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Health-Related Quality of Life After Colorectal Cancer in England: A Patient-Reported Outcomes Study of Individuals 12 to 36 Months After Diagnosis

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ABSTRACT

Purpose
This population-level study was conducted to define the health-related quality of life (HRQL) of individuals living with and beyond colorectal cancer (CRC) and to identify factors associated with poor health outcomes.

Patients and Methods
All individuals diagnosed with CRC in England in 2010 and 2011 who were alive 12 to 36 months after diagnosis were sent a questionnaire. This included questions related to treatment, disease status, other long-term conditions (LTCs), generic HRQL (EuroQol-5D), and cancer-specific outcomes (Functional Assessment of Cancer Therapy and Social Difficulties Inventory items).

Results
The response rate was 63.3% (21,802 of 34,467 patients). One or more generic health problems were reported by 65% of respondents, with 10% of patients reporting problems in all five domains. The reporting of problems was higher than in the general population and was most marked in those age less than 55 years. Certain subgroups reported a higher number of problems, notably those with one or more other LTCs, those with active or recurrent disease, those with a stoma, and those at the extremes of the age range (< 55 and > 85 years). Of respondents without a stoma, 16.3% reported no bowel control. Reversal of a stoma resulted in fewer severe bowel problems but more moderate problems than those who had never had a stoma. A quarter of rectal cancer respondents (25.1%) reported difficulties with sexual matters (compared with 11.2% of colon cancer respondents).

Conclusion
This study demonstrates the success of a national patient-reported outcomes survey. The results have the potential to support system-wide improvement in health outcomes through the identification of particular challenges faced by individuals after treatment for CRC.

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INTRODUCTION

The population living with or beyond a diagnosis of colorectal cancer (CRC) is increasing and is projected to increase from 1.2 million in 2012 to 1.5 million in 2022 in the United States[1] and from 240,000 in 2010 to 630,000 by 2040 in the United Kingdom.[2] Survivors of cancer report significant unmet needs.[3,4] Targeted aftercare may improve care quality through focused delivery of resources. However, this requires evidence of the prevalence, extent, and impact of resultant morbidities.

Patient-reported outcome measures (PROMs) may be used to drive changes in the organization and delivery of health care.[5] Provider organizations

are increasingly collecting cancer PROMs, but these data are not yet available on a national basis. This is in contrast to patient-reported experience measures, such as the English National Cancer Patient Experience Survey,[6] which collects information on patients' self-reported health care experience rather than self-reported outcomes (as measured by PROMs). Complementary information on survival is collected by the National Cancer Registration Service (NCRS).[7] The addition of patient-reported outcomes to robust survival and experience data will provide the potential for a comprehensive quality account of cancer services.

A growing body of evidence highlights the unwanted consequences of CRC treatment, including

bowel, urinary, and sexual problems.[8-10] Most of this information has been derived from highly selected groups, including clinical trials or small-scale retrospective hospital series, with a lack of whole population-based data. Although studies increasingly use cancer registries to identify more representative samples,[11] to our knowledge, none have previously reported at a national level in the United Kingdom.

Our primary objective was to define, at a population level, the health-related quality of life (HRQL) of individuals living with and beyond CRC diagnosed 12 to 36 months earlier in England. The secondary objective was to identify factors associated with poor reported health outcomes that could be used to support enhanced aftercare.

PATIENTS AND METHODS

Study Design and Survey Process

The study design followed that of a recent pilot study.[12] Individuals older than age 16 years surviving 12 to 36 months after a diagnosis of CRC (International Statistical Classification of Disease and Related Health Problems, Tenth Revision[13] codes C18 to C20) in 2010 or 2011 and treated in the National Health Service in England were identified via the NCRS. We estimate that more than 98% of all eligible individuals were identified.[14] Results from the pilot study demonstrated that HRQL and physical problems remained relatively constant with time (between 12 and 60 months after diagnosis)[12]; hence, only patients who were 12 to 36 months after diagnosis were included. Individuals were sent a questionnaire accompanied by a letter from their treating cancer center. Patients consented by returning completed questionnaires and declined by not returning the questionnaires or returning blank questionnaires. Two reminders were sent to nonresponders. A dedicated freephone helpline was provided to resolve any queries.

Permission to approach patients without informed consent was given by the National Information Governance Board [ref ECC 5-02(FT8)/12]. Ethical approval for research on the data captured by the survey was granted by the East of Scotland Research Ethics Committee (ref 08/S0501/66).

Questionnaire Design

The specific components of the questionnaire and the cognitive testing performed have been described elsewhere.[12] Briefly, the content (Data Supplement) included questions related to treatment, disease status, long-term conditions (LTCs), generic HRQL (EuroQol-5D [EQ-5D]),[15] CRC-specific outcomes (Functional Assessment of Cancer Therapy [FACT]),[16] social problems (Social Difficulties Inventory),[17] and experience of care.[6] Respondents could provide free text comments (to be reported elsewhere).

Data Handling

Age, sex, tumor site, and Dukes' stage of disease at diagnosis were obtained from cancer registration data. Age was categorized as less than 55, 55 to 64, 65 to 74, 75 to 84, and ≥ 85 years. Deprivation category was based on the Index of Multiple Deprivation,[18] derived using the postcode of residence.

A number of variables were derived from the questionnaire data. Self-reported race was grouped into white and nonwhite. Participants were asked if they had any other LTCs at the time of questionnaire completion and to identify these from a given list (Data Supplement). This variable was categorized as none, one, two, or ≥ three other LTCs. Information on self-reported disease status (remission, treated but still present, no treatment, recurrence, or not certain), treatments (surgery, radiotherapy, and chemotherapy), and stoma status (present, reversed, or never formed) was taken from the questionnaire. Records with missing data were retained and categorized as not reported.

The five-level version of the EQ-5D[15] records problems on five domains (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression). These data may be summarized as a single index score using a standard crosswalk algorithm[19]; scores range from −0.5 to 1, where 1 is the maximum score for an individual reporting no problems in any domain. The distribution of the EQ-5D scores is left skewed (median, 0.84; interquartile range, 0.71 to 1.0), with a large peak at the right tail (those scoring 1), and this makes it difficult to model. A simple approach was used to count the number of domains with a problem reported, regardless of the severity of the problem. Records with no response on one or more domains were excluded from this analysis (4.6%).

Cancer-specific questions from FACT were examined separately (FACT total score could not be calculated because not all questions were included as a result of previous cognitive testing).[4] Outcomes relating to bowel control, diarrhea, and urinary function are presented here. Analysis of questions relating to bowel function was limited to patients without a stoma, because it was
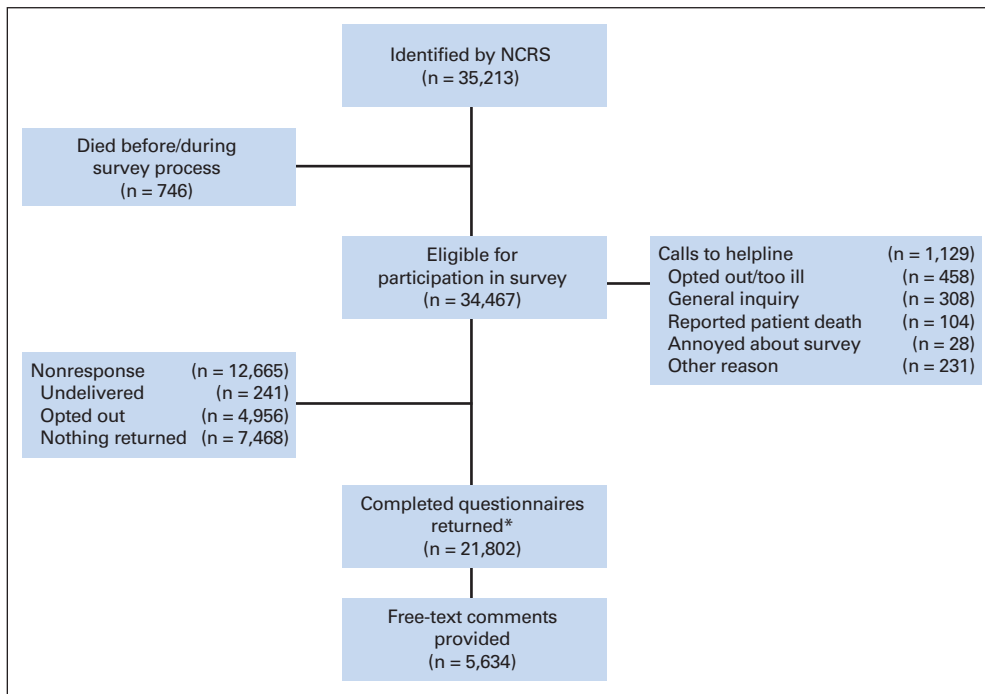
Fig 1. Flowchart showing survey process and responses. Response rate for survey was 63.3% based on number of questionnaires returned (n = 21,802) divided by number of patients eligible for participation (n = 34,467). (*) All questionnaires were included, whether partially or fully completed. Information about the completeness of the questions/sections used in this study is available in Appendix Table A2 (online only). NCRS, National Cancer Registration Service.

felt that individuals with a stoma present could interpret the questions in different ways. Records with no response to the question of interest were excluded (range, 4.4% to 8.5%).

The Health Survey for England 2011 (HSE 2011)[20] provided comparison with the general population. This household survey (8,610 individuals age > 16 years) measured HRQL using the EQ-5D. The CRC PROMs and HSE data sets were age and sex matched, creating a comparable sample of 4,615 individuals with EQ-5D responses on all five domains (this lower number reflects the different age profiles of the two surveys).

	Colon		Rectosigmoid		Rectum			Overall	
Demographic or Characteristic	No. of Respondents	%	No. of Respondents	%	No. of Respondents	%	P	No. of Respondents	%
Age, years							< .001		
< 55	1,054	7.8	167	11.0	819	12.2		2,040	9.4
55-64	2,938	21.6	385	25.5	1,831	27.3		5,154	23.6
65-74	4,869	35.9	558	36.9	2,397	35.7		7,824	35.9
75-84	3,876	28.5	342	22.6	1,415	21.1		5,633	25.8
≥ 85	840	6.2	60	4.0	251	3.7		1,151	5.3
Sex							< .001		
Male	7346	54.1	952	63.0	4,385	65.3		12,683	58.2
Female	6,231	45.9	560	37.0	2,328	34.7		9,119	41.8
Index of Multiple Deprivation							.002		
1, least deprived	3,501	25.8	343	22.7	1,640	24.4		5,484	25.2
2	3,399	25.0	363	24.0	1,598	23.8		5,360	24.6
3	2,932	21.6	326	21.6	1,484	22.1		4,742	21.8
4	2,212	16.3	271	17.9	1,175	17.5		3,658	16.8
5, most deprived	1,533	11.3	209	13.8	816	12.2		2,558	11.7
Race							.346		
White	12,905	95.1	1,435	94.9	6,418	95.6		20,758	95.2
Nonwhite	299	2.2	30	2.0	125	1.9		454	2.1
Not known	373	2.7	47	3.1	170	2.5		590	2.7
No. of long-term conditions							< .001		
None	2,750	20.3	319	21.1	1,582	23.6		4,651	21.3
1	3,901	28.7	484	32.0	2,091	31.1		6,476	29.7
2	2,872	21.2	315	20.8	1,336	19.9		4,523	20.7
≥ 3	3,371	24.8	307	20.3	1,303	19.4		4,981	22.8
Not reported	683	5.0	87	5.8	401	6.0		1,171	5.4
Dukes' stage of disease at diagnosis							< .001		
A	1,818	13.4	244	16.1	1,471	21.9		3,533	16.2
B	5,412	39.9	431	28.5	1,533	22.8		7,376	33.8
C	4,554	33.5	588	38.9	2,496	37.2		7,638	35.0
D	862	6.3	107	7.1	410	6.1		1,379	6.3
Not known	931	6.9	142	9.4	803	12.0		1,876	8.6
Disease status							< .001		
Remission	10,442	76.9	1,158	76.6	5,042	75.1		16,642	76.3
Treated but cancer still present	551	4.1	98	6.5	422	6.3		1,071	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	1,207	8.9	130	8.6	724	10.8		2,061	9.5
Not reported	858	6.3	78	5.2	316	4.7		1,252	5.7
Treatment							< .001		
Surgery alone	7,446	54.8	650	43.0	1,992	29.7		10,088	46.3
Surgery + chemotherapy	4,832	35.6	523	34.6	880	13.1		6,235	28.6
Surgery + chemotherapy + radiotherapy	326	2.4	181	12.0	2,437	36.3		2,944	13.5
Surgery + radiotherapy	91	0.7	46	3.0	696	10.4		833	3.8
Other*	561	4.1	77	5.1	590	8.8		1,228	5.6
Not reported	321	2.4	35	2.3	118	1.8		474	2.2
Stoma status							< .001		
No stoma	9,655	71.1	739	48.9	1,427	21.3		11,821	54.2
Reversed	957	7.0	350	23.1	2,071	30.9		3,378	15.5
Present	1,327	9.8	312	20.6	2,848	42.4		4,487	20.6
Not reported	1,638	12.1	111	7.3	367	5.5		2,116	9.7
Total	13,577	100	1,512	100	6,713	100		21,802	100

Table 1. Demographics and Clinical Characteristics of the Respondents by Tumor Site

*Chemotherapy plus radiotherapy, chemotherapy alone, or radiotherapy alone.

Statistical Analysis

Descriptive statistics were used to compare respondent characteristics, EQ-5D domain responses, and cancer-specific outcomes across CRC sites (colon, rectosigmoid junction, and rectum). χ^2 tests were used to compare categorical variables. Multivariable logistic regression was performed using a binary outcome variable—perfect health (no problems on EQ-5D) or less than perfect health ($\geq$ one problem). Variables predictive of less than perfect health were chosen initially based on their a priori clinical and public health importance, and final model selection was informed by univariable results and statistical validity (eg, collinearity among variables). Analyses were performed using Stata version 13 (Stata, College Station, TX).

RESULTS

Response Rates

NCRS identified 35,213 individuals diagnosed with CRC 12 to 36 months previously; 746 of individuals (2.1%) died before or during the survey process, giving a final eligible sample of 34,467 (Fig 1). Of these, 21,802 individuals returned completed questionnaires, generating a 63.3% response rate (RR). Respondent and nonrespondent characteristics were compared (Appendix Table A1, online only). Individuals age less than 55 years (RR, 56.0%) or more than 85 years (RR, 49.0%), those from a nonwhite ethnic group (Asian RR, 42.0%; black RR, 43.1%), and those living in the most socioeconomically deprived areas (RR, 52.1%) were less likely to participate.

Data Quality

Missing data levels were low, at approximately 5% for most fields. For example, 5.4% of respondents did not answer the question on LTCs and 5.7% did not report their disease status (Appendix Table A2, online only).

Characteristics of the Population

Across the sample, 62.3% of patients were diagnosed with colon cancers, 30.8% with rectal cancers, and 6.9% with rectosigmoid tumors. Rectal cancer respondents were younger, with a higher proportion being male (Table 1). Other LTCs were common, with only one fifth (21.3%) of patients reporting no LTCs and 43.5% of patients reporting two or more. Overall, 6.7% of respondents were diagnosed with metastatic disease (Dukes' stage D), and three quarters (76.3%) of respondents reported being in remission. Of the respondents, 92.3% reported having surgery, 46.8% chemotherapy, and 19.7% radiotherapy. The figures for surgery and chemotherapy were similar across the three sites, whereas, as would be anticipated as a result of best practice, a higher proportion of the group with rectal cancer (54.3%) received radiotherapy (compared with 3.5% of respondents with colon cancer and 16.9% of respondents with rectosigmoid cancer). A stoma was present in 9.8% of respondents with colon cancer, 20.6% of respondents with rectosigmoid cancer, and 42.4% of respondents with rectal cancer. In total, 34.9% of patients reported having had a stoma reversed.

Generic PROMs

A third of all respondents (34.5%) reported perfect health (no problems on any of the EQ-5D domains). Respondents with rectal cancer were more likely to report problems (70.9%) than respondents with rectosigmoid or colon cancer (63.8% and 63%, respectively; $P < .001$; Table 2). Problems were most commonly reported with

	% of Patients				% of All Patients (N = 20,794)
Domain	Colon (n = 12,920)	Rectosigmoid (n = 1,461)	Rectum (n = 6,413)	P	
Mobility				.077	
No problems	63.6	64.3	62.1		63.2
Problems	36.4	35.7	37.9		36.8
Total	100	100	100		100
Self-care				.001	
No problems	83.6	83.3	81.7		83.0
Problems	16.4	16.7	18.3		17.0
Total	100	100	100		100
Usual activities				< .001	
No problems	59.9	58.9	51.1		57.1
Problems	40.1	41.1	48.9		42.9
Total	100	100	100		100
Pain/discomfort				< .001	
No problems	60.5	58.5	49.1		56.9
Problems	39.5	41.5	50.9		43.1
Total	100	100	100		100
Anxiety/ depression				< .001	
No problems	65.4	63.7	60.3		63.7
Problems	34.6	36.3	39.7		36.3
Total	100	100	100		100

Table 2. EuroQol-5D Domain Responses by Tumor Site

pain/discomfort (43.1%) and usual activities (42.9%). Respondents with rectal cancer were significantly more likely to report problems in all domains except the mobility domain. Table 3 lists the number of problems reported in relation to the different population characteristics. Reporting of $\geq$ one problem was highest in those with active (90.8%) or recurrent (87.9%) disease, those with $\geq$ three other LTCs (83.3%), those with a stoma present (80.3%), and those older than age 85 (79.4%). Overall, 9.6% of respondents indicated having some level of problem in all five domains, and this was highest in those with active disease (24.1%) and those with $\geq$ three other LTCs (20.6%).

These effects persisted in multivariable analysis where $\geq$ three LTCs (odds ratio [OR], 5.56; 95% CI, 5.00 to 6.18 compared with no LTCs), active disease (OR, 5.38; 95% CI, 4.30 to 6.73 compared with remission), and presence of a stoma (OR, 2.34; 95% CI, 2.12 to 2.59 compared with no stoma) were the strongest predictors of less than perfect health (problems on $\geq$ one domain). In addition, being female, living in a more deprived area, and receiving treatment including radiotherapy and/or chemotherapy were predictive of less than perfect health. Individuals age 55 to 84 years were less likely to report problems (compared with those < 55 years old), whereas the oldest age group ($\geq$ 85 years) reported similar outcomes to those age less than 55 years.

Survivors of CRC were more likely to report problems on $\geq$ one domain than the general population (68.8% v 59.9% in the matched HSE 2011[20] data; $P < .001$). This was mainly seen in those younger than age 55 years, where 73.1% of survivors of CRC and 49.6% of the general population reported problems ($P < .001$; Fig 2). Outcomes were similar in the older age groups. Survivors of CRC with no other LTCs reported worse health than the general population with no LTCs (58.7% v 40.2% reporting problems, respectively; $P < .001$).

Table 3. Number of Generic Health Problems Reported (using the EuroQol-5D domains) by Patient Demographic or Clinical Characteristic

Demographic or Characteristic	No. of Respondents	No. of Domains With Problems Reported (% of respondents)						Odds of Reporting ≥ One Problem		
		None	1	2	3	4	5	Odds Ratio*	95% CI	P
Age, years										< .001
< 55	1,999	27.6	20.1	17.9	13.4	11.0	10.2	1.00		
55-64	4,998	36.1	20.1	14.0	11.2	9.5	9.1	0.62	0.55 to 0.70	
65-74	7,497	40.0	18.7	12.2	10.8	9.6	8.7	0.46	0.41 to 0.52	
75-84	5,262	30.5	16.7	14.6	15.0	13.5	9.7	0.63	0.56 to 0.72	
≥ 85	1,038	20.6	13.3	14.6	16.9	18.6	16.0	1.03	0.84 to 1.26	
Sex										< .001
Male	12,201	36.5	17.6	13.6	12.0	10.6	9.6	1.00		
Female	8,593	31.7	19.5	14.3	13.2	11.9	9.4	1.34	1.26 to 1.43	
Index of Multiple Deprivation										< .001
1, least deprived	5,281	38.7	19.9	14.7	10.8	9.5	6.3	1.00		
2	5,142	36.4	20.1	13.5	13.0	9.7	7.3	1.07	0.99 to 1.17	
3	4,512	33.4	18.5	14.2	12.5	11.6	9.9	1.17	1.07 to 1.28	
4	3,454	31.5	16.4	13.1	13.3	13.4	12.3	1.18	1.07 to 1.30	
5, most deprived	2,405	27.7	14.3	13.4	13.8	14.0	16.8	1.32	1.17 to 1.48	
Race										.387
White	19,869	34.6	18.6	13.9	12.5	11.1	9.3	1.00		
Nonwhite	431	31.6	13.0	14.2	14.4	12.8	14.2	0.98	0.78 to 1.22	
Not known	494	31.4	16.2	13.8	12.1	11.5	15.0	1.16	0.94 to 1.42	
No. of long-term conditions										< .001
None	4,523	47.6	21.4	14.0	7.8	5.5	3.6	1.00		
1	6,253	40.2	20.6	14.3	11.0	8.2	5.7	1.51	1.39 to 1.64	
2	4,316	31.4	18.6	14.6	13.7	12.0	9.7	2.40	2.18 to 2.64	
≥ 3	4,666	16.7	12.1	12.5	17.9	20.3	20.6	5.57	5.01 to 6.19	
No response	1,036	36.1	19.7	14.4	12.6	8.9	8.3	1.53	1.32 to 1.78	
Dukes' stage of disease at diagnosis										< .001
A	3,373	40.8	19.7	12.9	10.9	9.1	6.7	1.00		
B	6,999	37.9	18.8	13.5	11.3	9.8	8.7	1.09	0.99 to 1.20	
C	7,312	31.3	18.4	14.8	13.4	12.2	9.9	1.24	1.11 to 1.37	
D	1,328	22.4	17.0	13.9	16.7	15.7	14.2	1.36	1.15 to 1.62	
Not known	1,782	31.0	15.9	13.6	13.3	12.9	13.3	1.16	1.01 to 1.33	
Disease status										< .001
Remission	16,082	39.8	19.6	13.6	11.4	9.1	6.5	1.00		
Treated but still present	1,028	9.2	12.6	14.9	17.3	21.8	24.1	5.11	4.07 to 6.42	
No treatment	176	29.0	12.5	13.6	10.2	14.2	20.5	1.32	0.92 to 1.89	
Recurrence	554	12.1	12.8	15.9	19.7	20.4	19.1	4.14	3.17 to 5.40	
Not certain	1,951	14.3	14.4	15.5	16.7	18.9	20.1	3.28	2.86 to 3.76	
No response	1,003	28.3	16.7	13.4	13.9	12.7	15.2	1.38	1.18 to 1.60	
Treatment										< .001
Surgery alone	9,591	39.7	18.2	12.7	11.5	10.2	7.8	1.00		
Surgery + chemotherapy	6,043	34.4	20.6	14.7	12.0	10.0	8.4	1.31	1.20 to 1.43	
Surgery + chemotherapy + radiotherapy	2,833	24.3	17.2	15.9	15.3	14.1	13.2	1.45	1.29 to 1.64	
Surgery + radiotherapy	798	25.9	15.0	14.4	17.0	13.7	13.9	1.34	1.12 to 1.61	
Other†	1,167	26.0	16.4	14.1	13.7	14.7	15.2	1.35	1.15 to 1.59	
No response	362	23.8	13.0	14.1	12.2	17.7	19.3	1.45	1.10 to 1.91	
Stoma status										< .001
No stoma	11,372	39.8	19.0	12.8	11.3	9.9	7.3	1.00		
Reversed	3,269	34.9	20.5	15.7	12.7	9.1	7.1	1.43	1.30 to 1.57	
Present	4,309	19.7	15.8	15.7	15.8	15.9	17.1	2.34	2.12 to 2.59	
No response	1,844	35.7	17.4	13.1	11.7	11.9	10.2	1.06	0.95 to 1.18	
Site										
Colon	12,920	37.0	18.5	13.3	11.7	10.7	8.8			
Rectosigmoid	1,461	36.2	18.1	14.2	11.7	9.5	10.3			
Rectum	6,413	29.1	18.3	15.0	14.2	12.5	11.0			
Total	20,794	34.5	18.4	13.9	12.5	11.2	9.6			

*Adjusted for all variables in the table with the exception of tumor site as a result of the correlation with treatment and stoma status.
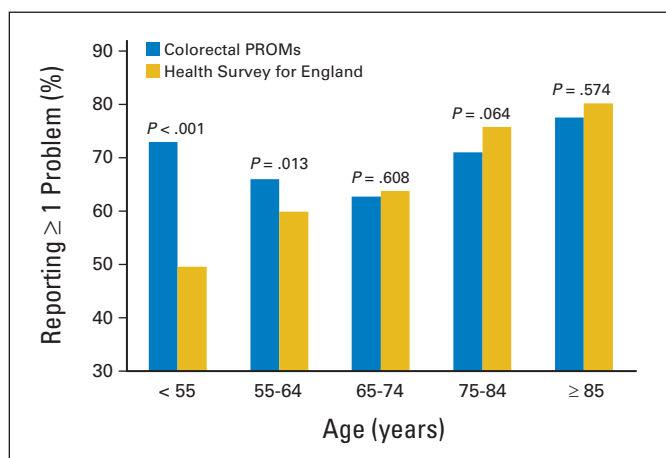†Chemotherapy plus radiotherapy, chemotherapy alone, or radiotherapy alone.

Fig 2. Percentage of respondents reporting less than perfect health (≥ one problem on the EuroQol-5D domains) in a matched sample of colorectal patient-reported outcome measures (PROMs) and Health Survey for England 2011 data (n = 4,615).

Cancer-Specific PROMs

Bowel control. Analysis of questions relating to bowel function was limited to those without a stoma present. Overall, 16.3% of respondents (without a stoma) reported having no control of their bowels (Table 4). This was higher in the group with colon cancer (17.5% compared with 15.4% and 13.0% of patients with rectosigmoid and rectal cancer, respectively; $P < .001$); however, the proportion answering "a little" or "somewhat" (moderate problems) was higher in the rectal cancer group (26.0% v 13.5% and 18.3% in the colon and rectosigmoid groups, respectively; $P < .001$). Patients with a reversed stoma were less likely to report having no bowel control than those who never had a stoma (12.0% v 16.6%, respectively; $P < .001$) but were more likely to report moderate problems ("a little" or "somewhat") than those with no stoma (25.9% v 14.0%, respectively; $P < .001$). Overall, 6.7% of respondents reported having diarrhea "quite a bit" or "very much," and this was similar across the three tumor sites ($P = .353$).

Urinary function. The proportion of respondents reporting problems with difficulty urinating or leaking urine was low; 3.8% and 4.6% of respondents answered "quite a bit" or "very much" to the questions regarding difficulty urinating and leaking urine, respectively (Table 4). A higher proportion of respondents reported problems with urinating more frequently (12.7%). When considered together, 15.4% of respondents answered "quite a bit" or "very much" to any of the three urinary function questions. The figure was higher for the rectal cancer group than the colon and rectosigmoid groups (17.9%, 14.1%, and 15.1%, respectively; $P < .001$). By sex, the figures were 16.0% in males and 14.5% in females ($P = .004$).

Body image and sexual matters. Overall, 10.1% of respondents reported difficulties with their appearance or body image (answered "quite a bit" or "very much"), and this percentage was higher in the rectal group (13.9% v 9.8% in the rectosigmoid group and 8.2% in the colon group; $P < .001$; Table 4). Individuals with a stoma (of whom the majority had rectal cancer) reported more difficulties (20.9% v 6.6% and 10.1% in the no stoma and reversed stoma groups, respectively; $P < .001$).

Rectal cancer respondents were more likely to report difficulties with sexual matters (25.1% answered "quite a bit" or "very much" v

11.2% of colon and 16.1% of rectosigmoid cancer respondents; $P < .001$; Table 4). Of those with a stoma present, 27.2% reported sexual difficulties compared with 10.8% without a stoma ($P < .001$). After radiotherapy, 30.1% of respondents reported sexual difficulties compared with 12.4% who were not irradiated ($P < .001$). A high proportion of respondents (36.9%) selected "does not apply" as their answer to the sexual difficulties question.

DISCUSSION

To our knowledge, this is the first study to report the HRQL outcome of a large nonselected national population living with and beyond a diagnosis of CRC. The major finding that more than one third of individuals surviving 12 to 36 months from a diagnosis of CRC report being in perfect health (ie, no problems on EQ-5D) is reassuring. However, certain subgroups report more problems, notably those with one or more other LTCs, those with active or recurrent disease, those with a stoma, and those at the extremes of the age range (< 55 and > 85). The results confirm emergent findings from previous smaller studies[21-24] and identify groups that may have ongoing health challenges requiring targeted support and services.

Poorer HRQL, relative to the general population, was most marked in the younger age group, with little difference seen in those older than age 65. This has been suggested previously by a single-institution study of 309 survivors in Germany.[21,22] This age effect may be explained by the gap hypothesis of quality of life,[25] with younger populations expecting to live in relatively good health, while older patients may have lower expectations or already be living with other LTCs.

Just more than 16% of all survivors of CRC without a stoma reported having no control of their bowels, with a further 17% reporting moderate problems (little or some control). These problems were not confined to the rectal cancer group and were highly prevalent relative to the general population. In HSE 2011,[20] 9% of those older than age 65 answered "yes" to the question, "Do you suffer from problems with controlling your bowels?" Reversal of a stoma appeared to result in fewer severe bowel problems but more moderate problems than those who had never had a stoma. This finding requires further investigation. Concerning sexual matters, 15.9% of respondents reported experiencing severe difficulties ("quite a bit" or "very much") with patients with rectal cancer reporting a higher percentage (25.1%). Obtaining reliable intelligence on this subject is complex.[26] In one trial, baseline and 2-year sexual function questions were answered by just 21% and 11% of women, respectively.[10] In the current study, although only 5.8% gave no response, more than one third of respondents answered "does not apply," and this response was higher in women than men (48.3% and 28.9%, respectively). The difficulties in capturing responses to questions on sexual function may explain the wide variation in results from previous studies; estimates of incidence of sexual dysfunction in survivors of CRC range from 23% to 69% in men and 19% to 62% in women.[27]

Severe urinary problems were reported by 15.4% of respondents. This relatively low proportion is reassuring. Research in the United States has shown that older survivors of CRC report similar levels of urinary incontinence compared with those without cancer.[28]

This study highlights easily identifiable factors associated with poor reported health outcomes. This emerging intelligence must be used by national initiatives, such as the National Cancer Survivor

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Table 4. Cancer-Specific Patient-Reported Outcomes by Tumor Site

Question	Colon		Rectosigmoid		Rectum		P	Overall	
	No. of Patients	%	No. of Patients	%	No. of Patients	%		No. of Patients	%
I have control of my bowels (in the past week)							< .001		
Very much	5,277	52.1	485	46.6	1,152	34.4		6,914	47.6
Quite a bit	1,718	17.0	206	19.8	896	26.7		2,820	19.4
Somewhat	902	8.9	128	12.3	552	16.5		1,582	10.9
A little	463	4.6	62	6.0	317	9.5		842	5.8
Not at all	1,771	17.5	160	15.4	436	13.0		2,367	16.3
Total	10,131	100	1,041	100	3,353	100		14,525	100
I have diarrhea (in the past week)							< .001		
Not at all	6,328	64.2	662	65.2	1,832	56.4		8,822	62.5
A little	2,247	22.8	245	24.1	893	27.5		3,385	24.0
Somewhat	621	6.3	51	5.0	299	9.2		971	6.9
Quite a bit	439	4.5	29	2.9	153	4.7		621	4.4
Very much	222	2.3	28	2.8	72	2.2		322	2.3
Total	9,857	100	1,015	100	3,249	100		14,121	100
I have difficulty urinating (in the past week)							< .001		
Not at all	10,439	84.1	1,125	81.8	4,670	75.8		16,234	81.4
A little	1,211	9.8	158	11.5	884	14.3		2,253	11.3
Somewhat	371	3.0	45	3.3	294	4.8		710	3.6
Quite a bit	185	1.5	27	2.0	165	2.7		377	1.9
Very much	204	1.6	21	1.5	149	2.4		374	1.9
Total	12,410	100	1,376	100	6,162	100		19,948	100
I urinate more frequently than usual (in the past week)							< .001		
Not at all	6,524	52.1	738	52.9	2,940	47.1		10,202	50.6
A little	3,279	26.2	342	24.5	1,653	26.5		5,274	26.2
Somewhat	1,254	10.0	141	10.1	733	11.7		2,128	10.6
Quite a bit	1,005	8.0	116	8.3	591	9.5		1,712	8.5
Very much	461	3.7	57	4.1	323	5.2		841	4.2
Total	12,523	100	1,394	100	6,240	100		20,157	100
I leak urine (in the past week)							< .001		
Not at all	8,964	72.4	967	70.4	4,192	67.5		14,123	70.8
A little	2,501	20.2	295	21.5	1,379	22.2		4,175	20.9
Somewhat	417	3.4	57	4.2	266	4.3		740	3.7
Quite a bit	291	2.4	29	2.1	209	3.4		529	2.7
Very much	204	1.6	25	1.8	160	2.6		389	1.9
Total	12,377	100	1,373	100	6,206	100		19,956	100
Have you had any difficulty concerning your appearance or body image? (in the past month)							< .001		
No difficulty	8,019	62.2	854	59.3	3,412	53.0		12,285	59.1
A little	2,416	18.7	306	21.3	1,593	24.7		4,315	20.8
Quite a bit	615	4.8	65	4.5	509	7.9		1,189	5.7
Very much	441	3.4	76	5.3	388	6.0		905	4.4
Does not apply	1,411	10.9	138	9.6	537	8.3		2,086	10.0
Total	12,902	100	1,439	100	6,439	100		20,780	100
Have you had any difficulty concerning sexual matters? (in the past month)							< .001		
No difficulty	5,301	41.6	564	39.2	1,941	30.6		7,806	38.0
A little	1,057	8.3	150	10.4	698	11.0		1,905	9.3
Quite a bit	580	4.5	94	6.5	546	8.6		1,220	5.9
Very much	854	6.7	137	9.5	1,045	16.5		2,036	9.9
Does not apply	4,958	38.9	493	34.3	2,121	33.4		7,572	36.9
Total	12,750	100	1,438	100	6,351	100		20,539	100

NOTE. Respondents stating that they had a stoma present and those who did not respond to the stoma question were excluded from this analysis.

Initiative in England,[29] to generate risk-stratified pathways of after-care. Coordination of care has been shown to be important in driving up the quality of supportive care in CRC.[4] Services must ensure this is provided to individuals at increased risk of morbidity. Similarly, cost-effective interventions for the alleviation of bowel morbidity after cancer have been identified. For example, a randomized trial found that structured algorithm-driven management of patients with GI symptoms after pelvic irradiation can give sustained

clinical improvement in bowel function.[30] The magnitude of bowel control problems reported in this study supports the widespread implementation of such interventions.

The survey achieved a response rate of 63%. This is higher than similar, but smaller, studies of survivors of CRC in the United States (54% response)[31] and Canada (34% response)[32] and comparable to a recent study of US veterans with CRC (63% response).[4] Studies from the Netherlands have reported higher response rates (> 70%), although some screening for eligibility was undertaken (eg, excluding terminally ill patients).[23,33] Our response rate is reported according to guidelines[34] without exclusion or screening of eligible individuals. There were differences in the characteristics of those who did and did not respond, with the elderly, ethnic minorities, and those from more socioeconomically deprived areas being less likely to participate. Given the characteristics of the nonrespondents, it is likely that they would experience poorer outcomes and that the results presented here may underestimate the true impact of CRC.

The analysis of HRQL focused only on the reporting (or not) of problems on the EQ-5D domains. The distribution of the EQ-5D data makes any analysis complex. In addition, we would argue that the calculation of scores from patient responses using weights from the general population is flawed. To overcome this, a simple approach has been presented.

Items were selected from the FACT subscales as a result of previous cognitive testing.[4] The effect of omission of items on the psychometric properties is not known. However, single-item responses have been evaluated separately, and any effect is likely to be similar across all subsample groups (ie, colon, rectosigmoid, rectal cancer).

Finally, this study relies on self-reports that have not been verified through comparison with patient records or other sources.

Encouragingly, however, in a large study of patients with breast cancer, excellent concordance was found in regard to disease- and treatment-related information between the medical record and patient self-report.[35]

This study demonstrates the success of a national patient-reported outcomes survey. Although one third of respondents reported no problems on assessment of HRQL, the results identify subgroups that are more likely to report problems. This approach has the potential to support system-wide improvement through the identification of particular challenges faced by individuals after treatment for CRC and those at greatest risk of poor outcomes.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Disclosures provided by the authors are available with this article at www.jco.org.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Health-Related Quality of Life After Colorectal Cancer in England: A Patient-Reported Outcomes Study of Individuals 12 to 36 Months After Diagnosis

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Appendix

Table A1. Comparison of Demographics and Clinical Characteristics Between Respondents and Nonrespondents

Demographic or Clinical Characteristic	Nonrespondents		Respondents		Total No.	Response Rate (%)
	No.	%	No.	%		
Sex						
Male	6,897	54.5	12,683	58.2	19,580	64.8
Female	5,768	45.5	9,119	41.8	14,887	61.3
Total	12,665	100.0	21,802	100.0	34,467	63.3
Age at diagnosis, years						
< 55	1,605	12.7	2,040	9.4	3,645	56.0
55-64	2,457	19.4	5,154	23.6	7,611	67.7
65-74	3,735	29.5	7,824	35.9	11,559	67.7
75-84	3,669	29.0	5,633	25.8	9,302	60.6
≥ 85	1,199	9.5	1,151	5.3	2,350	49.0
Total	12,665	100.0	21,802	100.0	34,467	63.3
Index of Multiple Deprivation						
1, least deprived	2,328	18.4	5,484	25.2	7,812	70.2
2	2,730	21.6	5,360	24.6	8,090	66.3
3	2,649	20.9	4,742	21.8	7,391	64.2
4	2,609	20.6	3,658	16.8	6,267	58.4
5, most deprived	2,349	18.5	2,558	11.7	4,907	52.1
Total	12,665	100.0	21,802	100.0	34,467	63.3
Race						
White	8,702	68.7	16,079	73.8	24,781	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
Not known	3,372	26.6	5,245	24.1	8,617	60.9
Total	12,665	100.0	21,802	100.0	34,467	63.3
Year of diagnosis						
2010	5,968	47.1	10,523	48.3	16,491	63.8
2011	6,697	52.9	11,279	51.7	17,976	62.7
Total	12,665	100.0	21,802	100.0	34,467	63.3
Tumor site						
Colon	8,119	64.1	13,577	62.3	21,696	62.6
Rectosigmoid	807	6.4	1,512	6.9	2,319	65.2
Rectum	3,739	29.5	6,713	30.8	10,452	64.2
Total	12,665	100.0	21,802	100.0	34,467	63.3
Dukes' stage of disease at diagnosis						
A	1,915	15.1	3,533	16.2	5,448	64.8
B	3,935	31.1	7,376	33.8	11,311	65.2
C	4,051	32.0	7,638	35.0	11,689	65.3
D	958	7.6	1,379	6.3	2,337	59.0
Not known	1,806	14.3	1,876	8.6	3,682	51.0
Total	12,665	100.0	21,802	100.0	34,467	63.3

NOTE. Based on cancer registry data available for all eligible individuals.

Table A2. Missing Response Data by Question

Question No.	Description	No. of Responses	Total No. of Respondents	Missing Responses No.	%
1	Treatment	21,328	21,802	474	2.2
3	Disease status	20,550	21,802	1252	5.7
4	Stoma status	19,686	21,802	2116	9.7
5-9	EuroQol-5D (all domains)	20,794	21,802	1008	4.6
12	Bowel control	14,525	15,199	674	4.4
14	Diarrhea	14,121	15,199	1078	7.1
17	Difficulty urinating	19,948	21,802	1854	8.5
18	Urinate more frequently	20,157	21,802	1645	7.5
19	Leak urine	19,956	21,802	1846	8.5
38	Sexual difficulties	20,539	21,802	1263	5.8
40	Body image	20,780	21,802	1022	4.7
72	Long-term conditions	20,631	21,802	1171	5.4
76	Ethnicity	21,212	21,802	590	2.7