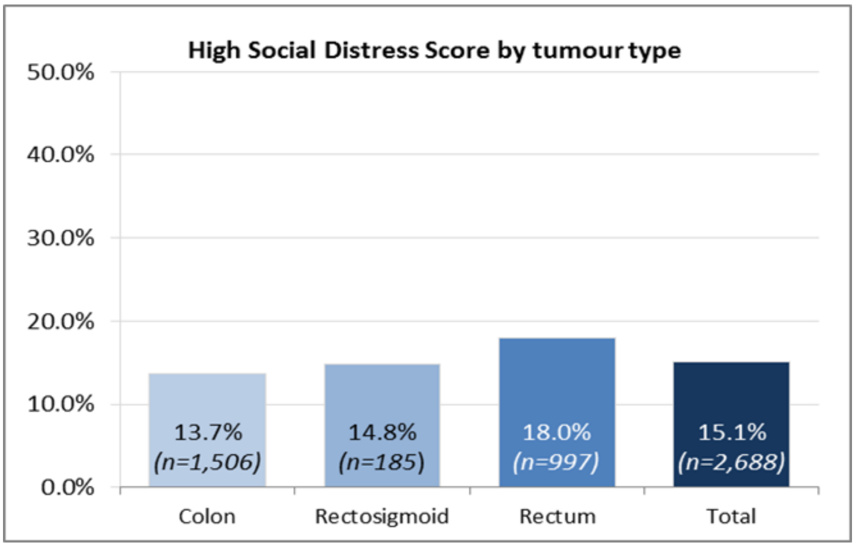


Ideally, levels of ‘perfect’ health in colorectal cancer survivors and the general population would have been compared according to the number of long term conditions reported, but this was not possible due to different list of conditions used in the colorectal PROMs and HSE 2011 surveys. Only those without any reported long-term conditions could be compared. ‘Perfect’ health was reported by 41% of colorectal cancer survivors and 60% of HSE 2011 respondents with no other long-term conditions.

Social Difficulties

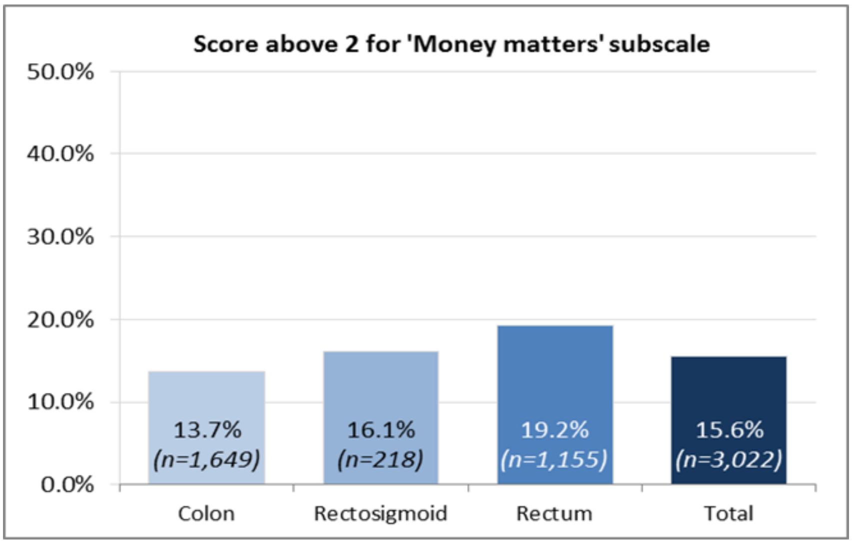
The Social Difficulties inventory was used to assess a number of problems that cancer survivors may experience related to aspects of life around family, social activities, finances and work. Overall 15% of colorectal cancer survivors were classed as being in ‘social distress’ (a score of 10 or more on the SD-16). Across the tumour types, a higher proportion of rectal cancer survivors were in ‘social distress’ (18%, compared to 14% for colon and 15% for rectosigmoid).

Figure 11- Proportion in 'social distress' on the SD-16 by tumour type



On the three subscales, those with rectal tumours had a higher proportion of people reporting negative outcomes. The largest difference was seen for the money matters subscale where 14% of colon cancer survivors reported a high score, compared with 19% of rectal cancer survivors (see national tool for details).

Figure 12 - Proportion reporting a score of 2 or more on the 'money matters' subscale



The SD-16 score for 'social distress' was examined by tumour type and patient characteristic. For sex there was no difference between males and females in 'social distress.' By age, the youngest age group (<55 years) and the oldest age group (85+) had the highest proportion of people in 'social distress'. Colorectal survivors from more deprived backgrounds tended to report more 'social distress.' Those in remission had the lowest levels of 'social distress.' Presence of a stoma and having more long term conditions were all associated with increased levels of ‘social distress.’ Levels of ‘social distress’ also varied by treatment type, those undergoing surgery alone reported the lowest ‘social distress.’ There were no major differences between tumour types. Survivors of rectosigmoid tumours differed on some characteristics, but the numbers from which the proportions are calculated are small. See the national tool for the tumour site breakdown by characteristic.

Figure 13 - Proportion of respondents in ‘social distress’ by age

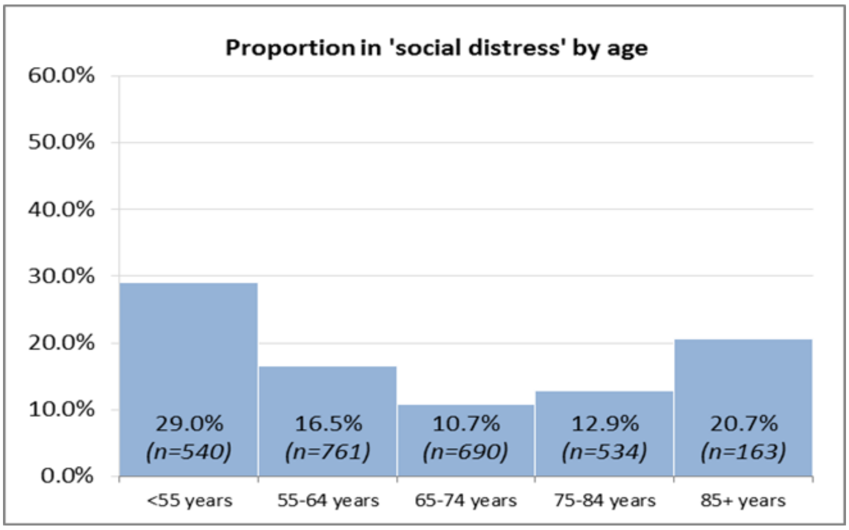


Figure 14 - Proportion of respondents in ‘social distress’ by sex

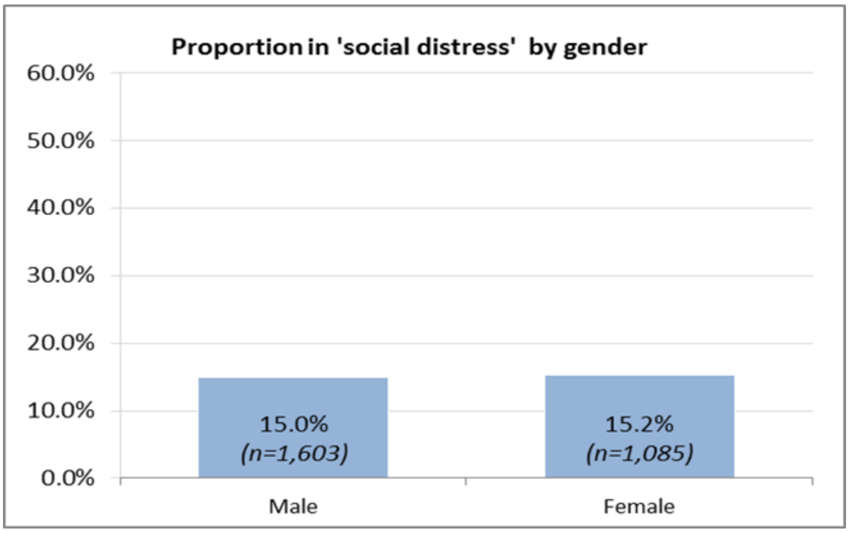


Figure 15 - Proportion of respondents in 'social distress' by deprivation quintile

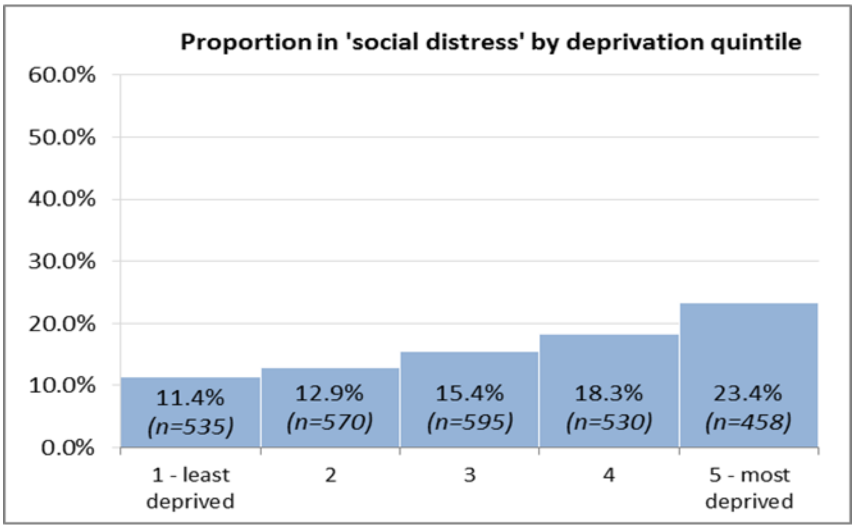


Figure 16 - Proportion of respondents in 'social distress' by disease status

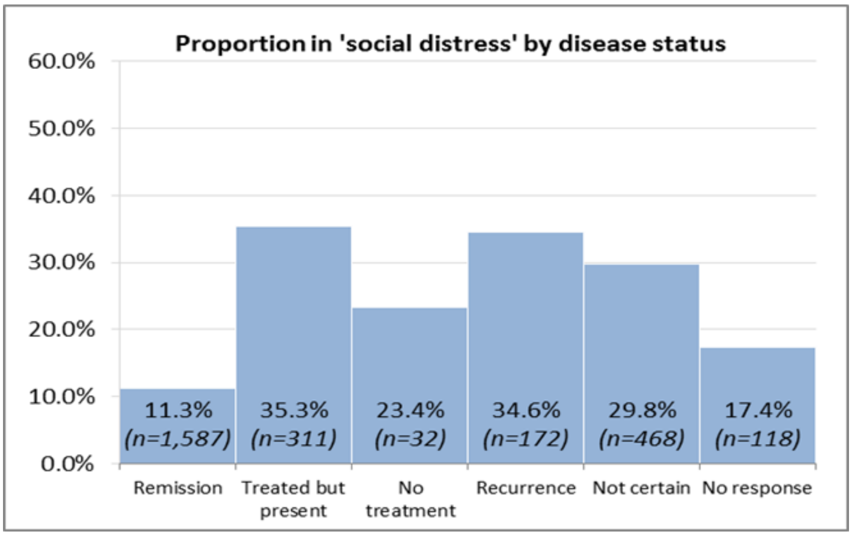


Figure 17 - Proportion of respondents in 'social distress' by number of long term conditions

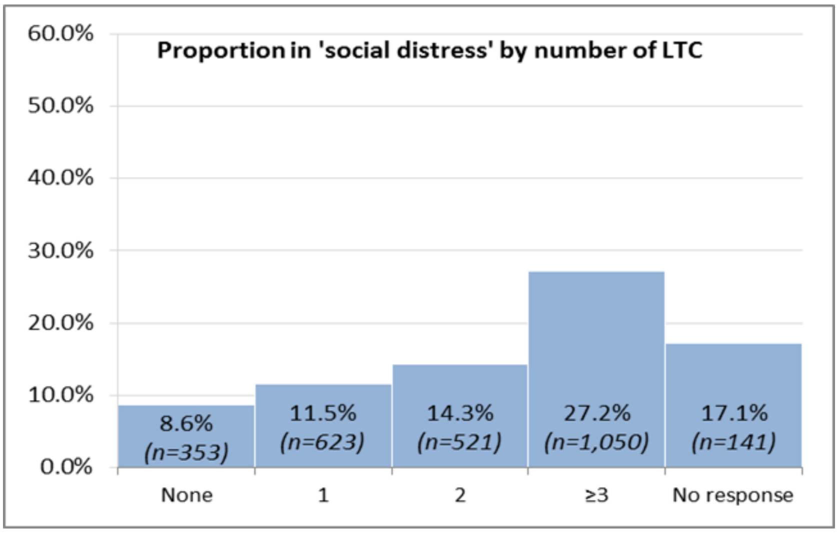


Figure 18- Proportion of respondents in 'social distress' by treatment type

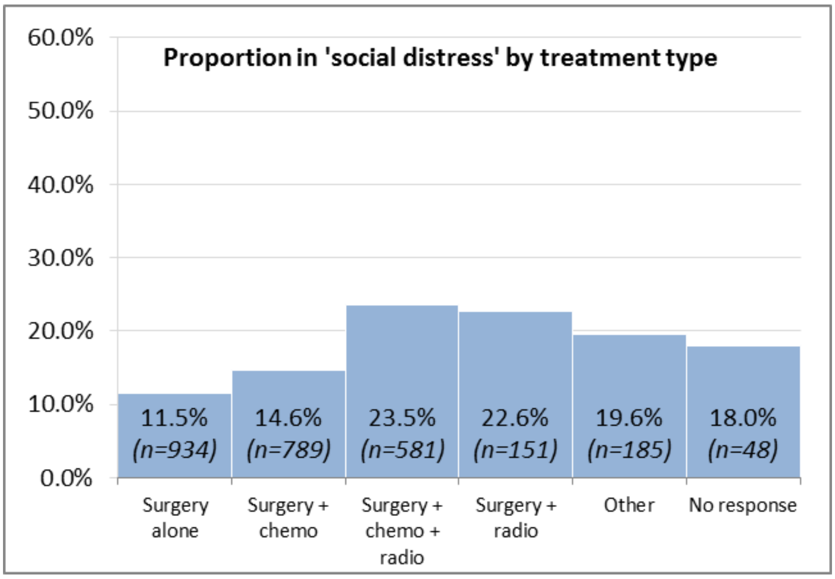
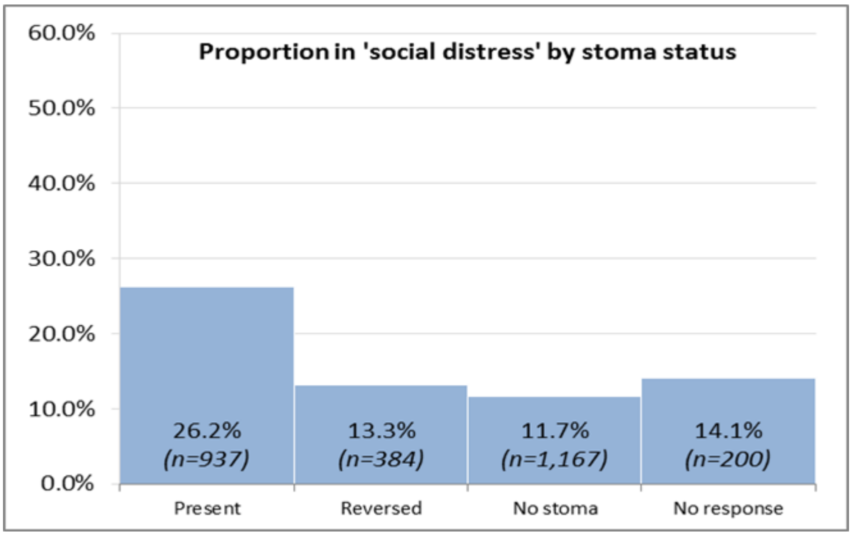


Figure 19- Proportion of respondents in 'social distress' by stoma status



In addition to the 16 SDI questions that make up the SD-16 score and subscales, there are five other questions which measure 'social distress.' These include questions around plans to have a family, sexual difficulties, concerns with where you live, travel plans and other areas of everyday life. Travel plans and sexual difficulties were the only areas where there was more evidence of social distress with 25% of respondents reporting 'quite a bit/very much' for difficulties around sexual matters and 22% reporting problems with travel. The difference across tumour types was also greatest for these two questions, with individuals with rectal tumours reporting more problems. Sexual difficulties will be explored in more detail in the next section.

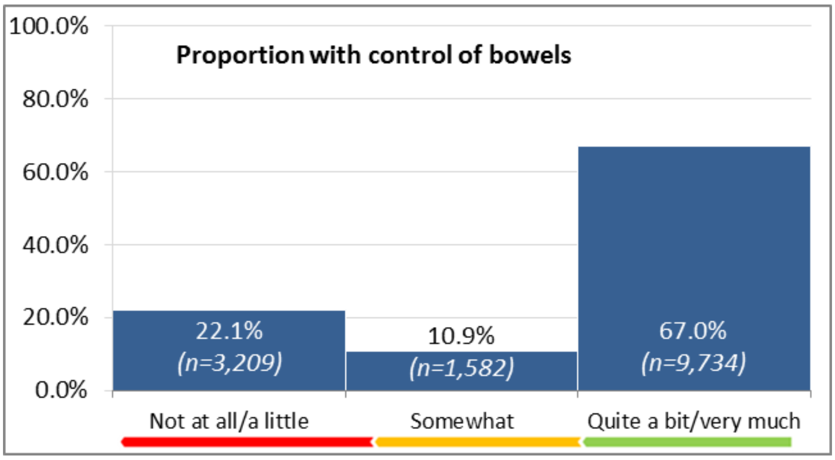
Condition- specific PROMs

The data was analysed to look at specific cancer-related outcomes. All of the condition-specific questions are presented by tumour type in the national tool. This section of the report focuses on the key issues that were identified around bowel control, urinary function, body image and sexual matters and psychological issues.

Bowel control

Bowel control is a key issue that affects quality of life in individuals with colorectal cancer. Figure 19 shows that 22% of respondents without a stoma felt they had little or no bowel control and 11% felt that they only had some control. This did not vary by tumour site, although the proportion answering 'Somewhat' was higher in the rectal cancer group (16.5% compared to 12.3% in the rectosigmoid group and 8.9% in the colon group).

Figure 20- Proportion of people without a stoma stating that they had control of their bowels

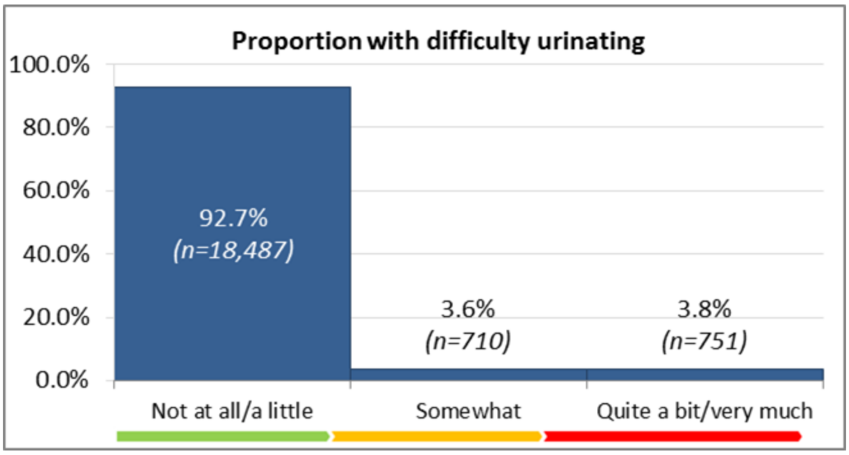


Those with a reversed stoma reported similar bowel control to those that had never had a stoma (21.4% and 22.3% respectively reported no or little control). 943 people (6.7% of respondents without a stoma) reported having diarrhoea 'Quite a bit or Very much.' This was similar across the three tumour sites.

Urinary function

Urinary function also negatively affects quality of life in individuals with colorectal cancer. The proportion of respondents reporting having difficulty urinating was 3.8%. Of the colorectal survivor respondents, 12.7% reported that they urinated more frequently and 4.6% answered 'Quite a bit/Very much' to the questions regarding leaking urine.

Figure 21 - Proportion of people who had difficulty urinating



When considered together, 15.4% of respondents answered ‘Quite a bit/Very much’ to any of the three urinary function questions. By tumour site, the figures were 14.1%, 15.1% and 17.9% for the colon, rectosigmoid and rectal cancer groups respectively. Urinary problems seemed to be slightly more of an issue for those people with rectal tumours rather than colon tumours.

Other functional outcomes

Key findings relating to other functional outcomes are presented below:

Swelling or cramps in the stomach area - 89% of respondents reported that they had no, or very little swelling or cramps. However 6% (1,024 individuals out of 20,175 who completed this question) said they had quite a lot, or a lot, of swelling or cramps in the stomach area. Across the 3 tumour sites, patients with rectum tumours reported slightly worse outcomes around this.

Good appetite -70% of respondents reported that they had a good appetite, however 20% (4,125 out of 20,497 people) reported having little or no appetite. This was similar by tumour type.

Losing weight -96% of respondents reported that they had either not lost weight or lost very little, and 402 individuals out of 1,9850 (2%) said they had lost quite a bit or a lot of weight. This was consistent across tumour sites.

Digesting food - 73% of respondents reported that they could digest food well, however 20% (3,998 people out of 20,326) reported had major problems digesting food. The reported negative impact on quality of life is proportionally much higher than on other FACT item questions suggesting that digestion of food is an issue for people with bowel cancer. The split by tumour type was fairly even.

Body image and sexual matters

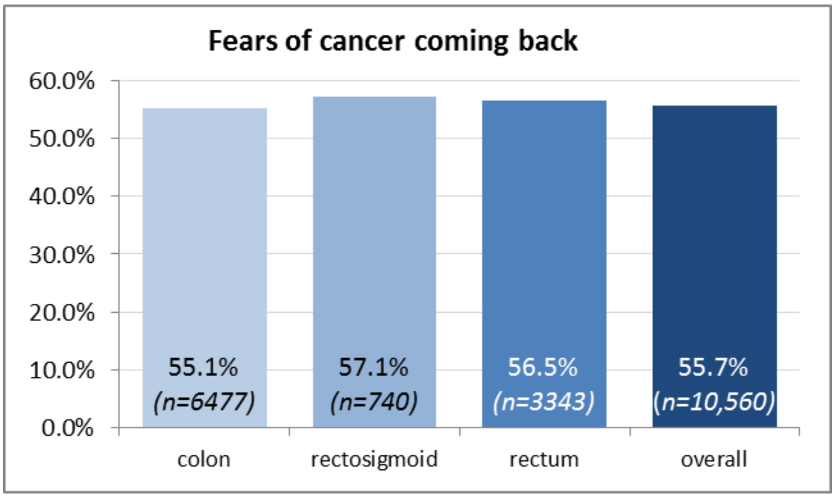
10.1% of respondents reported having difficulties with their appearance or body image (answered 'quite a bit/Very much') and this was higher in the rectal cancer group (13.9% compared to 9.8% in the rectosigmoid and 8.2% in the colon group). Individuals with a stoma (of which the majority have rectal cancer) report having more difficulties; 20.9% compared to 6.6% and 10.1% in the no stoma and reversed groups.

Rectal cancer respondents were more likely to report having difficulties with sexual matters (25.1% answered 'Quite a bit/Very much compared to 11.2% and 16.1% of colon and rectosigmoid respondents). 27.2% of individuals with a stoma reported sexual difficulties compared to 10.8% of those without a stoma and 30.1% of those that had radiotherapy reported difficulties compared to 12.4% that did not have radiotherapy. A high proportion of respondents selected 'Does not apply' as their answer to the sexual difficulties question (36.9%).

Psychological effects

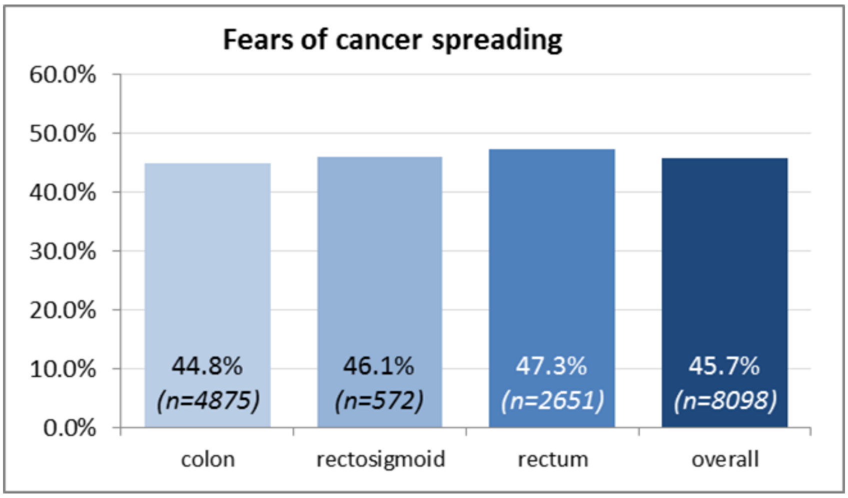
The psychological effects of colorectal cancer were examined. Respondents were asked to rate themselves on a set of statements. Over half of the respondents reported that they 'agreed' or 'strongly agreed' that they had fears about their cancer coming back.

Figure 22 - Proportion of people who 'agree/'strongly agreed they feared their cancer coming back



Nearly half the respondents said they agreed or strongly agreed that they feared the cancer spreading (just below 50% for each of the tumour types).

Figure 23 - Proportion of people who 'agree/'strongly agreed they feared their cancer spreading



Responses to the statements on 'trouble sleeping' and 'always feeling tired' were also quite high with around 40% of respondents agreeing or strongly agreeing with these statements. For responses to all nine statements around feelings and emotions, please see the national tool.

The overall HRQL of colorectal cancer survivors in England has been identified as being significantly lower than that of the general population. Bowel and sexual problems were commonly reported with rectal patients being most adversely affected. Whilst these findings are intuitive, the scale of the reported survey with nearly 22,000 respondents has enabled detailed interrogation by tumour site and a wide range of patient characteristics and comparison with normative population data with the subsequent identification of groups at increased risk of suffering impaired HRQL.

Respondents' comments

Of the 21,802 respondents who completed the closed questions of the PROMS survey, 25.8% took the option to provide comments. The content of these comments was analysed in order to gain more information about the perceptions respondents had of the quality of care they experienced.

Categories of comments

Comments were themed into groups summarised in Figure 24.

Figure 24 - Thematic framework of the experience of living with and beyond cancer derived from free-text responses to the PROMS survey questionnaire

Theme	Category	Sub-category
Experience of cancer diagnosis and treatment	Positive experiences of treatment	Excellent/ good general care
		Timely diagnosis
		Coordinated care
	Negative experiences of treatment	Diagnostic and treatment delays
		Poorly coordinated treatment
		Lack of emotional support
		Appointment cancellations
		Poor explanations / patient communication
		Poor in-patient care
Experiences of living beyond cancer	Lack of preparation by services	Lack of information on treatment side-effects
		Lack of information concerning possible psychological impact of cancer and treatments
		Lack of information on self-management strategies
	Positive experience of aftercare	
	Negative experiences of aftercare	Lack of aftercare/ poor admin
		Poor patient communication
		Lack of GP involvement
	Living with stoma	
	Living with co-morbidities	
	On-going Physical problems	Bowels
		Urinary problems
		Cognitive problems/memory loss
		Pain
		Impotence/ sex difficulties
		Fatigue
		Peripheral neuropathy
		Other physical problems
		Caring responsibilities
	On-going social and financial problems	Financial worries/ benefit problems
		Impact of cancer on friends/relatives
		Lack of social services support
		Fear of recurrence
	On-going emotional /psychological problems	Genetic concerns for relatives
		Poor body image
		Depression/ feeling isolated
		Anxiety
		Other psychological problems
		Keeping active
	Coping/ self-management strategies	Returning to employment
		Use complementary therapies (NPIs)
		Acceptance/ live life for today
		Support from friends/families
		Maintain ‘positive’ approach
		Adopting healthier lifestyles
		Other coping strategies
	No problems experienced	
Issues unrelated to the experience of living beyond cancer	Issues related to the questionnaire structure	
	Miscellaneous	
	Description of disease and treatment pathway	

The majority of comments were positive, with respondents expressing gratitude and praising individual healthcare professionals, departments, hospitals or the NHS as a whole.

> *“The process for diagnosis was excellent - GP acted very quickly and the [consultant] similarly discussed my condition and put in place a corrective action plan. This was coordinated extremely well by the specialist colorectal nurse. She has been a constant support and has acted as my point of contact throughout the three years I've been treated and followed up. ... In summary the whole process was faultless and should be used as an internal case study for how to get things right.”*

> *“After the diagnosis I received immaculate treatment on the NHS, which was excellent at all times from my Consultant Surgeon and Oncologist to all the staff which I met during my treatment. I received nothing but the best of care and kindness. I can't express enough the praise and thanks I owe them all for their care of me.”*

> *"I have received and am still receiving the best possible treatment from the surgeon oncologist and colorectal nurse. I have to have regular CT scans but so far they have been clear with no sign of any reoccurrence of the tumour. I remain very positive about my future health but I am aware that the return of the cancer is possible. I keep in touch with my colorectal nurse who has been superb. I have the highest regard for all of those people who have been involved in my treatment”*

However, alongside these very positive comments there were also many less favourable.

> *“In the early stages I feel that living with cancer would have been made easier for me had I been given more detailed information of what to expect i.e. after first op when a colostomy bag was fitted and it leaked for the first 3 months until problems were sorted and after reversal coping was horrendous and no information was given on what to expect when sent home from hospital.”*

> *“Care in the community was poor at best. GP was OK. NHS Direct did their best. It was nobody's job to check I was OK, which I was. If I had less home support [it] may have been a very different story. Aftercare in the community needs more attention and quickly”*

Collecting these comments, and analysing those that describe both positive and negative experiences of care, allowed the development of a deeper understanding of the elements of the services delivered that make a difference to the outcomes for respondents. The proportion of positive and negative comments are summarised in figure 25:

Figure 25 - Comments (n=2,076) relating to positive or negative experiences of care quality identified via text mining

Category	Sub-category	(n=)	%
Positive experiences	Excellent/ good general care	1045	50.3
	Timely diagnosis	109	5.2
	Positive aftercare	289	13.9
Negative experiences	Diagnostic and treatment delays	36	1.7
	Poor in-patient care	45	2.1
	Poor explanations / patient communication	78	3.7
	Lack of emotional support	78	3.7
	Lack of information on treatment side-effects	160	7.7
	Lack of information concerning possible psychological impact of cancer and treatments	43	2.0
	Lack of information on self-management strategies	135	6.5
	Lack of aftercare	191	9.2
	Lack of GP involvement	52	2.5
Stoma		365	17.5
Not relevant		242	11.6

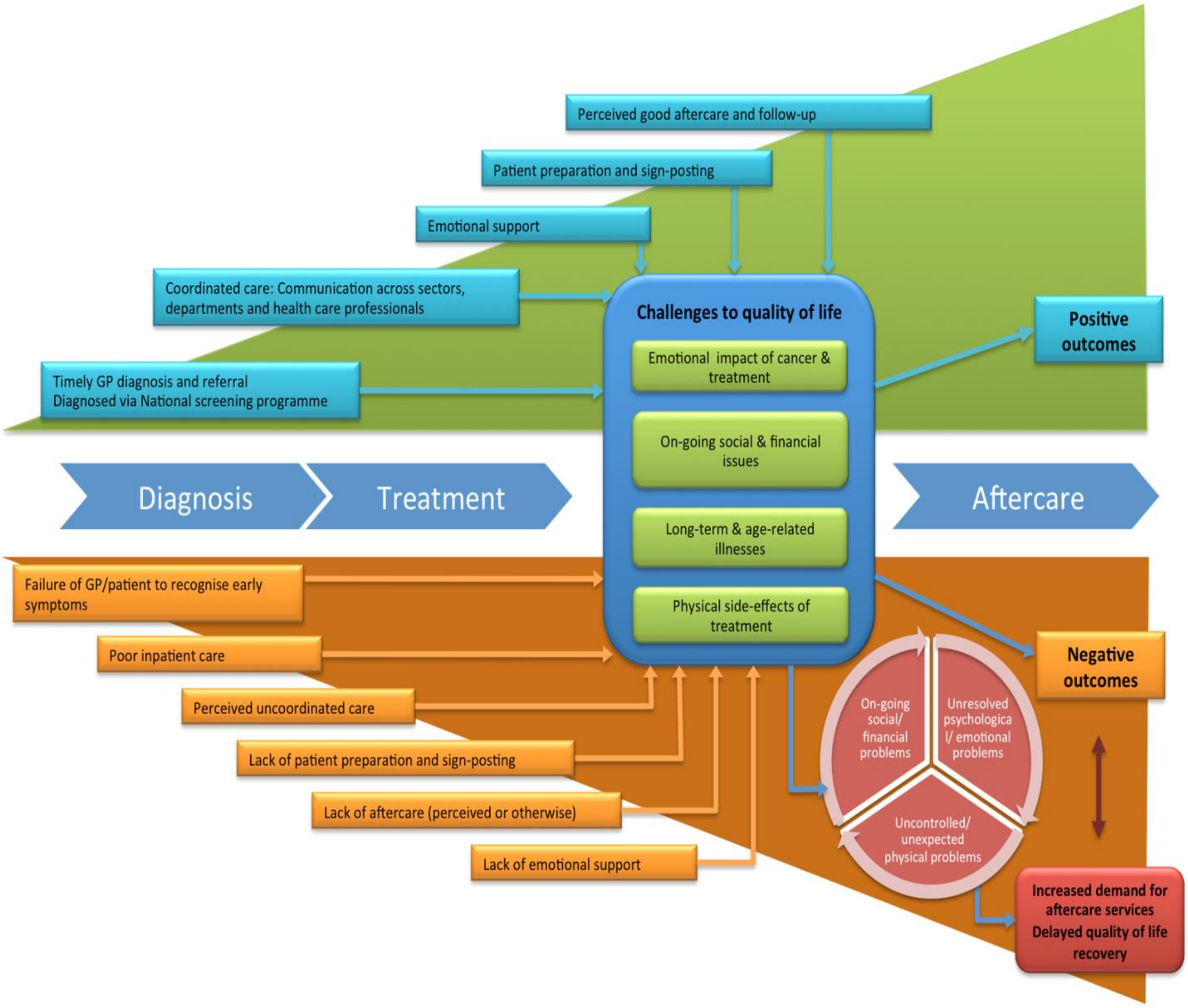
Note: Individual participants often provided free-texts comments that were divided into more than one category. Accordingly, total figure does not add up to 2,076

Patient experience

Respondents described different parts of their journey from a diagnosis of colorectal cancer to treatment and through to their experiences of aftercare. Respondents also identified several factors that challenged their path to recovery, and these were coded into four categories: emotional and psychological problems; social and financial issues; physical side-effects of cancer treatment; and comorbidities and age-related illnesses. The quality of services as perceived by the respondents depended on how effective they were in supporting management of these challenges to quality of life.

A tentative model was developed from the data to explain how different elements of care described by respondents determined whether their experiences of care were positive or negative (see fig. 26). The green-shaded top half of the figure has been used to represent those aspects of care associated with individual’s positive experiences. They comprise those elements of care to which respondents reportedly had access that minimised or addressed the challenges faced along the treatment pathway. The orange lower part of the figure lists the issues related to care that had a negative impact upon quality of life outcomes and delayed the transition to cancer survivorship. Quality of life may become worse if challenges are not addressed and a cycle of deterioration may develop, in which, for example, unresolved psychological issues worsen as a result of continuing uncontrolled physical treatment side-effects and/or on-going social and financial problems.

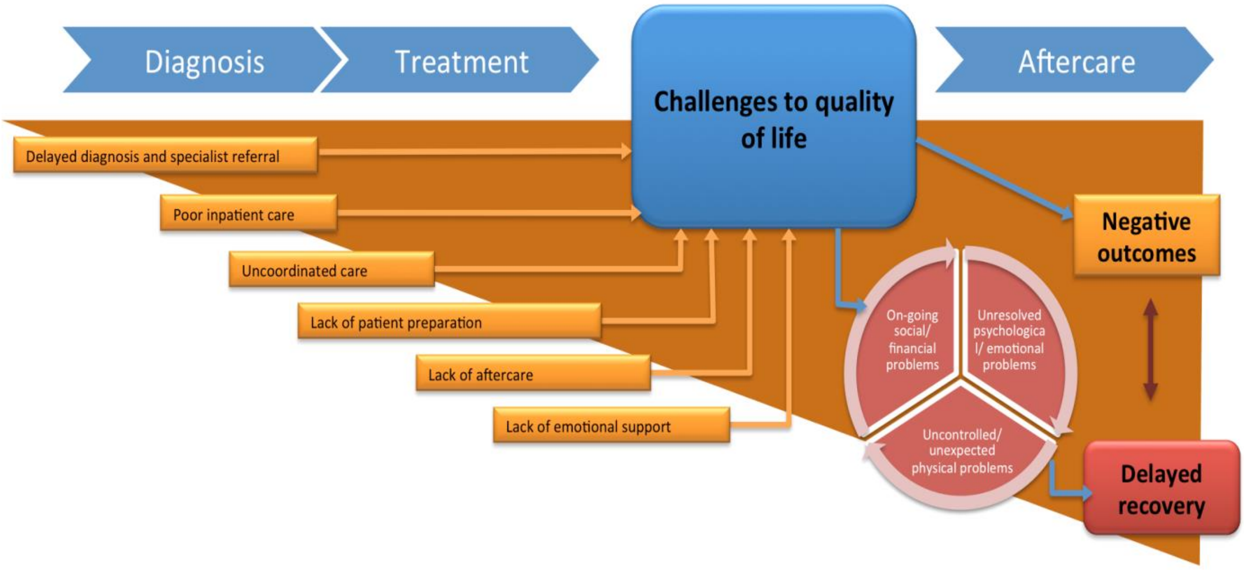
Figure 26 – Tentative model of factors determining the quality of patient experience



Factors associated with service delivery leading to negative outcomes

Negative outcomes were reportedly experienced when the care respondents received inadequately addressed the challenges to quality of life associated with a colorectal cancer diagnosis and treatment. Figure 27 indicates those elements of care that sometimes led to negative outcomes. These are illustrated by the quotes contained in the sections below.

Figure 27 - Factors associated with service delivery leading to negative outcomes



Delayed diagnosis

> *"I went to the GP for over a year highlighting my symptoms before a referral. I found many other patients at hospital experienced the same. Basically if you're youngish and not losing weight you don't get referred."*

> *"Very poor G.P. help in diagnosis or referral before my bowel cancer was discovered at an advanced stage. My wife's insistence was the main reason I was sent to the consultant as an emergency."*

Poor inpatient care

> *"Poor symptom control post-surgery whilst in-patient i.e.: No antiemetic - poor pain control - no emotional support."*

> *"Care on hospital ward poor due to lack of nurses & support staff."*

Un-co-ordinated care

> *"Appalling administration of appointments. Repeat cancellations by hospital and repeatedly putting appointments in wrong order... i.e. scan after the appointment to look at results. The system for management lets down the hard work done by medical & nursing staff."*

"I assume that my consultant has informed the practice of my case history but whenever I have contacted the practice for blood test results after hospital check-up appointments I'm told they do not have the information. I have no idea whether my GP knows I have been treated for cancer."

"In cancer care many specialists are involved, e.g. surgeons oncologists etc. There is lack of coordination between these specialists, i.e. no one seems to be in charge so that problems like stoma reversal are just seemingly from the patient's point of view forgotten"

Lack of patient preparation

"I felt I was not fully prepared for the after effects of having a permanent stoma as my operation happened within a matter of days of being diagnosed. I am very grateful of being cured but I feel I should have had more information about stoma issues."

"Would have appreciated having more information on what to expect being without a colon – i.e. 1) coping with flatulence going to the toilet frequently including the night resulting in tiredness leading to putting on weight & feeling poorly motivated as a result. 2) Length of time of problems & what to expect as they eased."

"The general information about chronic peripheral neuropathy was extremely vague. I have since found out a great deal through researching the internet. I would have welcomed more precise and extensive information about chronic CIPN before or at the time of treatment as this would have prepared me for the reality."

"Anxiety is the greater problem. It is not specific to anything in particular. It would have been good to have had someone to talk to at the outset so that I could have been made aware of the danger of [experiencing] it."

Lack of emotional support

"Psychological effects of living with an irreversible stoma. These effects are underplayed during pre-operative discussions. Some kind of follow-up support for mental and emotional wellbeing would be useful.

I did and still do feel 'abandoned' following surgery and treatment for colon cancer. I appreciate that the oncology and surgical departments are very busy but I would have liked some form of counselling following discharge."

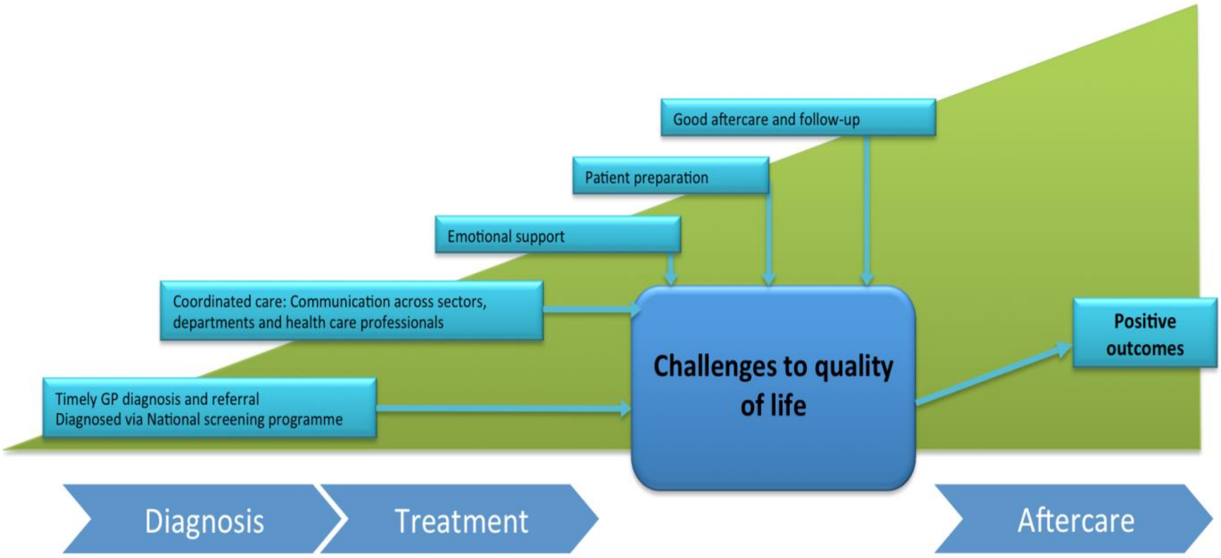
Lack of aftercare

> *"During diagnosis my nurses would do all that is possible to make my time as well as can be. After treatment it seems that you are just a number and the care aspect has gone at local level."*
>
> *"Care in the community was poor at best. GP was OK. NHS Direct did their best. It was nobody's job to check I was OK, which I was. If I had less home support may have been a very different story. After care in the community needs more attention and quickly."*
>
> *"Although I was allocated a CNS I do not feel there is enough support. I feel like I am being a nuisance if I send her an email or wasting her time. It is evident by her response that she does not properly read what I have typed. "*
>
> *"Post-operative recovery (in following weeks/months) at home not assisted by good home visit/GP support especially during chemotherapy."*
>
> *"My cancer care was very quick and good up to the diagnosis. The care afterwards has been haphazard with cancelled appointments and lack of information. "*

Factors associated with service delivery leading to positive outcomes

Positive outcomes were reportedly experienced when the care respondents received adequately addressed the challenges to quality of life associated with a colorectal cancer diagnosis and treatment. Figure 28 indicates those elements of care that sometimes led to positive outcomes, which are illustrated by the quotes contained in the sections below.

Figure 28 - Factors associated with service delivery leading to positive outcomes



Timely diagnosis and referral

> *"The rapid response between GP, hospital and consultant/surgeon from initial GP contact diagnosis consultation has no doubt contributed to the success of my cancer treatment."*

Diagnosed via National screening programme

> *"I am so thankful that I did the bowel screening test that came through the door. I had no symptoms at all. No one could believe it because I was so healthy. Everyone else made sure that they did the test when it was offered."*

> *"Because of symptoms shared with my GP (but ignored) I am grateful to the NHS screening programme that picked up my T4 tumour thanks to the postal test sample."*

Co-ordinated care

> *"Because of the excellent communication received from the medical staff throughout treatment I have always felt very confident & happy with all my treatment."*

Emotional support

"I think that the role of the colorectal nurse in providing on-going contact and reassurance is an absolutely vital one and is of great benefit in helping patients to understand their condition and what is happening to them, and thus to bolster their morale before during and after surgery and thereafter generally."

Patient preparation

"I received excellent care and attention from my consultant the nurses who cared for me after the operation and all the nurses. What I felt was important to me was: The consultant explained thoroughly what was wrong and what procedures I was to have"

"Although chemotherapy was far from pleasant the treatment I received from hospital could not have been better. I was kept informed and consulted at every step of my treatment."

"While the cancer still had the possibility of cure we were very happy that a high level of care was being given & everything possible was being done we felt well informed supported by our specialist and consultant & in good hands."

"I still have slight problems with bowel movements and wind but I was advised that this would be the case."

Good aftercare

"The excellent follow-up by the specialist nurses and the knowledge that I am still being regularly monitored after two years engenders confidence."

"I have been impressed and reassured by the frequent follow-up; monitoring and appointments and the friendliness and approachability of staff."

"I have excellent follow-up from [hospital] and a cancer specialist nurse in my area. I have been able to contact either one when especially worried or concerned."

"The NHS has been completely magnificent across all aspects of the system. The post-surgical chemo therapy regime was the toughest part of the treatment and this aspect of the system appeared to be the most under stress of numbers (e.g. lots of delays in the bloods/doctor consultation) in the outpatient system. Despite these pressures the staff behaved with great professionalism."

Summary of respondents' comments

From respondents' comments it is clear that the services required to ensure positive quality of life outcomes include both structural aspects of service delivery and access to supportive care. Structural aspects of care included coordinated care across primary and secondary sectors and hospital departments, including good communication links, and the provision of effective aftercare. Supportive services were indicated as necessary to prepare individuals for the difficulties that emerge during their treatment journey and beyond, to support them emotionally, with practical advice and sign-posing to financial, benefits and employment advice, including charities like Macmillan and other services they may need. Indeed, had these services been available to a large proportion of those who reported negative experiences of cancer care within this survey, then their quality of life might have been greatly improved. Thus, elements of good quality services identified by the survey should be consistently provided to all patients with colorectal cancer if their quality of life is to be improved include the following:

- Patients should be provided with clear explanations of their treatment options by health professionals
- Patients should be aware of who is responsible for coordinating their care, and feel able to contact a named clinical nurse specialist about worries and concerns they have without feeling they are wasting their time
- Patients should be made aware of the potential psychological impact of a cancer diagnosis and treatment, including feelings of isolation and increased fears of recurrence, and that this might occur at the end of active treatment
- Patients should have access to some form of emotional support across the patient journey from diagnosis, to treatment and aftercare, including counselling services, talking therapies and sign-posting to survivor support groups
- Patients should be made aware of the possible physical side-effects of treatment, especially: bowel problems like diarrhoea, constipation, whether or not they have a stoma formation; urinary problems of incontinence; mental cognition and memory loss; fatigue; and that these problems may endure for some months after the end of treatment
- Patients should be provided with practical advice and possible coping strategies for dealing with the physical side-effects of treatment
- Patients should have some sign-posting to services that will enable them to deal with social, financial and employment issues, especially organisations that can advise them of their employment rights, eligibility for benefits and social services
- Patients should be provided with prompt reporting of scan results and delays and cancellations of outpatient appointments should be minimised
- Patients should feel confident that their GP is aware of the treatment they have received from within the secondary sector, and feel able to approach their GP practice for advice

Discussion

This study has demonstrated that it is feasible to collect PROMs at a national level. The results of the survey have highlighted groups of survivors with lower health-related quality of life, for example, those aged under 55 or over 85 years, those with one or more other LTCs, those with active or recurrent disease, those with a stoma and those living in the most deprived areas.

The survey captured data on a number of specific functional outcomes. Nearly a quarter of colorectal cancer survivors (without a stoma) reported having no or little control of their bowels. Reversal of a stoma resulted in similar levels of reported bowel control as those who had never had a stoma. A quarter of rectal cancer survivors reported sexual difficulties. Over a third of respondents (predominantly females and older groups) answered 'does not apply' which may mean that the true figure is higher. Problems with digesting food and a lack of appetite were also commonly reported.

Qualitative analysis of the respondents' comments showed that a high proportion of patients reported positive experiences of care. However, substantial numbers had negative experiences and these relate particularly to lack of aftercare, information on self-management and information on treatment side-effects.

A number of study limitations need to be acknowledged. Firstly, the elderly, those from ethnic minorities and those living in more socio-economically deprived areas were less likely to participate in the survey. However, with a good response rate of 63.3% resulting in almost 22,000 returned surveys, this study provides some of the best evidence to date. Secondly, due to the highly skewed distribution of the EQ-5D scores, a measure of 'perfect' health was used but it is acknowledged that this may not capture the individuals 'true' health state. Additionally, the visual analogue scale of the EQ-5D was not included. Lastly, the study design did not include a control group to provide baseline data. Linkage with data from HSE 2011 allowed limited comparison to the general population, for example, the reduction in health-related quality of life was most marked in those aged under 65 with little difference seen in those over 65.

The data collected in this survey serve as a baseline for future system wide improvement initiatives. The results suggest areas where efforts could be best targeted to improve aftercare services, such as improving bowel control and sexual function (particularly in rectal cancer survivors) and in providing greater support for younger patients, those with multiple LTCs and with recurrent disease.

Further research

This report looks at the health outcomes of colorectal cancer survivors according to tumour type and across a range of respondent characteristics. However, this is only a snapshot of the data. There is a wealth of information from the survey on which further analysis can be undertaken. All of the data collected by the survey will be available from the Health and Social Care Information Centre and researchers can apply to use these data in order to further the understanding of the consequences of cancer and its treatment.

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Table 1 - Respondents and non-respondents to quantitative questions

Characteristic		Non-respondent		Respondent		Total	Response rate
		n	%	n	%	n	%
Sex	Male	6897	54.5	12683	58.2	19580	64.8
	Female	5768	45.5	9119	41.8	14887	61.3
Age at diagnosis	<55	1605	12.7	2040	9.4	3645	56.0
	55-64	2457	19.4	5154	23.6	7611	67.7
	65-74	3735	29.5	7824	35.9	11559	67.7
	75-84	3669	29.0	5633	25.8	9302	60.6
	85+	1199	9.5	1151	5.3	2350	49.0
Tumour site	Colon	8119	64.1	13577	62.3	21696	62.6
	Rectosigmoid	807	6.4	1512	6.9	2319	65.2
	Rectum	3739	29.5	6713	30.8	10452	64.2
Year of diagnosis	2010	5968	47.1	10523	48.3	16491	63.8
	2011	6697	52.9	11279	51.7	17976	62.7
Ethnic group	White	8702	68.7	16079	73.8	24781	64.9
	Mixed	35	0.3	40	0.2	75	53.3
	Asian	236	1.9	171	0.8	407	42.0
	Black	189	1.5	143	0.7	332	43.1
	Other	131	1.0	124	0.6	255	48.6
	Unknown	3372	26.6	5245	24.1	8617	60.9
Dukes' stage of disease at diagnosis	A	1101	8.7	2435	11.2	3536	68.9
	B	2561	20.2	5149	23.6	7710	66.8
	C	2223	17.6	4482	20.6	6705	66.8
	D	721	5.7	1045	4.8	1766	59.2
	Unknown	6059	47.8	8691	39.9	14750	58.9
Index of Multiple Deprivation	1 - least deprived	2328	18.4	5484	25.2	7812	70.2
	2	2730	21.6	5360	24.6	8090	66.3
	3	2649	20.9	4742	21.8	7391	64.2
	4	2609	20.6	3658	16.8	6267	58.4
	5 - most deprived	2349	18.5	2558	11.7	4907	52.1
Total		**12665**	**100**	**21802**	**100**	**34,467**	**63.3**

Table 2 - Characteristics of respondents

Characteristic		Colon		Rectosigmoid		Rectum		Overall	
		n	%	n	%	n	%	n	%
Age group	< 55 years	1054	7.8	167	11	819	12.2	2040	9.4
	55-64 years	2938	21.6	385	25.5	1831	27.3	5154	23.6
	65-74 years	4869	35.9	558	36.9	2397	35.7	7824	35.9
	75-84 years	3876	28.5	342	22.6	1,415	21.1	5,633	25.8
	85+ years	840	6.2	60	4	251	3.7	1151	5.3
	Total	13577	100	1,512	100	6,713	100	21802	100
Sex	Male	7346	54.1	952	63	4385	65.3	12683	58.2
	Female	6231	45.9	560	37	2328	34.7	9119	41.8
	Total	13577	100	1512	100	6713	100	21802	100
Index of multiple deprivation	1 - least deprived	3501	25.8	343	22.7	1640	24.4	5484	25.2
	2	3399	25	363	24	1598	23.8	5360	24.6
	3	2932	21.6	326	21.6	1484	22.1	4742	21.8
	4	2212	16.3	271	17.9	1175	17.5	3658	16.8
	5 - most deprived	1533	11.3	209	13.8	816	12.2	2558	11.7
	Total	13577	100	1512	100	6713	100	21802	100
Ethnic group	White	12905	95.1	1435	94.9	6418	95.6	20758	95.2
	Non-white	299	2.2	30	2	125	1.9	454	2.1
	Not known	373	2.7	47	3.1	170	2.5	590	2.7
	Total	13577	100	1512	100	6713	100	21802	100
Duke’s stage of disease at diagnosis	A	1223	9	170	11.2	1042	15.5	2435	11.2
	B	3795	28	311	20.6	1043	15.5	5149	23.6
	C	2896	21.3	338	22.4	1248	18.6	4482	20.6
	D	681	5	76	5	288	4.3	1045	4.8
	Not known	4982	36.7	617	40.8	3092	46.1	8691	39.9
	Total	13577	100	1512	100	6713	100	21802	100

Table 2 - Characteristics of respondents (continued)

Characteristic		Colon		Rectosigmoid		Rectum		Overall	
		n	%	n	%	n	%	n	%
Disease status	Remission	10442	76.9	1158	76.6	5042	75.1	16642	76.3
	Treated but still present	551	4.1	98	6.5	422	6.3	1071	4.9
	No treatment	154	1.1	16	1.1	34	0.5	204	0.9
	Recurrence	365	2.7	32	2.1	175	2.6	572	2.6
	Not certain	1207	8.9	130	8.6	724	10.8	2061	9.5
	No response	858	6.3	78	5.2	316	4.7	1252	5.7
	Total	13577	100	1512	100	6713	100	21802	100
Stoma status	Present	1327	9.8	312	20.6	2848	42.4	4487	20.6
	Reversed	957	7	350	23.1	2071	30.9	3378	15.5
	No stoma	9655	71.1	739	48.9	1427	21.3	11821	54.2
	No response	1638	12.1	111	7.3	367	5.5	2116	9.7
	Total	13577	100	1512	100	6713	100	21802	100
Treatment	Surgery alone	7446	54.8	650	43	1992	29.7	10088	46.3
	Surgery + chemo	4832	35.6	523	34.6	880	13.1	6235	28.6
	Surgery + chemo +radio	326	2.4	181	12	2437	36.3	2944	13.5
	Surgery + radio	91	0.7	46	3	696	10.4	833	3.8
	Other	561	4.1	77	5.1	590	8.8	1228	5.6
	No response	321	2.4	35	2.3	118	1.8	474	2.2
	Total	13577	100	1512	100	6713	100	21802	100
Long term conditions	None	2750	20.3	319	21.1	1582	23.6	4651	21.3
	1	3901	28.7	484	32	2091	31.1	6476	29.7
	2	2872	21.2	315	20.8	1336	19.9	4523	20.7
	3 or more	3371	24.8	307	20.3	1303	19.4	4981	22.8
	No response	683	5	87	5.8	401	6	1171	5.4
	Total	13577	100	1512	100	6713	100	21802	100