



Health related quality of life following colorectal cancer in England: a patient reported outcomes study

National Cancer Intelligence Network Data Briefing

Background

The number of people living with and beyond a diagnosis of colorectal cancer (CRC) is increasing, predicted to rise from 240,000 in 2010 to 630,000 by 2040 in the United Kingdom (UK). Cancer survivors report significant unmet need, and the consequences of CRC treatment may include bowel, urinary and sexual problems. Targeted aftercare may improve care quality, however, to target effectively we must first understand and quantify the extent of that need.

Patient-reported outcome measures (PROMs), may be used to drive change in the organisation and delivery of healthcare but these data are not yet available on a national basis.

This study aims to define the health-related quality of life (HRQL) of individuals in England living with and beyond CRC, and to identify factors associated with poor health outcomes.

Methods

All individuals over 16 years of age who had survived one to three years from a diagnosis of CRC in 2010 or 2011 were identified via cancer registration data. These individuals were sent a questionnaire and an accompanying letter from their Cancer Centre. The questionnaire included questions which related to treatment, disease status, other long term conditions (LTCs), general HRQL and cancer-specific outcomes.

Age, sex and Dukes stage of disease were obtained from cancer registry data and deprivation category (using the Index of Multiple Deprivation (IMD)) was derived from postcode. A number of variables were derived from the questionnaire data, including self-reported disease status, treatments received, stoma status, presence of other LTCs and ethnicity.

The Health Survey for England 2011 (HSE 2011) provided a comparison with the general population, as this survey used the same measure of HRQL. The two datasets were age and sex-matched to create a comparable sample.

Key messages

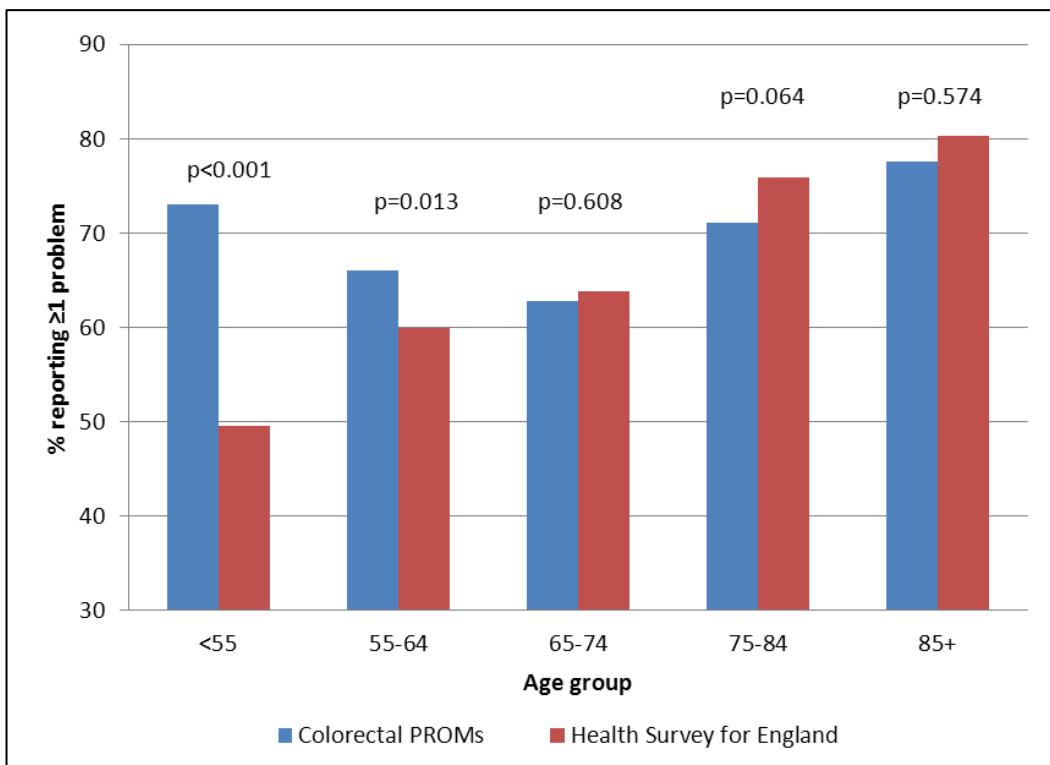
- 65% of the colorectal cancer survivors surveyed reported one or more generic health problems, which was higher than in the general population.
- Respondents with other long term conditions, those with active or recurrent disease, those with a stoma and those at the extremes of the age range (under 55 and over 85) reported a higher number of problems.

Results

Overall, 21,802 individuals completed the questionnaire (63.3% response). 65% of respondents reported one or more generic health problems and 10% reported problems in all five measured domains. The reporting of problems was higher than in the general population and was most marked in those aged less than 55 years (figure 1). Respondents with other LTCs, those with active or recurrent disease, those with a stoma and those at the extremes of the age range (under 55 and over 85) reported a higher number of problems. Lack of bowel control and difficulties with sexual matters were commonly reported.

This study demonstrates the success of a national PROMs survey. The results have the potential to improve targeted care by identifying factors associated with poor reported health outcomes following treatment for CRC.

Figure 1. Percentage of respondents reporting ‘less than perfect’ health (≥ 1 problem on the EQ-5D domains) in a matched sample of Colorectal PROMs and Health Survey for England 2011 data (n=4,615)



FIND OUT MORE:

This data briefing is based on the study:

Downing A, Morris EJA, Richards M *et al.* Health related quality of life following colorectal cancer in England: a patient reported outcomes study of 21,000 individuals 12-36 months post-diagnosis. *Journal of Clinical Oncology* – in press.

The PHE Knowledge and Intelligence Team Northern and Yorkshire is the lead KIT for colorectal cancer.

<https://www.gov.uk/government/organisations/public-health-england>

Public Health England’s National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working to drive improvements in cancer awareness, prevention, diagnosis and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.