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# Ethnic differences in cancer symptom awareness and barriers to seeking medical help in England

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**Background:** Ethnic differences in cancer symptom awareness and barriers to seeking medical help in the English population are not fully understood. We aimed to quantify these differences, to help develop more effective health campaigns, tailored to the needs of different ethnic groups.

**Methods:** Using a large national data set ( $n=38492$ ) of cross-sectional surveys that used the Cancer Research UK Cancer Awareness Measure, we examined how cancer symptom awareness and barriers varied by ethnicity, controlling for socio-economic position, age and gender. Data were analysed using multivariable logistic regression.

**Results:** Awareness of cancer symptoms was lower in minority ethnic groups than White participants, with the lowest awareness observed among Bangladeshi and Black Africans. Ethnic minorities were more likely than White British to report barriers to help-seeking. South Asians reported the highest emotional barriers, such as lack of confidence to talk to the doctor, and practical barriers, such as worry about many other things. The Irish were more likely than the White British to report practical barriers, such as being too busy to visit a doctor. White British participants were more likely than any other ethnic group to report that they would feel worried about wasting the doctor's time. Overall, Black Africans had the lowest barriers. All differences were statistically significant ( $P<0.01$  level), after controlling for confounders.

**Conclusions:** Our findings suggest the need for culturally sensitive and targeted health campaigns, focused on improving recognition of cancer symptoms among ethnic minorities. Campaigns should tackle the specific barriers prevalent in each ethnic group.

Britain is a multi-ethnic society, which has been described as a 'super-diversity' to reflect recent changes in its socio-demographic structure (Vertovec, 2007). The population with an ethnic minority background has doubled in size between 2001 and 2011 Census data collection (Office for National Statistics, 2012b). Super-diversity refers to a shift in recent immigration patterns, including a wider range of ethnicities from all over the world, and a dynamic interplay between factors such as religious and cultural behaviour norms, legal status and links with homeland (Vertovec, 2007). England has a higher percentage of ethnic minorities (14%) in

comparison with Scotland (4%) and Wales (4%) (Scotland's Census, 2011; Welsh Government, 2012; Office for National Statistics, 2012a).

Ethnic minorities in England are more likely than the White majority to have advanced stage at diagnosis, the key predictor of poor cancer survival (Velikova *et al*, 2004; Jack *et al*, 2009). Advanced stage at diagnosis is common among people with longer time to presentation after the onset of symptoms (Burgess *et al*, 2006). Low cancer symptom awareness and increased barriers to seeking medical help have been suggested as risk factors for longer

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time to presentation (Macleod *et al*, 2009). Some studies suggested that ethnic minorities have lower recognition of cancer symptoms (Scanlon and Wood, 2005; Waller *et al*, 2009), and more barriers to early symptomatic presentation than the majority population (Forbes *et al*, 2011). However, findings about ethnic differences in cancer awareness and barriers to help-seeking have not been consistent across studies.

Robb *et al* (2009) reported that ethnic minorities had lower cancer symptom awareness than White British people, which was not confirmed by Linsell *et al* (2008). While Robb *et al* (2009) found no ethnic differences in perception of barriers to help-seeking, another survey revealed several differences (Waller *et al*, 2009). For example, South Asian women had higher emotional barriers than other ethnic minorities, such as feeling embarrassed or not confident to talk to their general practitioner (GP). Black Africans had lower barriers than any other minority group, but other patterns were not clear (Waller *et al*, 2009). Evidence suggests that some barriers may be frequent among White British. In East London, White women were found to be more worried about wasting the doctor's time than Black or South Asian women (Forbes *et al*, 2011). However, another London-based study did not identify this barrier among White women (Marlow *et al*, 2014), perhaps because older women (65+) were not interviewed. Marlow *et al* (2014) suggested that some barriers to presentation of breast or cervical cancer symptoms were common regardless of ethnicity, such as fear of cancer. Other barriers were more culture-specific, such as reluctance of Indian women to discuss female body parts.

Drawing firm conclusions from previous studies is difficult for a number of reasons: for example, a sample limited to a particular geographical area and women only (Forbes *et al*, 2011; Marlow *et al*, 2014); lack of a White comparison group (Waller *et al*, 2009); and, not a large enough sample size to examine individual ethnic groups, so all minorities were categorised as 'Other' (Robb *et al*, 2009). Such broad categorisation does not acknowledge the heterogeneity that exists within the 'Other' group. Even within each of the broad ethnic subgroups, such as 'White', 'Black' and 'Asian', there are many diverse cultural practices, social values and health behavioural patterns (Nazroo, 2003). In addition, previous studies have not thoroughly assessed the role of socio-economic position (SEP), which is closely intertwined and interdependent with ethnicity (Williams *et al*, 2012).

Awareness raising campaigns were introduced in England to encourage early cancer presentation (Cancer Research UK, 2015), but they were not targeted to meet the needs of the ethnically diverse population. A clear understanding of gaps in cancer awareness and barriers prevalent in each ethnic group is necessary to improve the effectiveness of these campaigns; and, to understand the patterns of advanced-stage diagnosis by ethnicity. Therefore, this study aimed to quantify ethnic differences in cancer symptom awareness and barriers to symptomatic presentation in the English population, to help develop more effective health campaigns, tailored to the needs of different ethnic groups.

## MATERIALS AND METHODS

Cross-sectional surveys collected data across England, using the Cancer Research UK Cancer Awareness Measure (CAM) (Stubbs *et al*, 2009), during 2009/2011. Data from 18 surveys in total were collated into a uniquely large CAM data set ( $n = 49\,270$ ). Just under half of all surveys (43%) were collected using random probability sampling frame, such as Royal Mail postcodes or UK Electoral Roll. The rest of the surveys (57%) were collected using non-random probability sampling techniques, such as approaching people on the street. We assigned each participant a measure of SEP, based on their postcode of residence and the

income domain of indices of multiple deprivation, as previously described (Niksic *et al*, 2015). We classified participants into five groups of area income deprivation (ranging from 1—least deprived to 5—most deprived), based on quintiles in the English population (Department for Communities and Local Government, 2010). The same approach was used to calculate socio-economic deprivation groups, using the education and employment domain of the indices of multiple deprivation.

We excluded participants with missing information on gender ( $n = 58$ ), age ( $n = 2431$ ), area income deprivation ( $n = 8151$ ) and ethnicity ( $n = 138$ ). Ethnicity was self-reported, in response to a question: 'Which of these best describes your ethnic group?' We adopted the ethnic definitions of the 2011 Census for England to differentiate between the following nine ethnic groups: White British, White Irish, Indian, Pakistani, Bangladeshi, Chinese, Black African, Black Caribbean and Other (Office for National Statistics, 2012a). The ethnic group 'Other' included mixed race participants and those who described their ethnicity as 'other', including other White, other Asian and other Black backgrounds.

We used closed or prompted CAM questions, asking participants to recognise symptoms of cancer from the list of symptoms: 'The following may or may not be warning signs for cancer. We are interested in your opinion'. The list of prompted questions included the following: 'Do you think an unexplained lump or swelling could be a sign of cancer?'; 'Do you think persistent unexplained pain could be a sign of cancer?'; 'Do you think unexplained bleeding could be a sign of cancer?'; 'Do you think a persistent cough or hoarseness could be a sign of cancer?'; 'Do you think a persistent change in bowel or bladder habits could be a sign of cancer?'; 'Do you think persistent difficulty swallowing could be a sign of cancer?'; 'Do you think a change in the appearance of a mole could be a sign of cancer?'; 'Do you think a sore that does not heal could be a sign of cancer?'; 'Do you think unexplained weight loss could be a sign of cancer?'. Barriers to help-seeking were assessed using the questions: 'Sometimes people put-off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put you off going to the doctor?', and included the following: 'I would be too embarrassed'; 'I would be too scared'; 'I would be worried about what the doctor might find'; 'I would not feel confident talking about my symptom with the doctor'; 'It would be difficult to make an appointment with my doctor'; 'I would be too busy to make time to go to the doctor'; 'I have too many other things to worry about'; 'I would be worried about wasting the doctor's time'; 'It would be difficult for me to arrange transport to the doctor's surgery'; 'My doctor would be difficult to talk to'.

**Analysis.** We calculated cancer awareness and barriers scores by adding up 'yes' responses to the questions about cancer symptoms (range 0–9), and barriers to help-seeking (range 0–10), respectively. For example, a participant who recognised five potential cancer symptoms (five 'yes' responses) had cancer awareness score of five. Then we examined how cancer awareness and barriers scores varied between ethnic groups using Kruskal–Wallis tests. We examined the association between ethnic groups (independent variables) and both recognition of each cancer symptom and perception of each barrier to help-seeking (dependent variables), using logistic regression models. Because of multiple significance testing, the level of significance was set at  $P < 0.01$ . The multivariable logistic regression models included *a priori* defined confounders: age, gender and SEP (presented in tables as area income deprivation).

We repeated the analyses using: (1) education and employment deprivation measures, instead of area income deprivation; (2) 12 ethnic groups, with Other White, Other Asian and Other Black backgrounds analysed separately; and, (3) data from the surveys

that used random probability sampling only. All analyses were done using Stata 14.0 (STATA Corp, 2015).

**RESULTS**

The distribution of gender, age and ethnic groups in our sample was similar to that of the general population of England (Table 1), with differences between our sample and the population often not larger than one percentage point (Office for National Statistics, 2012a). Overall more women responded to the survey; in most ethnic groups just over half of participants were females, with the exception of Pakistanis and Bangladeshis. People from South Asian and Black minority groups were more likely to live in the most socio-economically deprived areas, especially Pakistanis and Bangladeshis, in line with trends in the population as a whole. Ethnic minority groups were younger than White participants, which is what we would have expected from national data (Office for National Statistics, 2011).

**Cancer awareness and barriers to help-seeking scores.** We found statistically significant ethnic differences in cancer awareness and barriers scores (Table 2). White British and White Irish reported a higher average number of recognised symptoms in comparison with ethnic minority groups. We observed a trend of lower cancer awareness score with higher socio-economic deprivation among all ethnic groups. Overall, Black Africans had lower barriers score than all other ethnic groups. We found age and gender differences in awareness and barriers score for all ethnic groups, except Chinese and South Asians. Overall, women had the highest cancer awareness and barriers scores; 15–34-year olds had the lowest awareness scores, and 75+ year olds had the lowest barriers scores.

Participants who recognised all nine symptoms, considered to be highly aware of cancer symptoms, by ethnic group were: 44% White British, 39% White Irish, 29% Other, 24% Chinese, 23% both Black Caribbean and Indian, 22% Pakistani, 20% Black African and 16% Bangladeshi participants. Participants who identified three or more reasons that would deter them from seeking medical attention were considered to have above-average barriers to help-seeking. These were, by ethnic group: 39% Indian, 37% Bangladeshi, 36% Chinese, 34% Pakistani, 33% Other, 33% White Irish, 29% White British, and 28% for both Black Caribbean and Black African participants.

**Recognition of individual cancer symptoms.** Ethnic minority groups were less likely to recognise each cancer symptom than White participants, and adjustment for age, gender and area income deprivation, made little difference to the results (Table 3). Unadjusted results are available in Supplementary Material 1. Black African and Bangladeshi participants least frequently recognised each cancer symptom, except a ‘sore that does not heal’ (Table 3). Chinese participants had the lowest recognition of this symptom, with 49% lower odds of recognising it compared with White British (OR=0.51; 99% CI: 0.34–0.76). The most frequently recognised symptom was an ‘unexplained lump or swelling’ (94% of all participants), which Bangladeshi participants recognised less frequently than any other ethnic group (77%). Bangladeshis had almost seven times lower odds of recognising lump as a symptom of cancer than White British (OR=0.15; 99% CI: 0.11–0.21). The largest difference between ethnic minorities and White British was in recognition of ‘change in the appearance of a mole’, which was recognised by only 59% of Bangladeshis compared with 94% of White British participants. ‘Persistent cough or hoarseness’ was another symptom with low recognition; recognised by only 51% of Black Africans, in comparison with 70% of White British. Black Africans had

**Table 1. Socio-demographic characteristics of the sample (n (%))**

Sample	Total n (%)	White British	White Irish	Indian	Pakistani	Bangladeshi	Black African	Black Caribbean	Chinese	Other
Comparison: England (2011 Census data)	38 492 (100.0)	31 563 (82.0)	447 (1.2)	768 (2.0)	610 (1.6)	403 (1.0)	885 (2.3)	784 (2.0)	174 (0.5)	2858 (7.4)
	53 012 456 (100.0)	42 279 236 (79.8)	517 001 (1.0)	1 395 702 (2.6)	1 112 282 (2.1)	436 514 (0.8)	977 741 (1.8)	591 016 (1.1)	379 503 (0.7)	5 323 461 (10.0)
<b>Gender</b>										
Women	21 534 (55.9)	17 959 (56.9)	244 (54.6)	391 (50.9)	283 (46.4)	170 (42.2)	450 (50.8)	451 (57.5)	92 (52.9)	1494 (52.3)
Men	16 958 (44.1)	13 604 (43.1)	203 (45.4)	377 (49.1)	327 (53.6)	233 (57.8)	435 (49.2)	333 (42.5)	82 (47.1)	1364 (47.7)
<b>Age (years)</b>										
15–34	9999 (25.9)	7067 (22.4)	121 (27.1)	341 (44.4)	275 (45.1)	181 (44.9)	360 (40.6)	251 (32.0)	85 (48.8)	1318 (46.1)
35–54	14 230 (36.9)	11 547 (36.6)	140 (31.3)	288 (37.5)	220 (36.0)	147 (36.5)	424 (47.9)	330 (42.1)	63 (36.2)	1071 (37.5)
55–74	11 982 (31.1)	10 847 (34.4)	156 (34.9)	124 (16.1)	108 (17.7)	72 (17.9)	272 (10.4)	153 (19.5)	21 (12.1)	409 (14.3)
75+	2281 (5.9)	2102 (6.6)	30 (6.7)	15 (1.9)	7 (1.1)	3 (0.7)	9 (1.0)	50 (6.4)	5 (2.9)	60 (2.1)
<b>Area income deprivation</b>										
1 (Most affluent)	4580 (11.9)	4027 (12.7)	39 (8.7)	74 (9.6)	19 (3.1)	13 (3.2)	36 (4.1)	27 (3.4)	24 (13.8)	321 (11.2)
2 (Less affluent)	5473 (14.2)	4830 (15.3)	53 (11.9)	97 (12.6)	44 (7.2)	19 (4.7)	27 (3.0)	44 (5.6)	22 (12.6)	337 (11.8)
3 (Deprived)	8084 (21.0)	6821 (21.6)	115 (25.7)	141 (18.4)	74 (12.1)	37 (9.2)	114 (12.9)	145 (18.5)	40 (23.0)	597 (20.9)
4 (More deprived)	8286 (21.5)	6532 (20.7)	111 (24.8)	185 (24.1)	134 (22.0)	70 (17.3)	271 (30.6)	225 (28.7)	34 (19.5)	724 (25.3)
5 (Most deprived)	12 069 (31.3)	9353 (29.6)	129 (28.8)	271 (35.3)	339 (55.6)	264 (65.5)	437 (49.4)	343 (43.5)	54 (31.0)	376 (30.7)

Table 2. Cancer awareness score and barriers to help-seeking score (mean number, s.d.) by ethnicity

Ethnic groups	White British		White Irish		Indian		Pakistani		Bangladeshi		Black Caribbean		Black African		Chinese		Other	
	Symp-toms	Barriers	Symp-toms	Barriers	Symp-toms	Barriers	Symp-toms	Barriers	Symp-toms	Barriers	Symp-toms	Barriers	Symp-toms	Barriers	Symp-toms	Barriers	Symp-toms	Barriers
Total	7.5 (1.9)	1.8 (2.1)	7.4 (1.9)	2.0 (2.2)	6.3 (2.4)	2.3 (2.4)	2.1 (2.2)	2.2 (2.2)	6.3 (2.4)	1.8 (2.1)	5.6 (2.7)	1.7 (2.1)	6.3 (2.4)	2.3 (2.5)	6.5 (2.5)	2.0 (2.2)	6.7 (2.4) <sup>a</sup>	2.1 (2.2) <sup>a</sup>
Gender																		
Women	7.6 (1.8)	1.9 (2.1) <sup>a</sup>	7.5 (1.8)	2.2 (2.4)	6.5 (2.2)	2.6 (2.5) <sup>a</sup>	2.3 (2.2) <sup>a</sup>	2.5 (2.1) <sup>a</sup>	6.6 (2.2) <sup>a</sup>	1.9 (2.3)	5.6 (2.7)	1.8 (2.2) <sup>a</sup>	6.5 (2.2)	2.4 (2.3)	6.7 (2.4) <sup>a</sup>	2.1 (2.2) <sup>a</sup>	6.3 (2.5)	1.9 (2.2)
Men	7.3 (2.0)	1.6 (2.0)	7.2 (1.9)	1.8 (1.9)	6.2 (2.5)	2.0 (2.3)	1.8 (2.2)	1.9 (2.2)	6.0 (2.5)	1.6 (1.8)	5.6 (2.7)	1.6 (2.1)	6.0 (2.5)	2.1 (2.7)	6.3 (2.5)	1.8 (2.2)	6.3 (2.5)	1.8 (2.2)
Age (years)																		
15-34	6.9 (2.1) <sup>a</sup>	2.3 (2.4) <sup>a</sup>	7.0 (1.9) <sup>a</sup>	2.5 (2.3) <sup>a</sup>	6.3 (2.4)	2.4 (2.4) <sup>a</sup>	2.3 (2.4)	2.4 (2.3)	5.7 (2.3)	2.3 (2.5) <sup>a</sup>	5.6 (2.6)	1.8 (2.0) <sup>a</sup>	6.1 (2.3)	2.6 (2.8)	6.3 (2.5) <sup>a</sup>	2.1 (2.3) <sup>a</sup>	6.6 (2.4)	1.9 (2.2)
35-54	7.5 (1.8)	1.9 (2.1)	7.5 (1.8)	2.3 (2.2)	6.4 (2.3)	2.6 (2.5)	1.9 (2.1)	2.0 (2.2)	5.5 (2.6)	1.7 (2.0)	5.8 (2.8)	1.5 (2.2)	6.5 (2.5)	2.0 (2.2)	6.6 (2.4)	2.0 (2.2)	6.6 (2.4)	1.9 (2.2)
55-74	7.8 (1.7)	1.4 (1.8)	7.6 (1.8)	1.4 (1.9)	6.3 (2.4)	1.6 (2.1)	1.7 (1.8)	1.7 (1.8)	5.4 (2.7)	1.3 (1.8)	5.5 (2.7)	2.0 (2.2)	6.3 (2.3)	1.9 (2.5)	7.0 (2.3)	1.7 (2.1)	6.4 (2.6)	1.8 (2.3)
75+	7.2 (2.1)	1.2 (1.8)	7.2 (2.2)	1.7 (2.7)	6.0 (2.2)	1.5 (1.7)	1.1 (1.3)	1.6 (1.5)	4.0 (3.5)	1.0 (1.7)	5.1 (2.1)	2.1 (2.1)	5.6 (3.4)	1.5 (1.7)	5.5 (2.7)	1.6 (1.9)	6.1 (2.5)	1.7 (2.1)
Area income deprivation																		
1 (Most affluent)	7.6 (1.8) <sup>a</sup>	1.7 (2.0)	6.9 (2.2)	1.9 (2.2)	7.5 (1.6) <sup>a</sup>	2.1 (2.4)	2.0 (2.4)	2.3 (1.8)	5.7 (2.3) <sup>a</sup>	1.9 (2.8)	5.3 (2.7)	1.4 (1.8)	6.6 (2.4)	2.1 (3.1)	7.3 (1.9) <sup>a</sup>	2.2 (2.2) <sup>a</sup>	6.8 (2.4)	2.1 (2.2)
2 (Less affluent)	7.6 (1.8)	1.8 (2.1)	7.4 (2.0)	1.8 (1.9)	6.7 (2.3)	2.2 (2.5)	1.7 (2.1)	2.1 (2.0)	6.4 (2.9)	1.5 (1.7)	6.6 (2.6)	2.0 (2.1)	7.3 (1.8)	2.8 (3.0)	6.7 (2.4)	2.3 (2.4)	6.4 (2.6)	1.9 (2.3)
3 (Deprived)	7.5 (1.8)	1.8 (2.1)	7.6 (1.8)	2.1 (2.3)	6.4 (2.4)	2.3 (2.5)	2.3 (2.7)	1.8 (1.9)	6.1 (2.8)	2.0 (2.4)	5.9 (2.8)	1.5 (2.1)	6.1 (2.8)	2.3 (2.3)	6.7 (2.4)	2.3 (2.4)	6.4 (2.6)	1.8 (2.3)
4 (More deprived)	7.4 (1.9)	1.8 (2.1)	7.6 (1.7)	2.0 (1.9)	6.4 (2.4)	2.4 (2.3)	1.9 (2.2)	2.2 (2.5)	6.3 (2.3)	1.6 (1.9)	5.6 (2.7)	1.6 (2.3)	6.5 (2.3)	1.8 (2.0)	6.4 (2.6)	2.4 (2.6)	6.1 (2.5)	1.9 (2.3)
5 (Most deprived)	7.3 (2.0)	1.8 (2.1)	7.2 (1.8)	2.0 (2.4)	5.8 (2.3)	2.3 (2.4)	2.1 (2.1)	2.1 (2.2)	5.2 (2.4)	1.8 (2.2)	5.6 (2.6)	1.8 (2.1)	5.8 (2.1)	2.4 (2.6)	6.1 (2.5)	2.4 (2.6)	6.1 (2.5)	1.9 (2.3)

<sup>a</sup>Statistically significant at P<0.05 level (95% confidence intervals). Possible range for Symptoms (cancer symptom awareness score) was 0 to 9. Possible range for Barriers (barriers to help-seeking score) was 0 to 10.

significantly lower odds of recognising this symptom than White British (OR = 0.55; 99% CI: 0.46–0.66).

Sensitivity analyses using area-level education or employment deprivation measures, instead of area income deprivation, hardly modified the results shown in Table 3 (results available on request). The results were also similar when 12 ethnic groups were analysed separately (Supplementary Material 2). Furthermore, restricting the analysis to the data collected via random probability sampling did not change Table 3 results (results available on request), suggesting they were not affected by the survey design.

**Perception of individual barriers to help-seeking.** Ethnic minority groups were generally more likely to identify barriers to presentation than White participants, and adjustment for age, gender and area income deprivation made little difference to the results (Table 4). Unadjusted results are available in Supplementary Material 3. In general, South Asians reported barriers to help-seeking more frequently than other ethnic groups (Table 4). Emotional barriers were the most common, reported by approximately a quarter of all South Asians, but slightly more frequently by Indian participants. Pakistanis had 51% higher odds of reporting embarrassment (OR = 1.51; 99% CI: 1.17–1.93); while Indian participants had two-fold higher odds of reporting lack of ‘confidence to talk about their symptoms with the doctor’ (OR = 2.03; 99% CI: 1.60–2.57), in comparison with White British. Practical barriers were also widespread, as over a quarter of South Asians reported being ‘worried about many other things’ (28%), and being ‘too busy’ to visit a doctor (24–31%).

Black participants had the lowest barriers, especially Black Africans. For example, they had 57% lower odds than White British of reporting that ‘worry about wasting the doctor’s time’ would be a barrier to help-seeking (OR = 0.43; 99% CI: 0.33–0.55). Chinese participants most frequently reported that they would find it ‘difficult to talk’ to the GP about their symptoms (23%). White Irish had 68% higher odds than White British of reporting that being ‘too busy’ would put them off going to the doctor (OR = 1.68; 99% CI: 1.26–2.23). White British participants were significantly more likely than any other ethnic group to report that they would be ‘worried about wasting the doctor’s time’. A quarter (25%) of White British reported this barrier in comparison with, for example, 18% of Black Caribbeans.

The most commonly reported barriers to seeking medical help were ‘worry about what the doctor might find’ (30%), and finding it ‘difficult to make an appointment’ (28%). We found no statistically significant differences between ethnic groups in relation to these barriers, or for being ‘too scared’ (borderline significance observed only for the ‘Other’). The only exception were Black Africans, who were significantly less likely than White British to report being too scared and having difficulties to make an appointment (Table 4). All minority ethnic groups, except Black Caribbeans, were more likely than White British to report that they would find it ‘difficult to arrange transport’ to the doctor’s surgery. We obtained similar results as those in Table 4 when using area level education or employment deprivation measures, instead of area income deprivation (results available on request), or when analysing 12, instead of 9, ethnic groups (Supplementary Material 4), or when we included data collected via random probability sampling only (results available on request).

DISCUSSION

**Main findings.** Ethnic minorities had lower symptom awareness and more widespread barriers to seeking medical help than White participants. Bangladeshis and Black Africans were least likely to recognise cancer symptoms. South Asians reported increased emotional and practical barriers. White British were more likely



**Table 3. Recognition of each cancer symptom according to the nine ethnic groups, with percentage of participants who recognised each symptom and odds ratios (99% confidence intervals) adjusted for age group, gender and deprivation (n = 38 492)**

Symptoms/ethnic groups	White British	White Irish	Indian	Pakistani	Bangladeshi	Black Caribbean	Black African	Chinese	Other
Unexplained lump or swelling	96% 1.00	94% 0.74 (0.43-1.26)	87% 0.27 <sup>a</sup> (0.20-0.36)	83% 0.23 <sup>a</sup> (0.17-0.31)	77% 0.15 <sup>a</sup> (0.11-0.21)	88% 0.32 <sup>a</sup> (0.24-0.43)	83% 0.22 <sup>a</sup> (0.17-0.28)	89% 0.33 <sup>a</sup> (0.17-0.63)	88% 0.30 <sup>a</sup> (0.25-0.35)
Unexplained persistent pain	79% 1.00	80% 1.05 (0.77-1.43)	71% 0.65 <sup>a</sup> (0.53-0.80)	71% 0.68 <sup>a</sup> (0.54-0.86)	70% 0.67 <sup>a</sup> (0.50-0.89)	72% 0.71 <sup>a</sup> (0.58-0.88)	66% 0.54 <sup>a</sup> (0.45-0.65)	80% 1.04 (0.63-1.69)	74% 0.74 <sup>a</sup> (0.66-0.84)
Unexplained bleeding	87% 1.00	88% 1.09 (0.75-1.59)	76% 0.55 <sup>a</sup> (0.44-0.69)	73% 0.51 <sup>a</sup> (0.40-0.65)	69% 0.44 <sup>a</sup> (0.33-0.58)	77% 0.56 <sup>a</sup> (0.45-0.70)	67% 0.36 <sup>a</sup> (0.30-0.44)	75% 0.53 <sup>a</sup> (0.33-0.84)	75% 0.53 <sup>a</sup> (0.47-0.59)
Persistent cough or hoarseness	70% 1.00	69% 0.98 (0.75-1.29)	59% 0.73 <sup>a</sup> (0.60-0.88)	57% 0.70 <sup>a</sup> (0.57-0.87)	53% 0.61 <sup>a</sup> (0.47-0.79)	56% 0.63 <sup>a</sup> (0.52-0.76)	51% 0.55 <sup>a</sup> (0.46-0.66)	58% 0.70 (0.47-1.05)	61% 0.78 <sup>a</sup> (0.70-0.87)
Bowel/bladder habits change	89% 1.00	89% 1.08 (0.72-1.62)	74% 0.41 <sup>a</sup> (0.33-0.51)	70% 0.37 <sup>a</sup> (0.29-0.46)	61% 0.25 <sup>a</sup> (0.19-0.33)	74% 0.41 <sup>a</sup> (0.33-0.51)	65% 0.28 <sup>a</sup> (0.23-0.33)	71% 0.36 <sup>a</sup> (0.23-0.55)	76% 0.46 <sup>a</sup> (0.41-0.53)
Difficulty in swallowing	77% 1.00	79% 1.14 (0.85-1.55)	61% 0.54 <sup>a</sup> (0.44-0.66)	58% 0.51 <sup>a</sup> (0.41-0.63)	49% 0.36 <sup>a</sup> (0.28-0.47)	62% 0.55 <sup>a</sup> (0.45-0.66)	51% 0.37 <sup>a</sup> (0.31-0.45)	60% 0.52 <sup>a</sup> (0.35-0.77)	64% 0.62 <sup>a</sup> (0.56-0.69)
Change in mole appearance	94% 1.00	89% 0.53 <sup>a</sup> (0.36-0.80)	75% 0.20 <sup>a</sup> (0.16-0.25)	67% 0.15 <sup>a</sup> (0.12-0.19)	59% 0.11 <sup>a</sup> (0.08-0.14)	77% 0.24 <sup>a</sup> (0.19-0.30)	66% 0.14 <sup>a</sup> (0.11-0.17)	74% 0.18 <sup>a</sup> (0.11-0.30)	79% 0.25 <sup>a</sup> (0.22-0.29)
Sore that does not heal	69% 1.00	68% 0.97 (0.75-1.27)	59% 0.75 <sup>a</sup> (0.61-0.91)	57% 0.72 <sup>a</sup> (0.58-0.89)	51% 0.58 <sup>a</sup> (0.45-0.76)	55% 0.60 <sup>a</sup> (0.50-0.72)	53% 0.60 <sup>a</sup> (0.51-0.72)	50% 0.51 <sup>a</sup> (0.34-0.76)	61% 0.79 <sup>a</sup> (0.72-0.88)
Unexplained weight loss	86% 1.00	84% 0.89 (0.64-1.26)	73% 0.53 <sup>a</sup> (0.43-0.66)	70% 0.46 <sup>a</sup> (0.37-0.59)	69% 0.46 <sup>a</sup> (0.35-0.61)	74% 0.53 <sup>a</sup> (0.43-0.66)	65% 0.37 <sup>a</sup> (0.31-0.45)	75% 0.58 <sup>a</sup> (0.37-0.92)	75% 0.57 <sup>a</sup> (0.51-0.65)

These estimates were derived from a model including one of the ethnic groups and each of the cancer symptoms, adjusted for age groups, gender and deprivation, measured using quintiles of the income domain of multiple deprivation index.  
<sup>a</sup>Statistically significant at P<0.01 level (99% confidence intervals).

**Table 4. Perception of each barrier to help-seeking according to the nine ethnic groups, with percentage of participants who reported each barrier and all odds ratios (99% confidence intervals) adjusted for age group, gender and area income deprivation (n = 38 492)**

Barriers/ethnic groups	White British	White Irish	Indian	Pakistani	Bangladeshi	Black Caribbean	Black African	Chinese	Other
Too embarrassed	16% 1.00	18% 1.11 (0.80-1.54)	25% 1.47 <sup>a</sup> (1.18-1.84)	26% 1.51 <sup>a</sup> (1.17-1.93)	24% 1.39 <sup>a</sup> (1.02-1.88)	18% 1.00 (0.78-1.29)	17% 0.85 (0.67-1.09)	23% 1.32 (0.82-2.11)	19% 1.04 (0.91-1.18)
Too scared	22% 1.00	22% 0.99 (0.73-1.34)	25% 1.06 (0.85-1.32)	23% 0.92 (0.71-1.20)	21% 0.81 (0.59-1.12)	20% 0.84 (0.66-1.06)	19% 0.72 <sup>a</sup> (0.57-0.91)	25% 1.05 (0.66-1.67)	22% 0.87 <sup>a</sup> (0.77-0.99)
Not confident to talk	10% 1.00	12% 1.14 (0.78-1.68)	21% 2.03 <sup>a</sup> (1.60-2.57)	16% 1.44 <sup>a</sup> (1.07-1.93)	13% 1.11 (0.74-1.65)	13% 1.17 (0.88-1.55)	13% 1.15 (0.88-1.50)	17% 1.47 (0.86-2.52)	15% 1.31 <sup>a</sup> (1.13-1.53)
Worry about what GP may find	30% 1.00	28% 0.91 (0.69-1.20)	31% 0.97 (0.79-1.19)	31% 0.94 (0.75-1.19)	31% 0.98 (0.74-1.30)	34% 1.14 (0.93-1.39)	33% 1.01 (0.84-1.23)	31% 0.95 (0.61-1.46)	29% 0.88 <sup>a</sup> (0.79-0.99)
Worry about many other things	17% 1.00	25% 1.58 <sup>a</sup> (1.18-2.11)	28% 1.62 <sup>a</sup> (1.30-2.01)	28% 1.66 <sup>a</sup> (1.30-2.11)	28% 1.70 <sup>a</sup> (1.26-2.28)	18% 0.97 (0.76-1.25)	17% 0.83 (0.65-1.06)	23% 1.19 (0.74-1.92)	23% 1.19 <sup>a</sup> (1.04-1.34)
Transport difficulties	5% 1.00	8% 1.58 <sup>a</sup> (1.00-2.49)	9% 1.79 <sup>a</sup> (1.27-2.52)	10% 1.94 <sup>a</sup> (1.34-2.81)	9% 1.91 <sup>a</sup> (1.21-3.00)	6% 1.15 (0.78-1.71)	9% 1.81 <sup>a</sup> (1.31-2.50)	10% 2.06 <sup>a</sup> (1.06-4.00)	7% 1.32 <sup>a</sup> (1.06-1.63)
Too busy	19% 1.00	28% 1.68 <sup>a</sup> (1.26-2.23)	31% 1.56 <sup>a</sup> (1.27-1.93)	24% 1.14 (0.88-1.47)	27% 1.37 <sup>a</sup> (1.01-1.84)	21% 1.03 (0.81-1.30)	20% 0.88 (0.70-1.10)	32% 1.59 <sup>a</sup> (1.03-2.45)	27% 1.23 <sup>a</sup> (1.09-1.39)
Worry about wasting GP's time	25% 1.00	24% 0.93 (0.70-1.25)	18% 0.62 <sup>a</sup> (0.48-0.79)	20% 0.69 <sup>a</sup> (0.53-0.91)	19% 0.66 <sup>a</sup> (0.48-0.93)	18% 0.61 <sup>a</sup> (0.48-0.78)	13% 0.43 <sup>a</sup> (0.33-0.55)	22% 0.78 (0.48-1.25)	20% 0.68 <sup>a</sup> (0.60-0.78)
Difficulty talking to GP	12% 1.00	16% 1.40 (1.00-1.97)	15% 1.12 (0.86-1.47)	13% 1.00 (0.73-1.38)	20% 1.60 <sup>a</sup> (1.15-2.23)	15% 1.15 (0.88-1.51)	13% 0.99 (0.76-1.29)	23% 1.85 <sup>a</sup> (1.14-2.99)	16% 1.24 <sup>a</sup> (1.07-1.43)
Difficulty making appointment	28% 1.00	27% 0.94 (0.71-1.25)	34% 1.18 (0.97-1.45)	27% 0.88 (0.69-1.12)	31% 1.06 (0.80-1.41)	25% 0.81 (0.65-1.01)	24% 0.71 <sup>a</sup> (0.57-0.87)	27% 0.85 (0.54-1.34)	29% 0.86 (0.85-1.08)

These estimates were derived from a model including one of the ethnic groups and each of the barriers, adjusted for age groups, gender and deprivation, measured using quintiles of the income domain of indices of multiple deprivation index.  
<sup>a</sup>Statistically significant at P<0.01 level (99% confidence intervals).

than any other ethnic group to report that they would feel worried about wasting the doctor's time. Black participants, especially Africans, were least likely to report barriers to seeking medical help. These results were stable after controlling for potential confounders, suggesting that ethnicity has an independent effect on cancer awareness and barriers to help-seeking.

**Strengths and limitations.** This is the largest study to assess ethnic differences in public cancer awareness and barriers to help-seeking in England; and, the first study to assess this question using a sample broadly representative of the general population, with fairly large groups within ethnic minorities. Our sample allowed us to examine differences within White, Black and South Asian minority groups as defined by the most recent Census classification (2011), using nine different ethnic groups. This meant that we could improve our understanding of cancer awareness and barriers to help-seeking within each ethnic group. Given our large sample, our results were more precise than those in previous studies. The stability and robustness of the results were confirmed by sensitivity analyses, and by controlling for key potential confounding factors—age, gender and socio-economic deprivation.

Possible limitations relate to the use of general CAM questionnaire, which did not allow a more in-depth investigation of awareness about, for example, breast or lung cancer symptoms only. Therefore, our cancer awareness score refers to the recognition of a range of possible cancer symptoms. However, it is necessary to quantify which symptoms of the most common types of cancer are adults from different ethnic groups in England able to recognise, prior to investigating site-specific cancer awareness. Some ethnic groups may have a greater propensity to give 'socially desirable' answers, as an attempt to present themselves in a better light (Bowling, 2002). For example, being 'too busy' may be seen as more aspirational and socially desirable among ethnic groups, such as the Chinese, who are stereotypically perceived as particularly hard-working. During interviews all participants were reassured of confidentiality and anonymity, which may have reduced social desirability bias. Approximately 50% of data on educational attainment were missing for participants from ethnic minority groups, and therefore, we did not include it in our analysis.

The CAM questionnaire did not include questions about country of birth or whether participants were first-, second- or third-generation immigrants. Therefore, we were not able to compare these subgroups. All participants in our sample were currently resident in England. We assumed that for most participants their self-defined ethnicity reflects their national identity, which may or may not relate to their country of birth. National identity is a multi-dimensional and subjective construct, which allows people to express which country they feel most affiliated to (Office for National Statistics, 2012b), and how they understand their rights, constraints and opportunities (Norton, 1997). It is possible that national identity is more important than country of birth in shaping health attitudes and behaviour of different ethnic groups, especially in second-generation immigrants. This question, however, is beyond the scope of our study and within the realm of medical anthropology. Finally, some people may prefer recourse to their culturally specific medical practices and traditional healing methods, and avoid the NHS altogether, in which case these barriers may not be applicable to them.

**Comparison with existing literature.** Only a few studies have addressed this research question using a validated questionnaire and including all major ethnic groups in the population. We confirmed the previous finding that ethnic minorities in the United Kingdom tend to have poor cancer awareness (Waller *et al*, 2009), and are less likely to recognise cancer symptoms than White British people (Robb *et al*, 2009; Forbes *et al*, 2011; Quafe *et al*, 2013). This pattern has also been observed in the United States, where African Americans and Hispanic people tend to lack

knowledge about cancer symptoms and have numerous misconceptions about cancer (Suarez *et al*, 1997; Barroso *et al*, 2000; Shokar *et al*, 2005). Rauscher *et al* (2010) found more misconceptions about breast lumps among African American and Hispanic women than White American breast cancer patients. These misconceptions were, for example, that pressing or touching the breast lump will cause it to become breast cancer, that one needs to get a lump checked only if it is painful, or only if it is growing. Evidence suggests that people born outside of Australia, such as in Asia or Middle East, have poorer knowledge about symptoms of colorectal cancer than Australian-born people (Koo *et al*, 2010). These differences might emerge from the nature of health campaigns, which do not necessarily take account of specific needs and cultural norms of smaller ethnic groups, because they are usually generic and designed for the majority.

Our findings contrast with studies suggesting that White and ethnic minority groups in England equally endorse barriers to help-seeking (Robb *et al*, 2009). The only exception was that Robb *et al* (2009) found that 40% of White British and only 24% of ethnic minorities reported being worried about wasting the doctor's time. We found similar trends, but with highly statistically significant differences. Waller *et al* (2009) found that worry about wasting the doctor's time was the most common barrier (41%) among ethnic minorities in England as opposed to White British in our study; and that the Chinese had the highest barriers to help-seeking rather than the South Asians in our study. These inconsistencies may be due to the lack of adjustment for relevant confounding factors (Robb *et al*, 2009) or smaller sample sizes, and therefore lower power in previous studies.

Ethnic minorities in our study, with the exception of the Irish, described their ethnicity as, for example, Pakistani, Bangladeshi or Chinese. According to the UN (2014) classification, these ethnic groups originally come from a range of developing, low- or middle-income countries. A high-income country, such as England, invests disproportionately more resources on preventive and health services than, for example, Bangladesh. This may explain partly why ethnic minorities had lower cancer awareness than the White majority. More specifically, the lowest cancer awareness was observed for participants from arguably the poorest, low-income countries, such as the Sub-Saharan Africa and Indian subcontinent (World Bank, 2015).

Interestingly, some barriers were widespread among all ethnic groups in our sample, such as worry about what the doctor might find. We also did not observe ethnic differences in feeling 'too scared' to visit a doctor, with the exception of Black Africans. Fear of cancer diagnosis may be the underlying emotion behind these two barriers, because people may experience fear if they think that their medical examination could result in cancer diagnosis. However, evidence about the association between this fear and help-seeking behaviour is contradictory (Balasooriya-Smeekens *et al*, 2015). For example, some studies found that fear of cancer diagnosis was associated with longer time to presentation of symptomatic breast cancer (Nosarti *et al*, 2000; Burgess *et al*, 2006), others found that this fear was associated with shorter time to presentation (O'Mahony *et al*, 2013), and some studies found no evidence of this association (Friedman *et al*, 2006). It is possible that fear of cancer diagnosis may act as a motivator or barrier to seeking medical help, depending on its intensity, duration, context, coping skills and socio-demographic characteristics of an individual.

Indian participants had slightly higher emotional barriers than Bangladeshi and Pakistani, but overall their results were similar. These three ethnic groups often share a range of similar traditional values, such as placing priority on family in dealing with matters of individual choice: the selection of clothes to wear, which university to attend, and whom to marry (Dale *et al*, 2002). Such decisions are likely to be the subject of negotiation within the family. Help-seeking behaviour may be closely related to 'izzat', which refers to maintaining family honour, and fear of bringing shame to

the family (Gilbert *et al*, 2004). In one example, *izzat* was considered more imperative than doctor–patient confidentiality—some South Asian women expressed fears that the GP might speak to the family about their symptoms, particularly if the GP shared the same ethnic background or was a family friend (Gilbert *et al*, 2004). However, having a doctor from a different ethnic background could introduce different types of problems, including language barriers or difficulty in understanding specific socio-cultural values, which may be embedded in medical consultations.

Black participants, especially Africans, least frequently reported barriers to presentation, which may reflect more assertive attitudes towards health-care services. Chinese participants were most likely to perceive difficulties in talking about their symptoms with the doctor, and difficulties in arranging transport to the surgery. Liang *et al* (2004) found the same barriers among Chinese Americans. They also reported the ability to speak English as a key barrier, followed by the need for help with transportation. Learning the English language is likely to be a challenge for Chinese native speakers, considering fundamental differences between an alphabetic and a logographic system. Such difficulties are likely to affect the complex navigation in the primary and secondary health care, and the navigation of the UK public transport system, which is only signposted in English.

White British, as well as the Irish, were more likely than any other ethnic group to report that being worried about wasting the doctor's time would deter them from seeking help, which confirmed and expanded previous findings (Forbes *et al*, 2011). The British stiff upper lip attitude and determination to remain stoical, despite a real threat that symptoms might be malignant, may influence help-seeking behaviour of the White majority. Scanlon *et al* (2006) revealed the same barrier during the interviews with both White British and Irish participants, who felt that they should not visit their doctor because their 'needs are not important enough' or they did not want to 'make a fuss'. The Irish reported more barriers related to socio-economic factors, such as more stress due to working hard to establish themselves abroad, and working in difficult conditions, which led them to neglect their health. Similarly, we observed more practical barriers, such as being too busy, among Irish than White British. Some people feel reluctant to appear to be overusing valuable NHS resources, in the light of recent concerns that NHS cannot effectively provide medical services to an increasingly elderly population.

An additional consideration is necessary before implementing these findings. Ethnic differences in cancer survival are not fully understood, and they might be attributable to the differences in socio-economic deprivation. While studies done in the United States (Ward *et al*, 2004; Newman *et al*, 2006) support the proposition that ethnic minorities have worse cancer survival than the majority population after controlling for deprivation, recent studies done in the United Kingdom (Maringe *et al*, 2015; Morris *et al*, 2015) and New Zealand (McKenzie *et al*, 2011) do not support this. The inconsistency might be due to methodological differences between the studies, or the fact that the NHS in the United Kingdom is free for everyone at the point of access. The NHS has no record about the exact number of minorities, such as elderly South Asian cancer patients who return to their home country to die, which may bias the survival estimates. However, even with limited effects on cancer survival, efforts to improve cancer awareness and encourage help-seeking in different ethnic groups may be beneficial for early diagnosis.

## IMPLICATIONS AND CONCLUSION

Future studies should explore reasons why different ethnic groups report specific barriers to help-seeking, the meaning attached to

each barrier, the effects of educational attainment and literacy skills, and the role of language and religion in cancer symptom awareness and barriers to help-seeking. Differences in cancer awareness and barriers between recent immigrants, and the first or subsequent generation immigrants should also be explored. The role of fear of cancer diagnosis in help-seeking behaviour of people with different socio-demographic and ethnic background requires further attention. Understanding ethnic differences in awareness about specific cancer sites, using Lung or Colorectal Cancer Awareness Measure, would also be useful. Prior to developing campaigns tailored to meet the needs of ethnically diverse population, it is essential to pilot these campaigns and evaluate their impact on early diagnosis and cancer survival.

Our findings are directly applicable to England, but it is likely that they may be extrapolated to the other developed, ethnically diverse countries with similar health-care system, which is free for everyone at the point of access. The findings may contribute to the NHS goals to reduce ethnic inequalities in cancer health (Department of Health, 2011). The term 'socially sensitive' has often been used to denote campaigns adjusted to suit the culturally specific needs of minority ethnic groups only. We suggest the expansion of this term to include the culturally specific needs of both the ethnic minority and the majority population.

Most campaigns aimed at encouraging early cancer presentation are not targeted to meet different needs of ethnically diverse population in England. We recommend the development of targeted campaigns to address these needs, while acknowledging the nuance within and between each ethnic group. Cultural competence, defined as an 'awareness of the cultural factors that influence another's views and attitudes' (Napier *et al*, 2014), needs to be introduced into health-care practice and campaigns. Ethnic minorities could benefit from educational campaigns aimed at improving their recognition of cancer symptoms (Scanlon *et al*, 2006; Forbes *et al*, 2011). South Asians may benefit most from campaigns aimed at alleviating their emotional barriers, by providing support and encouragement to discuss their symptoms, using culturally sensitive language and local community organisations (Netto *et al*, 2010). Practical barriers should be addressed among South Asians, the Irish and the Chinese, by clear educational messages that health should not be neglected (Scanlon and Wood, 2005; Scanlon *et al*, 2006), and by informing people of health services available nearby their place of work. Black people may benefit most from campaigns aimed at raising their cancer symptom awareness. These campaigns should address their misconceptions about cancer, with the assistance of religious and spiritual leaders (Koffman *et al*, 2008; Banning, 2011). Empathy and reassurance may be useful to address inhibitions of the majority population, such as the idea that going to the doctor will waste the doctor's time (Forbes *et al*, 2011). Without tackling this barrier it may not be possible to improve cancer survival rates in England. The development of targeted and culturally sensitive cancer awareness campaigns is likely to improve early presentation among all ethnic groups in England.

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## CONFLICT OF INTEREST

The authors declare no conflict of interest.

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