



Limited health literacy is a barrier to colorectal cancer screening in England: Evidence from the English Longitudinal Study of Ageing[☆]



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ABSTRACT

Objective. To determine the association between health literacy and participation in publicly available colorectal cancer (CRC) screening in England using data from the English Longitudinal Study of Ageing (ELSA).

Methods. ELSA is a population-based study of English adults aged ≥ 50 years. Health literacy, participation in the national CRC screening programme, and covariates were interview-assessed in 2010–11. All those age-eligible for screening from 2006 to 11 were included in the present analysis ($n = 3087$). The association between health literacy and screening was estimated using multivariable-adjusted logistic regression.

Results. 73% of participants had adequate health literacy skills. Screening uptake was 58% among those with adequate and 48% among those with limited health literacy skills. Having adequate health literacy was associated with greater odds of CRC screening (multivariable adjusted OR = 1.20; 95% CI: 1.00–1.44), independent of other predictors of screening: age (OR = 0.92; 95% CI: 0.91–0.94 per one year increase), female sex (OR = 1.31; 95% CI: 1.11–1.54), and being in a higher wealth quintile (OR = 1.88; 95% CI: 1.43–2.49).

Conclusions. Limited health literacy is a barrier to participation in England's national, publicly available CRC screening programme. Interventions should include appropriate design of information materials, provision of alternative support, and increased one-on-one interaction with health care professionals.

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Introduction

Colorectal cancer (CRC) is a leading cause of global cancer burden among men and women (Ferlay et al., 2010). In the United Kingdom (UK), CRC is the third most common incident cancer and cause of cancer death, with over 40,000 new cases and over 15,000 deaths in 2010 (Cancer Research UK, 2013). England is one of the first countries worldwide to implement a national, organised, publicly available screening programme using the faecal occult blood test (FOBT). The screening programme, entitled the National Bowel Cancer Screening Programme, is operated through the National Health Service (NHS) and was fully implemented in 2010. All adults aged 60–69 (currently being extended to 74) are eligible and receive a written screening invitation through the post with screening information and the home-based FOBT kit biennially beginning in the year of the 60th or 61st birthday.

Although the FOBT reduces mortality (Hewitson et al., 2008; Mandel et al., 1993), overall uptake of screening in England is low and

substantially socially graded. An analysis of the first 2.6 million invitations to the programme from 2006 to 09 found that overall uptake was 54%, but was substantially lower among men and among adults living in deprived and ethnically diverse neighbourhoods (von Wagner et al., 2011). A further source of inequality in CRC screening participation in England may be low health literacy. Health literacy is defined as an individual's capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Institute of Medicine, 2004). Limited health literacy is associated with increased use of emergency care services, elevated risks for several chronic diseases and overall mortality, and poorer use of preventive health services such as cancer screening (Baker et al., 1998; Bennett et al., 2009; Berkman et al., 2011; Bostock and Steptoe, 2012). Health literacy has inconsistently been associated with CRC screening in three American studies (Arnold et al., 2012; Miller et al., 2007; Peterson et al., 2007), although higher health literacy has been associated with increased knowledge and positive attitudes toward the benefits of screening (Arnold et al., 2012; Miller et al., 2007; Peterson et al., 2007).

In England's Bowel Cancer Screening Programme, the primary mode of communication with eligible adults is through written screening information materials mailed through the post. Therefore, limited health literacy skills may in part explain the overall low uptake of screening and social inequalities in screening: they may inhibit some individuals' capacity to understand, and subsequently engage with the written screening information (Davis et al., 2001; Dolan et al., 2004; von

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Wagner et al., 2009a). Health literacy has not yet been investigated with respect to its role in participation in CRC screening when made publicly available, as in England.

Using data from the population-based English Longitudinal Study of Ageing (ELSA), we aimed to determine: 1) the prevalence and predictors of limited health literacy in an English population eligible for CRC screening, 2) the association between health literacy and participation in the FOBT-based NHS Bowel Cancer Screening Programme in England.

Methods

Study sample

The ELSA is a longitudinal cohort study of the English population aged ≥ 50 years (Taylor et al., 2007). Data are collected biennially through computer-assisted interviews. The 'core' ELSA study population consists of participants from the original sample established in 2002 and newer participants added at each wave of data collection to account for ageing of the original sample. Male and female core ELSA participants aged 60–75 at wave 5 (2010–11) who completed the health literacy assessment and the CRC screening questions were eligible for the present analysis. This age group covers those eligible for FOBT screening with the NHS Bowel Cancer Screening Programme at any point from its inception in 2006 to the time of data collection in 2010–11.

In total, 8741 core participants with non-proxy interviews completed data collection at wave 5. Of these, 5041 (58%) were aged 60–75 years. Due to field-work logistics, the interview questions about cancer screening were introduced partway through data collection and subsequently screening data are not complete for the entire sample. Of the 5041 eligible participants, 3087 (61%) were asked the cancer screening questions. Of these, 2995 (97%) completed the health literacy assessment. Refusals were due to: reading problems ($n = 14$), sight difficulties ($n = 14$), health problems ($n = 15$), other reasons including anxiety, impaired concentration, distress, etc. ($n = 15$), or an unknown reason ($n = 34$). Refusals were included and coded as limited health literacy, as these people are likely to perform with limited health literacy skills in real-life settings (e.g. at the doctor's office) because of their difficulties. Therefore, they were included to maintain the population-representativeness of the sample and capture a more accurate range of the health literacy skills of the English population. The present analysis thus included 3087 men and women aged 60–75 years (Fig. 1).

Health literacy assessment

Health literacy was assessed using a four-item comprehension test based on a fictitious medicine label from the International Adult Literacy Survey (Thorn, 2009) (Appendix A). Health literacy was categorised as 'adequate' (4/4 questions answered correctly) or 'limited' (<4/4 answered correctly) to capture the point at which adults begin to have difficulty with everyday health tasks. Although whether and how health literacy skills may change over time are uncertain, health literacy scores among our sample are expected to be stable between data collection and the times of reported CRC screenings (within one year of

wave 5 data collection for 59% of those reporting screening and within two years for 96%). Health literacy was also measured at ELSA wave 2 (2004–5) and the scores did not change between waves 2 and 5 within individuals who remained in the study for both waves. Health literacy scores measured at wave 2 were not used for this analysis, as study attrition between waves was differential by health literacy score.

Colorectal cancer screening

Participants were asked if they had ever used a bowel testing kit (i.e. an FOBT kit) and whether the kit was part of the NHS Bowel Cancer Screening Programme. Only 49 out of the 1709 participants (<3%) who reported having completed an FOBT kit responded that the kit was not part of the NHS programme and 3 (<1%) responded that they did not know whether it was part of the programme; hence for this analysis we assume that completion of a FOBT kit equates with participation in the NHS programme. For convenience, the terms "completion of an FOBT kit" and "CRC screening" will hereupon be used synonymously.

Covariates

Sociodemographic covariates were: age, sex (male; female); educational attainment (no qualification; up to degree level; degree level or equivalent); net non-pension wealth (quintiles stratified at age 65 to account for changes in wealth following retirement) (Bostock and Steptoe, 2012); occupational class according to the 2010 National Statistics Socio-economic Classification (routine; intermediate; managerial or professional) (Office for National Statistics, 2010); and ethnic minority status (non-white; white).

Health-related covariates were: having a limiting long-standing illness (yes; no); having limitations in any one of six activities of daily living: dressing, walking across a room, bathing or showering, eating, getting in and out of bed, using the toilet (yes; no) (Bostock and Steptoe, 2012); having difficulty using the toilet including getting up and down (yes; no; this activity of daily living was also considered separately due to its specificity to completing an FOBT kit); having depressive symptoms, classified as scoring more than four on the eight-item Centre for Epidemiologic Studies depression scale (yes; no) (Radloff, 1977); self-reported general health (fair/poor; excellent/very good/good); and having ever been diagnosed with cancer (yes; no).

Statistical analysis

To achieve objective 1), the prevalence of adequate and limited health literacy were calculated. Unadjusted logistic regression modelling was used to generate odds ratios (ORs) and associated 95% confidence intervals (CIs) for the associations between health literacy and all covariates. Linear trend tests were used to assess graded relationships between ordered variables and health literacy. The same analyses were then conducted between participation in CRC screening and all covariates.

To achieve objective 2), the independent association between having adequate health literacy and participation in CRC screening was estimated using multivariable-adjusted logistic regression. Age, sex, educational attainment, and net non-pension wealth were forced into the model and all health-related covariates associated with screening with $p < 0.20$ in bivariate analysis were included in the initial model and retained if their deletion resulted in a $\geq 10\%$ change in the OR for the association between health literacy and CRC screening (Rothman and Greenland, 1998).

Two sensitivity analyses were conducted. The first excluded those who refused to complete the health literacy assessment ($n = 92$) to ensure that these participants were not misclassified in a way to cause bias. The second excluded those who reported completing FOBT-based CRC screening outside of the national programme ($n = 49$). All regression modelling was performed with population weights applied to account for differential non-response across population subgroups (NatCen Social Research, 2012). All statistical tests were two-sided and performed at the 95% confidence level. All statistical analyses were conducted using StataSE 12.0 (StataCorp, College Station, TX).

Results

Nearly one in three ELSA participants eligible for CRC screening lacked adequate health literacy skills (Table 1). Health literacy was non-differential by gender, while those with higher educational

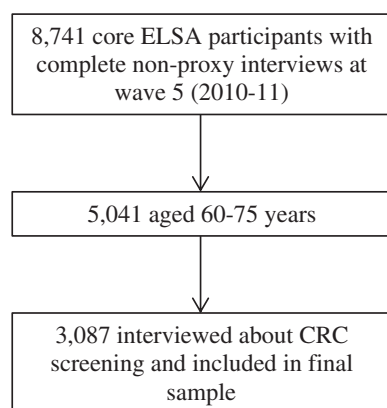


Fig. 1. Inclusion flow diagram, the English Longitudinal Study of Ageing, England, 2010–11 ($n = 3087$).

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