



Medicines & Healthcare products
Regulatory Agency



Quality of Life of Colorectal Cancer Survivors in England: Patient Reported Outcome Measures Survey (PROMS)

Version 1.0

Date: 09 May 2019



Documentation Control Sheet

Over time, it may be necessary to issue amendments or clarifications to parts of this document. This form must be updated whenever changes are made.

Version	Affected Areas Summary of Change	Prepared By	Reviewed By
1.0	First CPRD-NCRAS- Colorectal Cancer PROMS data release for set 17	Tarita Murray- Thomas	Eleanor Yelland

Version 1.0

- First version (09 May 2019)



Quality of Life of Colorectal Cancer Survivors in England: Patient Reported Outcome Measures Survey (PROMS) Data Dictionary

Data coverage

The Quality of Life of Colorectal Cancer Survivors in England: Patient Reported Outcome Measures Survey (PROMS) was conducted in January 2013.



Column Description	Column Name	Field Type	Valid Content
Pseudonymised patient ID	e_cr_patid	INTEGER	Unique patient identifier based on ENCORE data. In some cases, the same person may have multiple patient IDs. Patient IDs will be retained even after two patient records are found to be the same person.
What treatments have you received for your bowel (colorectal) cancer?	Q1_1	INTEGER	1.Radiotherapy
What treatments have you received for your bowel (colorectal) cancer?	Q1_2	INTEGER	2.Chemotherapy
What treatments have you received for your bowel (colorectal) cancer?	Q1_3	INTEGER	3. Surgery
How long is it since you completed your initial treatment for bowel (colorectal) cancer?	Q2	INTEGER	1.I am still having my initial treatment; 2. It is less than 3 months since my initial treatment; 3. It is between 3 and 12 months since my initial treatment; 4. It is between 1 and 5 years since my initial treatment; 5. It is more than 5 years since my initial treatment; 6.Don't know / can't remember
How has your bowel (colorectal) cancer responded to treatment?	Q3	INTEGER	1.My colorectal cancer has responded fully to treatment (I am in remission); 2. My colorectal cancer has been treated but is still present; 3. My colorectal cancer has not been treated at all; 4.My colorectal cancer has come back after it was originally treated; 5. I am not certain what is happening with my colorectal cancer
If you have a stoma (e.g. colostomy) is it:	Q4	INTEGER	1. Still present; 2. Reversed; 3. This does not apply to me
Mobility	Q5	INTEGER	1.I have no problems in walking about; 2.I have slight problems in walking about; 3.I have moderate problems in walking about; 4. I have severe problems in walking about; 5.I am unable to walk about



Column Description	Column Name	Field Type	Valid Content
Self care	Q6	INTEGER	1.I have no problems washing or dressing myself; 2.I have slight problems washing or dressing myself; 3. I have moderate problems washing or dressing myself; 4.I have severe problems washing or dressing myself; 5.I am unable to wash or dress myself
Usual activities (work, study, housework, family or leisure activities)	Q7	INTEGER	1.I have no problems doing my usual activities; 2.I have slight problems doing my usual activities; 3.I have moderate problems doing my usual activities 4. I have severe problems doing my usual activities; 5.I am unable to do my usual activities
Pain/discomfort	Q8	INTEGER	1.I have no pain or discomfort; 2.I have slight pain or discomfort; 3.I have moderate pain or discomfort; 4.I have severe pain or discomfort; 5.I have extreme pain or discomfort
Anxiety/depression	Q9	INTEGER	1.I am not anxious or depressed; 2.I am slightly anxious or depressed; 3.I am moderately anxious or depressed; 4.I am severely anxious or depressed; 5.I am extremely anxious or depressed
I have swelling or cramps in my stomach area	Q10	INTEGER	0.Not at all; 1. A little bit; 2. Some-what; 3. Quite a bit; 4. Very much
I am losing weight	Q11	INTEGER	0.Not at all; 1. A little bit; 2. Some-what; 3. Quite a bit; 4. Very much
I have control of my bowel	Q12	INTEGER	0.Not at all; 1. A little bit; 2. Some-what; 3. Quite a bit; 4. Very much
I can digest my food well	Q13	INTEGER	0.Not at all; 1. A little bit; 2. Some-what; 3. Quite a bit; 4. Very much
I have diarrhoea	Q14	INTEGER	0.Not at all; 1. A little bit; 2. Some-what; 3. Quite a bit; 4. Very much
I have a good appetite	Q15	INTEGER	0.Not at all; 1. A little bit; 2. Some-what; 3. Quite a bit; 4. Very much



Column Description	Column Name	Field Type	Valid Content
I like the appearance of my body	Q16	INTEGER	0.Not at all; 1. A little bit; 2. Some-what; 3. Quite a bit; 4. Very much
I have difficulty urinating	Q17	INTEGER	0.Not at all; 1. A little bit; 2. Some-what; 3. Quite a bit; 4. Very much
I urinate more frequently than usual	Q18	INTEGER	0.Not at all; 1. A little bit; 2. Some-what; 3. Quite a bit; 4. Very much
I leak urine	Q19	INTEGER	0.Not at all; 1. A little bit; 2. Some-what; 3. Quite a bit; 4. Very much
Do you have an ostomy appliance/ stoma?	Q20	INTEGER	0.Not at all; 1. A little bit; 2. Some-what; 3. Quite a bit; 4. Very much
I am embarrassed by my ostomy appliance/ stoma	Q21	INTEGER	0.Not at all; 1. A little bit; 2. Some-what; 3. Quite a bit; 4. Very much
Caring for my ostomy appliance/ stoma is difficult	Q22	INTEGER	0.Not at all; 1. A little bit; 2. Some-what; 3. Quite a bit; 4. Very much
Do you have any difficulty in controlling your bowels (e.g. any accidents)?	Q23	INTEGER	1.No; 2. Yes
If yes, how often do you have difficulties?	Q24	INTEGER	1.Monthly; 2. Weekly; 3. Daily; 4. Constantly; 5. It varies
In the past week, on how many days have you done a total of 30 minutes or more physical activity, which was enough to raise your heart rate?	Q25	INTEGER	1-None; 2-1 day; 3-2 days; 4- 3 days; 5-4 days; 6- 5 days; 7- 6 days; 8-7 days
Have you had any difficulty in maintaining your independence	Q26	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have you had any difficulty in carrying out your domestic chores?	Q27	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have you had any difficulty with managing your own personal care?	Q28	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have you had any difficulty with looking after those who depend on you?	Q29	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	Q30	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have you had any difficulty with benefits?	Q31	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have you had any financial difficulties?	Q32	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have you had any difficulty with financial services?	Q33	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much



Column Description	Column Name	Field Type	Valid Content
Have you had any difficulty concerning your work?	Q34	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have you had any difficulty with planning for your own or your family's future?	Q35	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have you had any difficulty with communicating with those closest to you?	Q36	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have you had any difficulty with communicating with others?	Q37	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have you had any difficulty concerning sexual matters?	Q38	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have you had any difficulty concerning plans to have a family?	Q39	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have you had any difficulty concerning your appearance or body image?	Q40	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have you felt isolated?	Q41	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have you had any difficulty with getting around?	Q42	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have you had any difficulty with where you live?	Q43	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have you had any difficulty in carrying out your recreational activities?	Q44	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have you had any difficulty with your plans to travel or take a holiday?	Q45	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
Have you had any difficulty with any other area of your everyday life?	Q46	INTEGER	1.No difficulty; 2. A little; 3. Quite a bit; 4. Very much
I have fears about my cancer spreading	Q47	INTEGER	1.Strongly agree; 2. Agree; 3. Neither agree nor disagree; 4. Disagree; 5. Strongly disagree; 6. Does not apply to me
I have fears about my cancer coming back	Q48	INTEGER	1.Strongly agree; 2. Agree; 3. Neither agree nor disagree; 4. Disagree; 5. Strongly disagree; 6. Does not apply to me
I have fears about death and dying	Q49	INTEGER	1.Strongly agree; 2. Agree; 3. Neither agree nor disagree; 4. Disagree; 5. Strongly disagree
I experience memory loss	Q50	INTEGER	1.Strongly agree; 2. Agree; 3. Neither agree nor disagree; 4. Disagree; 5. Strongly disagree
I have trouble sleeping	Q51	INTEGER	1.Strongly agree; 2. Agree; 3. Neither agree nor disagree; 4. Disagree; 5. Strongly disagree



Column Description	Column Name	Field Type	Valid Content
I have trouble concentrating	Q52	INTEGER	1.Strongly agree; 2. Agree; 3. Neither agree nor disagree; 4. Disagree; 5. Strongly disagree
I always feel tired	Q53	INTEGER	1.Strongly agree; 2. Agree; 3. Neither agree nor disagree; 4. Disagree; 5. Strongly disagree
I experience mood swings	Q54	INTEGER	1.Strongly agree; 2. Agree; 3. Neither agree nor disagree; 4. Disagree; 5. Strongly disagree
I am often irritable	Q55	INTEGER	1.Strongly agree; 2. Agree; 3. Neither agree nor disagree; 4. Disagree; 5. Strongly disagree
Do you have an up to date written care plan?	Q56	INTEGER	1.Yes, definitely; 2. Yes, I think so; 3. No; 4.I do not need a care plan; 5. Don't know
Do you have a named nurse who you can contact if you have a worry about your cancer care?	Q57	INTEGER	1.Yes; 2. No; 3. Don't know
Do you know who to contact if you have a concern about any aspect of living with or after cancer?	Q58	INTEGER	1.Yes, definitely; 2. Yes, I think so; 3. No
Do you think that hospital staff did everything they could to support you following your cancer treatment?	Q59	INTEGER	1.Yes, all of the time; 2. Only some of the time; 3. Never; 4.I did not need any support
Do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?	Q60	INTEGER	1.Yes, all of the time; 2. Only some of the time 3. Never; 4. My general practice is not involved; 5.I do not need any support
Following your initial cancer treatment have you been given enough care and help from health and social services (for example, district nurses, home helps or occupational therapists)?	Q61	INTEGER	1.Yes, definitely; 2. Yes, to some extent; 3. No; 4. I did not need help from health or social services 5. Don' t know / can't remember
Do you consider yourself to be a 1.Smoker; 2. Ex-smoker; 3. Non-smoker	Q62	INTEGER	1. Smoker; 2. Ex-smoker; 3. Non-smoker
If an ex-smoker, how long ago did you stop?	Q63	INTEGER	
Did you receive any advice or information on any of the following issues?	Q64_1	INTEGER	
Did you receive any advice or information on any of the following issues?	Q64_2	INTEGER	
Did you receive any advice or information on any of the following issues?	Q64_3	INTEGER	
Did you receive any advice or information on any of the following issues?	Q64_4	INTEGER	



Column Description	Column Name	Field Type	Valid Content
Did you receive any advice or information on any of the following issues?	Q64_5	INTEGER	
Did you receive any advice or information on any of the following issues?	Q64_6	INTEGER	
Did you receive any advice or information on any of the following issues?	Q64_7	INTEGER	
Did you receive any advice or information on any of the following issues?	Q64_8	INTEGER	
Did you receive any advice or information on any of the following issues?	Q64_9	INTEGER	
Did you receive any advice or information on any of the following issues?	Q64_10	INTEGER	
Did you receive any advice or information on any of the following issues?	Q64_11	INTEGER	
Would it have been helpful to have had more advice or information on any of the following issues?	Q65_1	INTEGER	1.Diet and lifestyle
Would it have been helpful to have had more advice or information on any of the following issues?	Q65_2	INTEGER	2.Physical activity and exercise
Would it have been helpful to have had more advice or information on any of the following issues?	Q65_3	INTEGER	3.Financial help or benefits
Would it have been helpful to have had more advice or information on any of the following issues?	Q65_4	INTEGER	4.Free prescriptions
Would it have been helpful to have had more advice or information on any of the following issues?	Q65_5	INTEGER	5.Returning to or staying in work
Would it have been helpful to have had more advice or information on any of the following issues?	Q65_6	INTEGER	6.Information / advice for family / friends / carer
Would it have been helpful to have had more advice or information on any of the following issues?	Q65_7	INTEGER	7. The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)
Would it have been helpful to have had more advice or information on any of the following issues?	Q65_8	INTEGER	8.The psychological or emotional aspects of living with and after cancer
Would it have been helpful to have had more advice or information on any of the following issues?	Q65_9	INTEGER	
Would it have been helpful to have had more advice or information on any of the following issues?	Q65_10	INTEGER	10.I have all the information and advice I need
What year were you born?	Q66	INTEGER	YYYY



Column Description	Column Name	Field Type	Valid Content
Are you male or female?	Q67	INTEGER	1.Male 2. Female
Do you look after, or give any help or support (not as part of your paid employment) to family members, friends, neighbours or others because of either:	Q68	INTEGER	1. Long term physical or mental health/ disability, or 2. Problems relating to old age
Which of the following best describes your sexual orientation?	Q69	INTEGER	1.Heterosexual / straight (opposite sex); 2. Bisexual (both sexes); 3. Gay or lesbian (same sex); 4. Other; 5. Prefer not to answer
Which statement best describes your living arrangements?	Q70_1	INTEGER	1. I live with partner/spouse/family/friends
Which statement best describes your living arrangements?	Q70_2	INTEGER	2.I live alone
Which statement best describes your living arrangements?	Q70_3	INTEGER	3.I live in a nursing home, hospital or other long-term care home
Which statement best describes your living arrangements?	Q70_4	INTEGER	4.Other
Do you have a long-standing health condition?	Q71_1	INTEGER	1.Yes
Do you have a long-standing health condition?	Q71_2	INTEGER	2.No
Do you have a long-standing health condition?	Q71_3	INTEGER	3.Don't know / can't say
Which, if any, of the following conditions do you have?	Q72_1	INTEGER	1.Alzheimer disease or dementia
Which, if any, of the following conditions do you have?	Q72_2	INTEGER	2.Angina
Which, if any, of the following conditions do you have?	Q72_3	INTEGER	3.Arthritis
Which, if any, of the following conditions do you have?	Q72_4	INTEGER	4.Asthma or another chronic chest problem
Which, if any, of the following conditions do you have?	Q72_5	INTEGER	5.Blindness or visual impairment
Which, if any, of the following conditions do you have?	Q72_6	INTEGER	6.Deafness or hearing impairment
Which, if any, of the following conditions do you have?	Q72_7	INTEGER	7.Diabetes
Which, if any, of the following conditions do you have?	Q72_8	INTEGER	8.Epilepsy
Which, if any, of the following conditions do you have?	Q72_9	INTEGER	9.Heart condition
Which, if any, of the following conditions do you have?	Q72_10	INTEGER	10.High blood pressure



Column Description	Column Name	Field Type	Valid Content
Which, if any, of the following conditions do you have?	Q72_11	INTEGER	11.Kidney disease
Which, if any, of the following conditions do you have?	Q72_12	INTEGER	12.Learning difficulty
Which, if any, of the following conditions do you have?	Q72_13	INTEGER	13.Liver disease
Which, if any, of the following conditions do you have?	Q72_14	INTEGER	14.Long term back problems
Which, if any, of the following conditions do you have?	Q72_15	INTEGER	15.Long-standing mental health problem
Which, if any, of the following conditions do you have?	Q72_16	INTEGER	16.Long-standing neurological problem
Which, if any, of the following conditions do you have?	Q72_17	INTEGER	17.Another long-standing condition
Which, if any, of the following conditions do you have?	Q72_18	INTEGER	18.I do not have any of these conditions
What was your employment status before you were diagnosed with cancer?	Q73	INTEGER	1.Full time employment; 2. Part time employment; 3. Homemaker; 4. Student (in education); 5. Retired; 6. Unemployed and seeking work; 7. Unemployed unable to work for health reasons; 8. Other
What is your employment status currently?	Q74	INTEGER	1.Full time employment; 2. Part time employment; 3. Homemaker; 4. Student (in education); 5. Retired; 6. Unemployed and seeking work; 7. Unemployed, unable to work for health reasons; 8. Other
If you are currently employed at the moment, are you:	Q75	INTEGER	1.Not working at all; 2. Working less hours than usual; 3. Working your usual hours; 4. Working more hours than usual; 5. This question does not apply to me
To which of these ethnic groups would you say you belong?	Q76	INTEGER	1.British; 2.Irish; 3.Any other White background;4.White and Black Caribbean; 5.White and Black African; 6. White and Asian; 7. Any other Mixed background; 8.Indian; 9.Pakistani; 10.Bangladeshi; 11.Any other Asian background; 12.Caribbean; 13.African; 14.Any other Black background; 15. Chinese; 16.Any other ethnic group



Column Description	Column Name	Field Type	Valid Content
Broad ethnic group	-	STRING	Option to group ethnicities (e.g. white/ non-white/ unknown) Data not collected by CPRD