Cancer symptom experience and help-seeking behaviour in the UK adult population during the COVID-19 pandemic

Executive summary

Background: The impact of the COVID-19 pandemic on UK public attitudes towards cancer is likely to be considerable, translating into impact on the National Health Service (NHS), and ultimately patients, from delayed referrals, missed screening and later-stage cancer diagnosis. Earlier stage cancer diagnosis via the symptom presentation route has been severely disrupted, for instance with around 350,000 fewer people on an urgent General Practitioner (GP) suspected cancer referral route in March-November 2020 in England alone, a reduction of 19% compared to the previous year [1]. During the first UK lockdown, the government message to "stay home, protect the NHS, save lives" intended to control the spread of COVID-19 but also sent a strong signal to the public that cancer can wait [2]. This led to concerns that members of the public may not be seeking help due to fear of coronavirus infection in healthcare settings and other perceived barriers such as concerns about placing additional burden on the NHS [3].

Aim: To assess the impact of COVID-19 on cancer attitudes and behaviours in the UK adult population, generating rapid evidence to guide recommendations for relevant public health messages supporting timely symptom presentation in primary care.

Methods: A population-based sample of N=7,543 UK adults aged 18+ was recruited online between August and September 2020 (Phase 1). Two online surveys were conducted in parallel, the COVID-19 Health and Help-Seeking Behaviour Study (CABS) and the Cancer Research UK (CRUK) COVID-19 Cancer Awareness Measure (COVID-CAM). Key measures were aligned across the two surveys and data pooled where appropriate. Survey measures included self-reported experiences of 15 potential cancer symptoms during the preceding six months and barriers to medical help-seeking. Sampling weights were applied to adjust for population representativeness in key characteristics. Descriptive statistical analyses of pooled survey data were used to identify (i) sample characteristics, (ii) the prevalence of potential cancer symptoms (unweighted and weighted), (iii) symptom help-seeking behaviour among those who had experienced potential cancer symptoms, and (iv) help-seeking barriers and enablers. Qualitative interviews were conducted with 30 participants sampled according to age, gender and symptom experience. Interview data were analysed thematically to explore experiences of symptoms and perceptions of medical help-seeking.

Key messages:

- Survey findings indicate that potential cancer symptoms were commonly experienced during the first six months of the UK pandemic (March-August 2020). Of 3,025 (40.1%) participants who experienced potential symptom(s), nearly half (44.8%) reported not contacting their GP for any symptom during this time, even for red flags such as coughing up blood. Overall help-seeking behaviour over this six month period appears to be lower than help seeking reported over a 12 month period in pre-pandemic studies, although methodological differences including variation in symptom reporting time frames mean direct comparisons between the studies are not possible.

- Worries about wasting healthcare professionals' time, over-stretching limited healthcare resources, access to healthcare services and COVID-19 infection were frequently reported barriers to medical help-seeking in the CABS survey. This was notable among participants who had experienced a symptom, with the qualitative interview data revealing reluctance to contact primary care services due to concerns about catching or transmitting coronavirus. Participants described putting their health concerns on hold to avoid burdening the NHS, suggesting a compounding of the 'British stiff upper lip' phenomenon observed in pre-COVID-19 research [4].
- Qualitative interviews indicated that where participants identified a new or changing symptom, this was often attributed to their pre-existing health condition. Participants were fearful of seeking medical help in hospitals, in part due to media reporting of COVID-19 in hospitals. When participants had contacted their GP, they reported positive experiences that contrasted with their expectations. They wanted to retain remote consulting as an option after the pandemic, with face-to-face appointments available based on clinical need.

Recommendations:

In addition to recent help-seeking campaigns that have happened in some areas of the UK, well-timed and evidence-led nationally funded and coordinated cancer awareness campaigns are needed to signal that cancer cannot wait and that NHS services are open safely for people with any unusual or persistent symptoms. Clear, consistent information from a trusted source is needed to encourage confidence in contacting the GP promptly, explain the changes to GP practice procedures and what to expect, and alleviate worries about NHS capacity and infection control in hospital settings. Credible patient stories with an emphasis on positive outcomes could be important in counteracting COVID-19 media reporting and supporting engagement with hospital outpatient appointments, treatments or investigations. Campaign messaging should be designed sensitively to legitimise seeking help for unusual or persistent symptoms, without causing undue distress. During the current pandemic situation of a renewed government-led public campaign to "stay at home", cancer awareness campaigns will need to be carefully timed for optimal credibility and impact. Evaluation of campaign activity will be key, to ensure that it reaches the intended audiences, delivers its objectives and does not exacerbate inequalities.

Policy report context:

This report presents preliminary analyses of CABS Phase 1 data. The pre-registered study protocol and analysis plans are available at https://osf.io/zxyp3. Additional results will be shared whereby further interrogation of the data may reveal subtle differences in the pattern of findings. Data will also be collected in February and March 2021 to understand the latest impact of the pandemic and monitor changes in attitudes and behaviours over the course of the pandemic. It will also be important to consider the current findings alongside evidence from studies of COVID-19 impact on consultations and referrals in primary care, to assess overall impact of the pandemic on the cancer diagnostic pathway and inequalities and inform where COVID-adapted interventions are required.

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Funding source: The research is funded by the Economic and Social Research Council as part of UK Research and Innovation's rapid response to COVID-19 (grant reference ES/V00591X/1).

Symptom help-seeking results

Survey results:

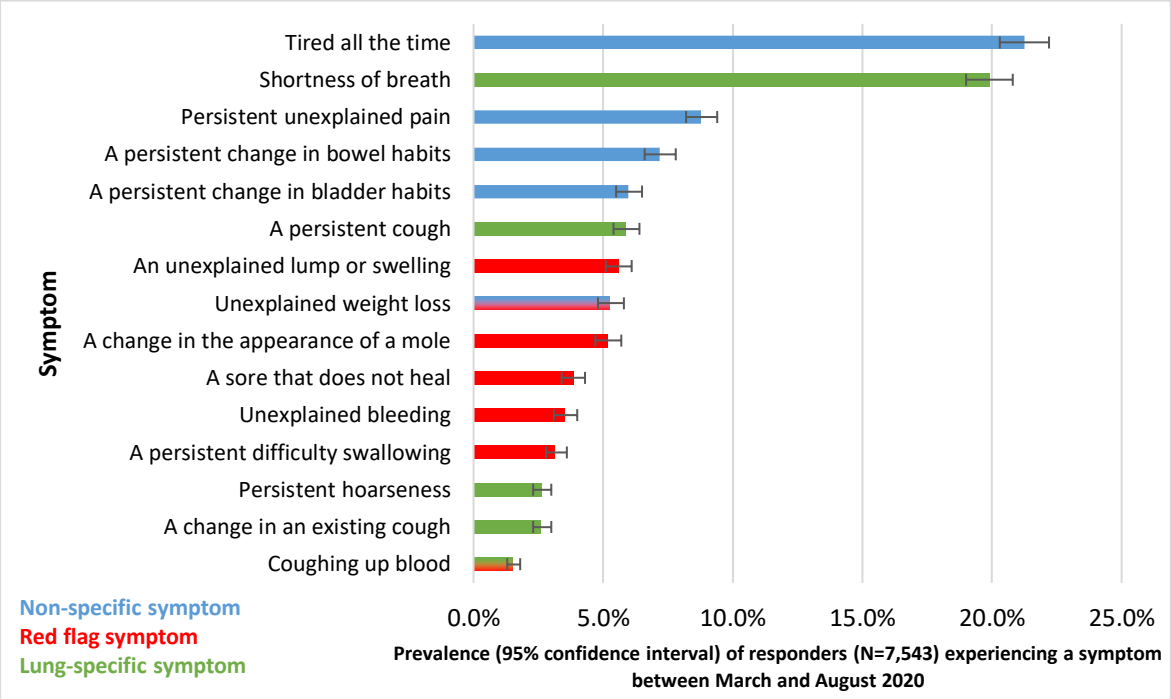
(i) Sample characteristics

Almost half the unweighted pooled sample was age 55 years and over (47.4%) and female (49.2%) **(Appendix Table 1).** Most respondents were of White ethnic background (88.6%) and living in England (65.0%). Over one third had university level education or higher (38.3%). Current smokers and former smokers comprised 18.8% and 32.3% of the sample, respectively. Within the CABS sample (n=1,876), three quarters reported having at least one comorbid health condition (74.8%).

(ii) Prevalence of potential cancer symptoms

During the six months from the onset of the pandemic in March 2020, 40.1% of survey participants (n=3,025) had experienced at least one potential cancer symptom, with a median of 2 symptoms reported per participant (range 1-15). Nearly one third (30.3%) had experienced at least one non-specific symptom[1], and almost a fifth reported at least one red flag symptom[2] (17.6%) and at least one symptom possibly indicative of lung cancer[3] (18.4%). The prevalence of individual symptoms ranged from 21.3% (tired all the time) to 1.5% (coughing up blood) **(Figure 1)**. Among those reporting that they were 'tired all the time', had 'a persistent cough' and 'shortness of breath', around half said the symptom pre-dated the pandemic (826/1,603, 51.5%; 219/444, 49.3% and 510/1,052, 48.5% respectively).

Figure 1: Prevalence of potential cancer symptoms experienced during the pandemic (March to August 2020)



[1] Tired all the time, persistent unexplained pain, persistent change in bowel or bladder habits, unexplained weight loss.
[2] Unexplained lump or swelling, unexplained weight loss, change in the appearance of a mole, a sore that does not heal, unexplained bleeding, coughing up blood.
[3] Shortness of breath, persistent cough, persistent difficulty swallowing, persistent hoarseness, change in an existing cough, coughing up blood.

Women (42.2%), younger (age 18-24 years, 51.2%) and older (age 75+ years, 45.9%) age groups, people with lower education (O level/GCSE=40.6%; no formal education=43.9%), people from mixed ethnic backgrounds (44.8%) and current smokers (50.8%) were more likely to report at least one potential cancer symptom in the last six months **(Appendix Table 2)**. Within the CABS sample, people with a comorbid health condition (53.7%) were more likely to have experienced a potential cancer symptom.

(iii) Symptom help-seeking behaviour

Among participants who experienced at least one potential cancer symptom, 54.1% (1,636/3,025) had contacted the GP for at least one of those symptoms; 44.8% (1,355/3,025) had not contacted the GP for any of their symptoms **(Table 1)**. A small proportion 'preferred not to say' across all symptoms (1.1%). Participants had not sought help for red flag symptoms including coughing up blood (30.7% of those who experienced this symptom did not seek help), an unexplained lump or swelling (41.0% did not seek help) or a change in the appearance of a mole (58.6% did not seek help). Less than half of those who reported non-specific symptoms (e.g. 'a persistent change in bowel habits', 47.0%) sought help from their GP. Around half of those experiencing lung-specific symptoms such as 'a persistent cough' (51.8%) had sought help.

Among respondents who had experienced a symptom in the past six months, the proportion reporting concern that their symptom might be serious ranged from 14.7% (235/1,603) in those with persistent tiredness to 28.9% (33/114) in those who reported coughing up blood.

Overall symptom help-seeking over the first six months of the pandemic in the current study (44.8%) appears to be lower than symptom help-seeking reported over a 12 month period pre-pandemic in the USEFUL study (40.5%) [5]. However, direct comparison is not possible because of methodological differences between the studies, including variation in symptom reporting time frames.

Table 1 includes pre-COVID data on individual symptom help-seeking over a 12-month period. The proportion of participants in the current study who had contacted their GP during the first six months of the pandemic was lower than the proportion who had contacted their GP over a 12 month period pre-COVID [5] for individual symptoms including 'coughing up blood', 'tired all the time', 'unexplained weight loss' and 'shortness of breath'. Proportions seeking help for 'persistent change in bowel habits', 'persistent cough' and 'change in an existing cough' were comparable. A higher proportion in the current study contacted their GP over the first six months of the pandemic for 'persistent difficulty swallowing' and 'persistent hoarseness' than over a 12-month period pre-pandemic. Direct comparison between these studies is precluded by methodological differences, such as variation in symptom reporting time frames.

Table 1: Participants experiencing potential cancer symptoms during March to August 2020 and associated symptom help-seeking

Data are n (%) and unweighted unless otherwise stated

Potential cancer symptom	Had symptom[1]	Had symptom - weighted[2]	Did not contact GP in the last 6 months[3]	Did not contact GP in the last 12 months - USEFUL Study[4]	Contacted GP in the last 6 months	Contacted GP in the last 12 months - USEFUL Study[4]
	n / 7,543 (%)	n / 7,543 (%)	n /S (%)	n (%)	n /S (%)	n (%)
Non-specific symptom						
A persistent change in bowel habits	541 (7·2)	525 (7·0)	267 (49·4)	682/1,323 (51·5)	254 (47·0)	641/1,323 (48·5)
A persistent change in bladder habits	450 (6·0)	414 (5·5)	216 (48·0)	-	227 (50·4)	-
Tired all the time	1,603 (21·3)	1,614 (21·4)	1,031 (64·3)	1,778/3,078 (57·8)	540 (33·7)	1,300/3,078 (42·2)
Persistent unexplained pain	662 (8·8)	646 (8·6)	286 (43·2)	-	361 (54·5)	-
Non-specific/Red flag symptom						
Unexplained weight loss	395 (5·2)	433 (5·7)	205 (51·9)	152/341 (44·6)	179 (45·3)	189/341 (55·4)
Red flag symptom						
A change in the appearance of a mole	391 (5·2)	402 (5·3)	229 (58·6)	-	157 (40·2)	-
An unexplained lump or swelling	422 (5·6)	418 (5·5)	173 (41·0)	-	239 (56·6)	-
Unexplained bleeding	267 (3·5)	291 (3·9)	115 (43·1)	-	143 (53·6)	-
A persistent difficulty swallowing	237 (3·1)	248 (3·3)	97 (40·9)	557/884 (63·0)	128 (54·0)	327/884 (37·0)
A sore that does not heal	291 (3·9)	297 (3·9)	146 (50·2)	-	128 (44·0)	-
Red flag/Lung-specific symptom						
Coughing up blood	114 (1·5)	127 (1·7)	35 (30·7)	31/91 (34·1)	67 (58·8)	60/91 (65·9)
Lung-specific symptom						
Shortness of breath	1,052 (13·9)	966 (12.8)	538 (51·1)	1,228/2,647 (46·4)	484 (46·0)	1,419/2,647 (53·6)
Persistent hoarseness	200 (2·7)	206 (2·7)	95 (47·5)	941/1,319 (71·3)	96 (48·0)	378/1,319 (28·7)
A persistent cough	444 (5·9)	401 (5·3)	209 (47·1)	1,088/2,189 (49·7)	230 (51·8)	1,101/2,189 (50·3)
A change in an existing cough	196 (2·6)	219 (2·9)	84 (42·9)	153/298 (51·3)	100 (51·0)	145/298 (48·7)
All potential cancer symptoms	***3,025 (40·1)[5]***	***2,909 (38·6)***	***1,355/3,025 (44·8)[6]***	***3,974/9,810 (40·5)***	***1,636/3,025 (54·1)[7]***	***5,836/9,810 (59·5)***
Non-specific symptom	***2,284 (30·3)[5]***	***2,261 (30·0)***				
Red flag symptom	***1,327 (17·6)[5]***	***1,310 (17·4)***				
Lung-specific symptom	***1,386 (18·4)[5]***	***1,289 (17·1)***				

n=number, n/S = number of respondents representing each symptom help-seeking behaviour/number of respondents who had this symptom.

[1] Denominator includes those who did not have a symptom and those who preferred not to say (around 1% of the sample).

[2] All data are weighted to match the UK adult population on age, gender, ethnicity and country.

[3] Includes participants who had not contacted the GP yet, but planned to. Did not contact GP and Contacted GP columns are mutually exclusive. Denominator includes participants who preferred not to say.

[4] Comparator data for participants who did and did not contact the GP in the last 12 months (Hannaford et al., 2020).
[5] At least one potential cancer symptom reported.
[6] Reported not contacting the GP for symptoms reported in the last 6 months. Did not contact GP and Contacted GP columns are mutually exclusive. Denominator includes 34 (1.1%) who preferred not to say across all their symptoms.
[7] Reported contacting the GP for at least one symptom in the last 6 months.

(iv) Barriers and enablers to medical help-seeking

The most frequently endorsed barriers to medical help-seeking in the overall sample were worry about wasting the healthcare professional's time (15.4%), worry about putting extra strain on the NHS (12.6%), not wanting to be seen as someone who makes a fuss (12.0%), difficulty in getting an appointment with a particular healthcare professional (10.3%) and worry about catching coronavirus (9.6%). Remote consulting was not a common barrier to medical help-seeking (4·8%) **(Appendix Table 3).** All barriers were more commonly reported by those who had experienced a potential cancer symptom in the past six months compared to those who had not.

Within the COVID-CAM sample (n=5,667), over three quarters of all respondents (78.1%) reported at least one prompt to consulting with a medical professional about their health. Help-seeking enablers included having a symptom that was 'bothersome' (17.8%), did not go away (16.7%), painful (14.2%) or unusual (12.5%) or feeling that 'something wasn't right' (12.7%) **(Appendix Table 4)**.

Of the overall sample (N=7,543), around two thirds reported feeling safe from COVID-19 if they needed to attend an appointment at their GP practice (5,142/7,543, 68.2%) or hospital (4,613/7,543, 61.2%). Nearly three quarters (5,452/7,543, 72.3%) were worried about delayed cancer tests and investigations due to COVID-19.

Qualitative interview results:

Thirty participants were interviewed post survey completion. Just over half the interviewees were male (n=17) and had received a higher education qualification or degree (n=19). Most lived in Wales (n=25) and were from a White ethnic background (n=23). The average age of interviewees was 55 years. Exemplary quotes are included in **Appendix Table 5**.

Symptom experiences

Many participants reported noticing a change to their health or wellbeing during the six months from the start of the first UK lockdown. Participants commonly attributed symptoms experienced to changes in existing health conditions or possible side-effects of medication. This was more notable for non-specific symptoms such as persistent tiredness and shortness of breath. Participants described this rationalisation leading to a delay in their help-seeking, or no help-seeking at all, to avoid bothering the doctor when they assumed that they already knew the cause. Even where participants reported red flag symptoms, there was discussion of delaying due to concerns about the NHS being over-stretched during the pandemic. Several participants described accessing other services as a way of easing pressures on their GP practice, for example by phoning 111 or contacting their pharmacist. When making decisions about help-seeking, participants were weighing the risks of their clinical need against the risks of catching or exposing others to COVID-19 and burdening the NHS. Some participants conveyed the sentiment that the least they could do to help was to stay away from the NHS.

Fear of help-seeking

All participants expressed fear or nervousness about presenting to primary or secondary care during the pandemic. For some, levels of fear were very high. Fear and anxiety were commonly associated with 'the unknown' and potentially encountering other members of the public who may not adhere to social distancing guidance when accessing healthcare facilities. These acted as barriers to timely medical help-seeking. Changes to GP practice procedures invoked worry and hesitancy due to not knowing or understanding the new measures. Examples provided included the use of new online and telephone triage systems, one-way systems in medical buildings and use of face masks and hand sanitiser. Participants understood the need for these adaptations, though felt that more support and/or guidance could be provided on how to navigate these changes for the first time. Participants expressed particular concern for patients with low digital literacy and those with English as a second language or additional mobility needs.

Fear of attending secondary care was particularly acute. Participants described 'scaremongering' media reports of hospitals being over-run with coronavirus cases and stories of those entering hospital healthy and leaving with the infection. Some participants reported being too scared to attend secondary care for appointments, treatments or procedures, even when they knew they needed to. They made this decision knowing that it could be to the detriment of their health and wellbeing. However, most of those who did attend face-to-face in primary and/or secondary care described feeling 'safe' and 'secure' when doing so. Participants expressed surprise that attending healthcare was at odds with their expectations and vision of what it was going to be like. Several participants felt saddened that they had been manipulated by the media into feeling scared and avoiding healthcare, with consequences for their health.

Experiences of help-seeking

When participants had contacted their GP, they were pleased overall with the quality of care received and the use of remote/virtual procedures including online and telephone triage systems. Participants described disclosing details of their health and medical history before a decision was made about whether they could speak to or see a doctor. Some were hesitant in doing so, feeling that this requirement impacted on their privacy. The use of telephone consultations was praised by most participants who had received them. Many participants reported being happy to retain remote consulting, in the knowledge that face-to-face appointments with their doctor would be available based on clinical need.

Next steps:

We will model the determinants of symptom help-seeking behaviour in those who experienced possible cancer symptoms during the UK lockdown, including any influences of sociodemographic, clinical and psychological factors. Further analyses will be carried out to assess influences on anticipated symptom presentation, cancer screening intentions and cancer prevention behaviours in Phase 1 and Phase 2 (to be conducted in February-March 2021).

References

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Appendix

Table 1: Selected sociodemographic characteristics

All results are n (%) unless otherwise stated

	Pooled sample N=7,543	CABS N=1,876	COVID-CAM N=5,667
Age (years) at last birthday			
18-24	543 (7.2)	12 (0.6)	531 (9.4)
25-34	945 (12.5)	53 (2.8)	892 (15.7)
35-44	1,149 (15.2)	132 (7.0)	1,017 (17.9)
45-54	1,221 (16.2)	202 (10.8)	1,019 (18.0)
55-64	1,282 (17.0)	417 (22.2)	865 (15.3)
65-74	1,795 (23.8)	738 (39.3)	1,057 (18.7)
75+	497 (6.6)	271 (14.4)	226 (4.0)
Missing/other/prefer not to say	111 (1.5)	51 (2.7)	60 (1.1)
Gender			
Male	3,807 (50.5)	1,044 (55.7)	2,763 (48.8)
Female	3,709 (49.2)	827 (44.1)	2,882 (50.9)
Non-binary, transgender female or other	27 (0.4)	5 (0.3)	22 (0.4)
Ethnicity			
White	6,685 (88.6)	1,821 (97.1)	4,864 (85.8)
Mixed/Multiple ethnic groups	143 (1.9)	19 (1.0)	124 (2.2)
Asian/Asian British	458 (6.1)	15 (0.8)	443 (7.8)
Black/African/Caribbean/Black British	154 (2.0)	14 (0.7)	150 (2.6)
Other ethnic group	96 (1.3)		86 (1.5)
Prefer not to say	7 (0.1)	7 (0.4)	NA
Country/Region			
England	4,904 (65·0)	76 (4·1)	4,828 (85·2)
Wales	2,045 (27.1)	1,797 (95.8)	248 (4.4)
Scotland	456 (6.0)	19 (1.0)	453 (8.0)
Northern Ireland	105 (1.4)		105 (1.9)
England:			
North East England	265 (3.5)		265 (4.7)
North West England	621 (8.2)		618 (10.9)
Yorkshire and Humberside	479 (6.4)		476 (8.4)
East Midlands	417 (5.5)		415 (7.3)
East Anglia	503 (6.7)		500 (8.8)
West Midlands	513 (6.8)		508 (9.0)
South East England	830 (11.0)	24 (1.3)	806 (14.2)
South West England	473 (6.3)	9 (0.5)	464 (8.2)
London	803 (10.6)	27 (1.4)	776 (13.7)
Prefer not to say	33 (0.4)	-	33 (0.6)
Highest level of education			
Degree or higher degree	2,892 (38.3)	897 (47.8)	1,995 (35.2)
A levels or further education	2,447 (32.4)	542 (28.9)	1,905 (33.6)
O levels/GCSEs	1,565 (20.7)	268 (14.3)	1,297 (22.9)
No formal qualifications	412 (5.5)	105 (9.6)	307 (5.4)
Still studying	81 (1.1)	9 (0.5)	72 (1.3)
Prefer not to say	74 (1.0)	26 (1.4)	48 (0.8)
Other	72 (1.0)	29 (1.6)	43 (0.8)
Smoking status			
Never smoked	3,586 (47.5)	842 (45.9)	2,744 (48.4)
Former smoker	2,435 (32.3)	839 (44.7)	1,596 (28.2)
Current smoker	1,417 (18.8)	150 (8.0)	1,267 (22.4)
Other/prefer not to say	105 (1.4)	45 (2.3)	60 (1.1)

Pre-existing medical conditions			
No comorbid health condition	-	472 (25.2)	-
At least one comorbid health condition	-	1,404 (74.8)	-

Abbrev: CABS = COVID-19 Health and Help-Seeking Behaviour Study cohort recruited via HealthWise Wales and social media; COVID-CAM = Cancer Research UK's COVID-19 Cancer Awareness Measure sample recruited via Dynata, an online panel provider; NA = Not available as an option.
All data are weighted to match the UK adult population on age, gender, ethnicity and country.

Table 2: Proportion of respondents experiencing potential cancer symptoms during the six months from the onset of the pandemic in March 2020 by selected sociodemographic characteristics[1]
All results are n (%) unless otherwise stated

	Yes - at least one symptom N=3,025
Age (years) at last birthday	
18-24	278 (51.2)
25-34	405 (42.9)
35-44	435 (37.9)
45-54	450 (36.9)
55-64	489 (38.1)
65-74	690 (38.4)
75+	228 (45.9)
Missing/other/prefer not to say	50 (45.0)
Gender	
Male	1,445 (38.0)
Female	1,565 (42.2)
Non-binary, transgender female or other	15 (55.6)
Ethnicity	
White	2,679 (40.1)
Mixed/multiple ethnic groups	64 (44.8)
Asian/Asian British	177 (38.6)
Black/African/Caribbean/Black British	63 (40.9)
Other ethnic group	39 (40.6)
Prefer not to say	3 (42.9)
Highest level of education	
Degree or higher degree	1,098 (38.0)
A levels or further education	1,006 (41.1)
O levels/GCSEs	635 (40.6)
No formal qualifications	181 (43.9)
Still studying	45 (55.6)
Prefer not to say	31 (41.9)
Other	29 (40.3)
Smoking status	
Never smoked	1,192 (33.2)
Former smoker	1,069 (43.9)
Current smoker	720 (50.8)
Other/prefer not to say	44 (41.9)
Pre-existing medical conditions[2]	***N=889***
No comorbid health condition	135 (28.6)
At least one comorbid health condition	754 (53.7)

[1] Comparisons have not been tested for associations

[2] CABS sample only (N=1,876)

* Cells have been suppressed as potentially identifiable and counts are less than 5

Table 3: Barriers to consulting with a medical professional
All results are n (%) unless otherwise stated

Barriers[1]	Pooled sample N=7,543	At least one symptom experienced n=3,025	No symptoms experienced[2] n=4,428
I worried about wasting the healthcare professional's time	1,158 (15.4)	653 (21.6)	505 (11.4)
I worried about putting extra strain on the NHS	954 (12.6)	578 (19.1)	376 (8.5)
I didn't want to be seen as someone who makes a fuss	907 (12.0)	540 (17.9)	367 (8.3)
I found it difficult to get an appointment with a particular healthcare professional	774 (10.3)	448 (14.8)	326 (7.4)
I worried about catching coronavirus	721 (9.6)	415 (13.7)	306 (6.9)
I found it difficult to get an appointment at a convenient time	643 (8.5)	321 (10.6)	322 (7.3)
I worried they wouldn't take my symptom(s) seriously	601 (8.0)	380 (12.6)	221 (5.0)
I didn't want to talk to a receptionist/ administrative person about my symptom(s)	518 (6.9)	304 (10.0)	214 (4.8)
I worried about what they might find wrong with me	421 (5.6)	231 (7.6)	190 (4.3)
I had too many other things to worry about	401 (5.3)	271 (9.0)	130 (2.9)
It would have been difficult for me to discuss my health problem remotely (by phone, email or video call)	361 (4.8)	231 (7.6)	130 (2.9)
I found it embarrassing talking about my symptoms	354 (4.7)	216 (7.1)	138 (3.1)
I was too busy to make time to seek medical attention	329 (4.4)	195 (6.4)	134 (3.0)
I worried about the possibility of having treatment	304 (4.0)	196 (6.5)	108 (2.4)
I didn't feel confident talking about my symptom(s)	272 (3.6)	160 (5.3)	112 (2.5)
I worried about the impact on my employment from taking time off	227 (3.0)	144 (4.8)	83 (1.9)
I had symptoms that might have been related to coronavirus	143 (1.9)	105 (3.5)	38 (0.9)
Nothing put me off/delayed me in seeking medical attention	3,039 (40.3)	859 (28.4)	2,180 (49.2)
Prefer not to say	114 (1.5)	31 (1.0)	83 (1.9)

[1] Participants were asked: *"Thinking about the last time you considered seeing or speaking to a medical professional about your health, did any of the following put you off, or make you delay doing so? (This may have been an appointment with a medical professional (e.g. a doctor, nurse or pharmacist) in person, online or over the phone). Please select all that apply".* More than one barrier could be selected therefore numbers do not amount to the denominator (pooled sample N=7,543) or those with at least one potential cancer symptom experienced (n=3,025) and percentages do not amount to 100%.
[2] Includes those who preferred not to say.

Table 4: Enablers to consulting with a medical professional (COVID-CAM sample only)
All results are n (%) unless otherwise stated

Enablers[1]	COVID-CAM N=5,667
I had a symptom that was 'bothersome'	1,007 (17.8)
I had a symptom that didn't go away	949 (16.7)
I had a symptom that was painful	806 (14.2)
I had a feeling that something wasn't right	721 (12.7)
I had a symptom that was unusual for me	706 (12.5)
I had a symptom, but I didn't know what was causing it	682 (12.0)
My friends or family encouraged me to go	461 (8.1)
I could have a remote consultation (for example, by phone, email or video call)	446 (7.9)
I had a symptom that I thought might be a sign of cancer	282 (5.0)
I had seen information about this symptom in the media	136 (2.4)
I knew someone who had a similar symptom, and it turned out to be serious	121 (2.1)
Other	971 (17.1)

[1] Participants were asked**:** *"The last time you saw or spoke to a medical professional about your health, did any of the following play a role in your decision to do so?"* More than one enabler could be selected therefore numbers do not amount to the denominator (CRUK sample N=5,667) and percentages do not amount to 100%.

Table 5: Exemplary participant quotes for qualitative findings

Theme	**Exemplary Participant Quotes** *(participant gender, age (years), nation of residency)*
Symptom experiences	"INT: Okay and has the pandemic affected or changed how you think about doctors' visits and appointments at all? RES: I would certainly said I've been more reluctant, I, I would have stayed away, erm, and just dealt with it, rather than perhaps going to see a doctor at an early stage." *(64948240, Female, 46, Wales)* "RES: ... over the weekend I had a, second time in my life, a bad migraine, erm, and thankfully I'm feeling better but I had thought to myself at what point am I going to go to the GP about, erm, not feeling better. And will I ... you know am I less likely to go because they're under strain? And I probably am a bit less likely to go, delay it a little bit longer, which I do now, so." *(64078317, Female, 46, England)* "RES: …it's certainly changed my mind because like I say I'm of the mindset that says if it's not sort of life threatening critical then, you know, it can wait. Erm, so yes, you know I had a certainly different mentality and part of that I think is, you know, because of the strain that was put on the health service and all those within it initially that you perhaps didn't want to disturb them" *(65205685, Female, 63, Wales)*
Fear of help-seeking	"RES: … I haven't been there, the last time I went there, I think it was in the January when I had my um, my annual COPD and CHD review… So, I hadn't been there since, and then I was reading all these horror stories, you know, the stuff we were seeing on the telly, you know, the people were going into places, and they didn't even know they had the virus, they wasn't showing symptoms… And passing it on and I was thinking, this could happen to me in the doctor's surgery, but when I actually went to the surgery, you know, the whole layout had changed, it had all new furniture put in there, so it could be wiped down." *(65205685, Female, 63, Wales)* "RES: …I think a lot of people are very wary about contacting their GP, both in terms of GP being too busy, they don't want to be a problem to the GP, and with the new systems I think a lot of people, especially of an older age, aren't very IT minded. I think that's putting them off, having to go online and do it all online… A lot of people can't even do that… Although it is working fine for those of us who can go online, it might not cover everyone… I have a cousin who, I think she's 80 next January – she phoned the surgery and she spoke to them and they told her to go online. She says I can't go online. And the receptionist told her well you'd better get used to it, that's the way it's going to be from hereon. She wasn't very nice to her… So that put her off." *(63986310, Male, 76, Wales)* "RES: You see I have to go round the back of the blooming doctors, and that was a nightmare, because it was a little tiny path, my husband had to make sure I didn't fall out of the wheelchair, because it's so … it's such a little path to get round. In through the back and out through the front, a one-way system like… in one way and out another. INT: So, would you normally … okay, and it didn't matter that you were in a wheelchair then, had they … it was … RES: And they know I'm in a wheelchair all the time like." *(64018114, Female, 44, Wales)* "RES: Well, um, if … if you're asking about hospital, I was supposed to go to hospital in lockdown see, but the thing is, I was too frightened

	because of Covid, I thought I'm not going to hospital, because of Covid. And I needed stitches in my knee, because I fell and I landed on my knee in the … landed on my both knees in the living room, I fell over the mat. And um, I sliced my knee open, and I needed stitches bad, but I didn't go. My husband used butterfly stitches and done it that way. But I wouldn't go because of Covid see, because I was too frightened, because I didn't want to get Covid." *(64018114, Female, 44, Wales)* "RES: …I mean my view to hospitals, prior to being in one myself, was that, you know there were people dying all over the place in every ward, every corridor with corona virus. So yes, I would have been, as I say, certainly very cautious to have, err, to have wanted to put myself in, err, that situation…. you know I was so impressed with how the hospital were operating when I was in there and, as I say if I'd had vision or understood, erm, what it was looking like, how it was working I probably wouldn't have had any concerns at all. I think the hospitals were the safest, erm, safest place to be, erm, is my view after the event, seeing how fantastically well the staff were, you know at following procedure etc… So yes if, you know, if you get that message across that, err, that a hospital, as I say, is probably the safest place than bloody Tesco's or the local pub or whatever. You know, you're very safe there." *(65205685, Female, 63, Wales)*
Experiences of help-seeking	"RES: … the surgery did a triage thing, the doctor called me and asked me to go and see them and, erm, that, that worked okay, you know, under the restrictions of the local GP, erm, surgery, you know… They have, they've got, er, to be quite stringent processes… Yeah, I was content there, no, no, er, no serious misgivings, er, you accept their protocols and, er, the new way of doing things and, and that was fine actually, no problem." *(64026131, Male, 62, Wales)* "RES: Like I said that assumption a lot of people make as well… They assume that because you're okay, you're seeing them in real life, you're okay talking to them over the video, like I said I, I really don't feel comfortable using those video things. I can't sort of speak normally over them. I feel very disconnected from the person I just, I find it really hard to do." *(64027453, Male, 38, Wales)* "RES: It has changed the whole system, you can't just make an appointment to go and see somebody, it's, you have to go online, type in briefly what your problem is and then decide whether they call you back or whether they tell you what to do or whether they say I think we should meet face to face. Usually a telephone conversation first and then decide okay perhaps you'd better come down and see me. Which I did once… I think the system works very well actually. INT: Do you, so how does it compare then before the pandemic? Could you just make an appointment in those …? RES: You could but it was always sort of three or four weeks ahead… With the new system, you seem to get some response within the next twenty-four hours which is a big improvement." *(63986310, Male, 76, Wales)*