

How important is symptom recognition in leading people to seek a test for COVID-19? [SPI-B: 30 November 2020]

Key points

- Interpretation of symptoms is likely hampered by low levels of knowledge among the UK population that the symptoms to be aware of are cough, fever, loss of sense of taste and loss of sense of smell [Medium confidence]. At best, 81% recognise two of these symptoms. Campaign material, official spokespeople and those speaking in the media should make efforts to restate the precise symptoms of COVID-19. Identifying new routes to communicate these symptoms should be prioritised.
- A belief that COVID-19 symptoms are generally unusual or severe may prevent some people from interpreting their own mild symptoms as being related to COVID-19, and hence requesting a test or self-isolating [Low confidence]. Messaging should emphasise that even mild symptoms can mean that you have COVID-19 and explain the rationale for acting on them.
- Perceived and real practical barriers to accessing a test or self-isolating likely deter people from attempting to seek a test [Medium confidence]. This includes issues such as lack of knowledge about eligibility, not knowing how to access a test, inability to travel to a test centre, lack of trust in data protection issues, and not trusting the test's accuracy. Improving accessibility, and communicating about the ease of access, may help.
- Some population groups are likely to have particular needs in relation to symptom recognition [High confidence]. This includes parents of young children, people with comorbidities, people from minority ethnic groups, people from lower socio-economic groups, and people who are receiving less information about the pandemic in general. Targeted messaging to such groups may be particularly beneficial.
- Fears of stigma and discrimination may delay responding to symptoms by booking a test [Medium confidence]. Public health interventions should address stigma and discrimination targeted towards individuals affected by COVID-19 by changing attributions made by the public to develop more acceptable attitudes towards individuals affected by COVID-19. This could minimise delays to help-seeking behaviour.

Background

Around 72% of adults infected with SARS-CoV-2 will develop symptoms [1]. Proportions of children and teenagers who develop symptoms is much lower [2] [3]. Guidance from NHS England is that people should seek a test for COVID-19 if they have any one of: a high temperature; a new, continuous cough; a loss or change to their sense of smell; or a loss or change to their sense of taste [4]. In this report, we limit our definition of “COVID-19 symptoms” to this set as the core symptoms which members of the UK public are asked to be alert to, while recognising that COVID-19 is also associated with a much broader range of symptoms.

Some people who have COVID-19 symptoms do not obtain a test. For the week of 5 to 11 November NHS TT identified 167,369 cases of COVID-19, largely via testing of symptomatic people conducted under pillar 2 [5]. For 8 to 14 November, ONS estimated that there were 272,300 new cases of COVID-19 in England (95% credible interval: 240,100 to 308,700 [6]). This suggests that roughly 60% of cases were detected by NHS TT. Modelling suggests that policies that encourage more people who have COVID-19 symptoms to seek a test are likely to be particularly beneficial in improving the overall effectiveness of test, trace and isolate systems [7].

In this paper, we provide an overview of the academic literature on factors that may determine whether someone seeks a test for COVID-19 when symptomatic, focusing in particular on the earliest steps in that process – detecting, identifying and responding to symptoms.

To inform this review, we searched medline and psychinfo for papers with the term ‘symptom’ AND (‘covid’ OR ‘coronavirus’ OR ‘SARS’) and limited the results to those published in English in 2020. This resulted in 1797 citations. We have excluded from our paper studies relating to asymptomatic testing (e.g. mass testing) or which were ambiguous as to whether they referred to symptomatic or asymptomatic testing. We would caution that this is not a formal systematic review.

The process of deciding to seek a test

Seeking a test when symptomatic can be considered a special case of ‘help seeking behaviour.’ Multiple models exist that attempt to explain the factors that determine if, when and how a person will seek help for a given set of symptoms. The key stages in this process can be summarised [8] as relating to:

- the *detection* of bodily changes as symptoms;
- the *interpretation* of those symptoms;
- the *response* to that interpretation.

A range of factors may affect each of these three steps. Again, while different models exist, it is possible to break these factors down [8] according to whether they relate to:

- *Knowledge*; including both awareness about the potential meaning of specific symptoms and sufficient health literacy to have a good understanding of concepts such as ‘early detection.’
- *Attention*; relating to the process of monitoring yourself for specific symptoms and attending to the potential future consequences of a symptom.
- *Expectation*; which includes beliefs about the likelihood of symptoms which in turn affects attention, and also beliefs about the duration, prevalence and novelty of symptoms which affects how they are interpreted.
- *Identity* of the individual; which can affect the likelihood that a given symptom will be seen as indicating an illness, whether symptoms are ‘normalised’ to prevent worries about their implications interfering with important social roles, and the impact of your social network in

prompting, facilitating or hindering specific responses to symptoms. The role of a 'lay referral system' in which people seek advice on their symptoms from trusted friends and relatives is well recognised [9].

These factors can all, in turn, be influenced by sociodemographic factors.

Evidence from previous infectious disease outbreaks

Several cross-sectional surveys and qualitative studies have explored the factors associated with help seeking in general, and seeking a test in particular, in the context of previous infectious disease outbreaks. These are described in a recent rapid review [10]. Among the key themes identified in the review as impacting on these behaviours were:

Knowledge-related factors, including:

- Education about symptoms and routes of transmission, which made people more confident about reporting symptoms and helped them understand the rationale behind reporting;
- Perception of the disease as severe;
- Understanding the importance of early response to symptoms;
- Knowledge about the efficacy of the measures or treatments that are used;
- Knowledge about what happens after symptoms are reported, in terms of the testing process, and a fear of what might happen in the subsequent steps through the healthcare process.

Expectation-related factors, including:

- Perceiving that symptoms needed to be 'unusual' in order to be reported, for example in terms of severity or duration;
- A sense of hope about recovery if treatment could be obtained and, conversely, a sense of fatalism about the lack of effective treatment;
- A desire for 'peace of mind.'

Identity-related factors, including:

- The presence of personal risk factors which elevated the perceived sense of threat;
- Social pressure, in terms of fear of passing the disease to others and pressure from others to seek help;
- Trusting staff involved in providing tests or healthcare;
- Fear of being stigmatised by others in the workplace or community.

Several practical factors were also identified, including:

- Physical proximity of the healthcare facility, which removed transport barriers;
- Privacy concerns, particularly in the context of healthcare workers reporting symptoms;
- Economic factors, including an inability to afford healthcare or fears about a negative impact on employment or a lack of paid sick leave.

Evidence from the COVID-19 outbreak: detection of symptoms

We are unaware of any studies that have assessed changes in, or factors associated with, the likelihood of people detecting COVID-19 related bodily changes. A variety of factors are theoretically relevant, which include expectation, negative mood, attention and demographic attributes such as gender and ethnicity [8] [11]. This is likely to be particularly true for mild symptoms. Detection of symptoms may also be particularly problematic where someone other than the case is responsible

for detecting, interpreting and / or responding to symptoms. For example, there may be particular difficulties for parents who must determine whether a young child is feeling poorly [12].

Evidence from the COVID-19 outbreak: interpretation of symptoms

Several cross-sectional or qualitative studies relating specifically to COVID-19 support the idea that interpretation of symptoms, and various factors that influence interpretation, are associated whether people request a test.

One key factor is knowledge of what the symptoms of COVID-19 are. Polling has repeatedly shown that recognition of COVID-19 symptoms in the UK population is sub-optimal (Table 1). If someone does not know that a given symptom is associated with COVID-19, they are unlikely to request a test if they experience it, unless prompted by, for example, a family member or colleague.

Table 1: Rates of symptom recognition in the UK

Survey panel (sample size).	Date of data collection	Percentage who recognised individual symptoms	Percentage who recognised multiple symptoms
Predictiv [13] (n=6,149)	20 to 22 April	Not reported	Cough & fever: 59.1%
BMG [14] (n=42,127)	2 March to 5 August	Not reported	Cough, fever & loss of smell or taste: 48.9%
YouGov [15] (not reported)	3 to 4 June	Cough: 87% Fever: 83% Loss of taste and / or smell: 72%	Cough & fever 76% Cough, fever & loss of taste and / or smell: 59%
Ipsos MORI [16] (n=2,237)	17 to 20 July	Cough: 71% Fever: 76% Loss of sense of smell or taste: 58%	Cough, fever & loss of sense of smell or taste: 31% Two out three: 81%

The CORSAIR study is an analysis of the Department of Health and Social Care’s regular polling data of UK adults (n≈2,000 per wave). It uses the BMG data reported in Table 1. Several factors were identified in an early pre-print for this work as being associated with symptom knowledge. People who could identify fever, cough, and loss of sense of smell or loss of sense of taste as the symptoms of COVID-19: did not think they had already had COVID-19; felt better informed about the symptoms of COVID-19; agreed that asymptomatic transmission was possible; were concerned about passing COVID-19 to someone who might be at risk; felt that their personal behaviour had an impact on how coronavirus spreads; and perceived government information to be less credible. We speculate that an underlying factor accounting for all these variables might be how much information about the pandemic an individual is receiving.

CORSAIR also asks respondents to report whether they have experienced symptoms in the past seven days and a) what actions they have taken since experiencing symptoms (for those with symptoms) or b) what actions they would take if they developed “symptoms of coronavirus (high temperature/fever, new, continuous cough, or loss of taste/smell)” the following morning (for those

without symptoms). In both cases “I [requested / would request] a test to confirm whether I have coronavirus” is presented as an option. In the most recently analysed wave (23 to 25 November 2020), for those with symptoms, 20.5% reported having requested a test. A pre-print for the CORSAIR study based on data up to 5 August found that self-reported reasons for not requesting a test largely related to symptom interpretation, namely: not thinking that your symptoms were due to COVID-19 (20%); because symptoms improved (16%); and because symptoms were only mild (16%). These explanations may suggest that an expectation that COVID-19 symptoms should be somehow ‘unusual’ may be deterring people from requesting a test, or that the perceived value of a test is low where symptoms are mild.

These findings correspond with those of an OC&C survey commissioned by the Department of Health and Social Care (n=3,049, 6-11 August [17]). These suggest that, among people who think they might have had COVID-19 but did not request a test, the main reason for not seeking a test was “my symptoms weren’t very severe” (reported by 54%).

Similar findings have been reported in a series of qualitative interviews with parents of school children in the UK, conducted 15th to 20th April [18]. Across the course of a wide-ranging interview, parents’ interpretations of COVID-19 symptoms appeared to be determined by four factors. First, whether the symptoms were perceived as “normal for us” (e.g. a sense that you will just “know” if something is out of the ordinary in yourself or your child). Second, whether the parent tended to “err on the side of caution” when there was a lack of certainty about how to interpret symptoms. Third, some parents appeared to “normalise” symptoms either by focusing on their mild nature or lack of any unusual characteristics or because they could think of an alternative, less threatening explanation. Fourth, and probably relating to all of the other factors, temperature appeared to be more likely to trigger a possible COVID-19 interpretation than cough. Identification of symptoms of COVID-19 may be particularly problematic for parents of young children, who can experience 8 to 10 upper respiratory tract infections per year [2].

The idea that the unusualness or severity of symptoms affects whether people interpret them as COVID-19 is supported by a survey using a convenience sample of people in the Philippines (n=147), recruited via social media [19]. Overall, participants were ‘very willing’ to go to a COVID testing facility if they experienced shortness of breath or a sudden loss of their sense of taste or smell, but were only moderately willing to go if they experienced a fever for several days or a cough for several days. Similarly, the main reasons for not seeking testing when symptoms are present were “it is very likely I am just normally sick” and “the symptoms are mild and will just get better anyway.”

Whether symptoms are perceived as unusual is likely to be determined by the quality of the symptoms themselves, but will also differ between groups. For example, difficulties have been reported in attempting to differentiate symptoms of COVID-19 from acute toxicities and persistent symptoms in patients with cancer [20].

More anecdotally, the sense that some people within the UK are confused about how to interpret mild symptoms that might be a sign of COVID-19 is backed up by reports from headteachers (e.g. “Some (fortunately very few) parents will insist that their child's cough should be ignored as they are convinced that it is not coronavirus and that school should take them in [21]”) and by field trips by the C-19 Taskforce (e.g. “misunderstanding of COVID symptom guidance has resulted in workers with one of the symptoms continuing to attend their place of work whilst others with minor symptoms would...self-isolate [22].”)

As the pandemic progresses and more people receive positive tests, the interpretation of symptoms across the population may change. Believing that you have previously had COVID-19 is associated with believing that you now have some immunity to it, greater levels of out-of-home activity, and less worry about COVID-19 [13]. It is possible that believing you have previously had COVID-19 is also associated with a reduced likelihood of interpreting future symptoms as being associated with COVID-19, although this has not been studied. This may be a particularly relevant consideration in the context of discussions about mass testing.

Evidence from the COVID-19 outbreak: response to symptoms

Surveys provide divergent information on people's intentions to obtain a test once they recognise that they have symptoms of COVID-19. In the CORSAIR study, people without symptoms were told to imagine that they have "symptoms of coronavirus" and asked what actions they would take. Only 60.1% reported that they would request a test. In the OC&C survey, around 80% of respondents gave a score of 7 out of 10 or higher on a scale of 0 (highly unlikely) to 10 (highly likely) when asked "if you developed symptoms of coronavirus, how likely would you be to request and complete a test [17]." In polling conducted by the Behavioural Insights Team (n=5,807, 26 to 28 June [23]), a subsample of respondents were asked to "imagine you had a cough and high temperature. You know these are coronavirus symptoms, though your symptoms are mild." Respondents were asked if they would accept a free coronavirus test: 93% said yes. It is not clear why these three surveys give different results. We speculate that it may be to do with the way response options were framed: CORSAIR presented 'get a test' as one of many possible options that could be selected, while the OC&C and BIT surveys appear to have used standalone questions to assess likelihood of requesting a test. The use of stand-alone questions may have made more salient the social desirability of choosing the 'right' answer.

This uncertainty notwithstanding, there are some clear barriers that deter people who interpret their symptoms as possibly COVID-19 from getting a test. Many of these relate to difficulties or concerns about the process of being tested. For example, in the CORSAIR study, the only factor that was found to be strongly associated with not requesting an antigen test when symptomatic was having low confidence that you could return a home-testing kit via courier: 14.6% who did not request reported thinking they were not eligible as a reason, while 13.5% reported not knowing how to request a test. Perceived practical barriers relating to testing were also noted in a national survey in Australia (n=1,369, June 2020 [24]). This survey identified that 49% of people strongly agreed (96% agreed to some extent) that "over the next four weeks, I plan to get tested if I have COVID-19 symptoms (cough, sore throat, fever)." Two of the main reported barriers to getting tested were 'I don't know how, when and where to get tested' (7.1%) and 'I am worried I will get infected with COVID-19 at the testing clinic' (5.9%). In the UK, confusion about eligibility for testing has been common: 59% of respondents to the OC&C survey reported being unaware of whether they were eligible for a test [17] and 58% were not confident that they knew when to get a test. Being unable to afford to travel to a test site was reported as a barrier by 9% of those who reported being unlikely to get tested in this study, while concerns about being exposed to COVID-19 during testing were cited by 12%. In the OC&C data, not trusting the Government with your data and not trusting the test's effectiveness were each cited by 12% of people who were unlikely to request a test.

Aside from concerns about the process, perceptions about the likelihood of having COVID-19, social factors, and the utility of testing have also been identified as issues in one online convenience sample of 485 people in Nigeria [25]. Here willingness to disclose symptoms to a public health telephone service was only associated with whether participants thought themselves to be at risk of contracting COVID-19. Willingness to have a test was associated with perceived risk of contracting

COVID-19, knowing someone who has taken the test, and thinking it is important for people to know their COVID-19 status.

Evidence from the COVID-19 outbreak: demographic factors

The attention individuals give to bodily changes such as symptoms can be understood through socio-cultural models including the perception, explanation and behavioural options to respond to it [26].

A large survey of adults in Australia (n=4,362, 17-22 April) found that respondents with inadequate health literacy were less likely to be able to name at least three key symptoms of COVID-19 compared to respondents with adequate health literacy [27]. People were also less likely to recognise the symptoms of COVID-19 if they: were aged 18-25 or 56-90, spoke a language other than English at home, were male, had lower educational status, did not have private health insurance, were not in paid employment, and lived either alone or without children.

In the CORSAIR study [14], the demographic factors most strongly associated with not recognising the symptoms of COVID-19 were younger age, not identifying as White British, male gender and hardship (a variable composed of three items asking about skipping meals, struggling to make ends meet, finding your current living situation difficult). Symptom recognition in these groups may be lower if health communication does not take into account socio-cultural factors including trust in organisations that provide guidance on symptoms, message source, content and mode of delivery which may result in key information about symptoms not reaching different groups.

Where symptoms are recognised, the interpretation of this can be informed by culture [26]. Symptoms that are attributed to external factors such as fate or religious principles of karma, may result in reluctance to get tested or seek active treatment if symptomatic [28]. Coping responses are shaped according to illness attributions and instead of engaging with healthcare services, some individuals may engage in faith-based coping strategies such as prayers. Socio-moral attributions of karma and illness may result in stigma attached to testing positive. As a result, some community groups are less willing to take a test and/or share a positive test result with others [28]. Stigmatisation and the fear of being labelled as someone who carries an infectious disease can result in delayed help-seeking until symptoms are unmanageable or may result in not seeking care at all [29].

Qualitative research during the pandemic indicates individuals in some minority ethnic groups would only take a test after showing symptoms for more than two weeks and would not take a test if they were asymptomatic to retain a sense of control over their health outcomes [28]. Previous research indicates perception of the ability to control illness is linked to increased engagement with health services [30]. However, reports of mistrust towards health services during the pandemic include concerns that engaging with services will result in poorer health outcomes [28] and reports of the disproportionate impact of COVID-19 on minority ethnic groups may reinforce these concerns resulting in lower control beliefs. OC&C data [17] suggest that key workers are slightly less likely to intend to request a test when symptomatic, due to greater concerns about being exposed while completing a test, worries about what others might think, concerns about missing out financially if the test is positive, and not having the time to take a test.

A systematic review of ethnicity and clinical outcomes in COVID-19 found some minority ethnic groups might be less likely to get tested when experiencing symptoms due to barriers to accessing services, loss of trust in health services and psychosocial stressors that arise due to systemic issues underpinned by unequal power relations and beliefs [31].

Physical barriers include challenges of obtaining the information required to book or access a test particularly for individuals with low digital literacy and English language skills, and concerns about privacy of data and proximity of the Test and Trace programme with the government resulting in increased reluctance to book a test [28].

A cultural model of support may also serve as a barrier to engaging with health services. A study exploring the risk of severe COVID-19 in minority ethnic groups found more frequent visits from family and friends is associated with lower risk of COVID-19 hospitalisation which may reflect the role of social support in enabling individuals to remain at home when symptomatic [32]. Groups that prioritise extended kin networks focus on the family as the primary mechanism of support. Health is considered the result of, and a resource of, the well-functioning group, rather than an individual asset which could lead to an expectation that family members seek help from known or in-group members [26] particularly where symptoms can be managed in the home.

Impact of interventions to date

We are not aware of any formal evaluations of attempts to improve responses to symptoms among people who have COVID-19 related symptoms. Some suggestions have been proposed, however.

The OC&C survey asked respondents to state which of a set of options would make it more likely for them to complete a test. The top options over-all were “if a government / NHS agency personally asked me to” (endorsed by 50%), “if I could complete it at home” (48%), “more convenient locations” (48%) and “more choices of testing locations” (41%). This suggests that practical considerations relating to the ease of testing are likely to improve uptake.

In an online vignette study, Lunn and colleagues randomised 500 participants to view standard information from Ireland’s Health Service Executive, a simple decision aid tree about what actions to take when symptomatic, and a complex tree [33]. Participants were then presented with vignettes of people with COVID-19 symptoms and asked what actions they should take. Significantly more participants made the correct decision that COVID-19 symptoms should result in self-isolation when shown the complex decision tree, with a beneficial effect of the simple tree also being observed for vignettes involving flu-like symptoms.

Policy recommendations

1. Lack of knowledge about the symptoms of COVID-19 will reduce the likelihood of someone responding to their symptoms appropriately [Medium confidence]. Advertising, official spokespeople (including ministers and members of SAGE), and those taking part in media interviews should state the precise symptoms of COVID-19 whenever possible in order to improve recognition, rather than referring simply to “symptoms.” Identifying additional, new routes to communicate these symptoms to the public should be prioritised.
2. Believing that the symptoms of COVID-19 are severe or somehow unusual may prevent people from interpreting mild symptoms as requiring a test [Low confidence]. Emphasising in messaging that even mild symptoms may signify the presence of COVID-19 may help people better interpret their symptoms.
3. It is possible that even where mild symptoms are interpreted as possibly COVID-19, their mild nature affects people’s response to them [Low confidence]. Clearly articulating the rationale and benefits of responding to mild symptoms (e.g. to loved ones, colleagues, the wider community) could help in prompting detection, interpretation and response. Identifying the most effective ways to communicate this is beyond the scope of this paper, but general principles are discussed [elsewhere](#). Enlisting the ‘lay referral system’ may also help, for example by encouraging family

members, peers and colleagues to encourage and support symptomatic people to self-isolate and seek a test when symptomatic.

4. Response is also governed by perceptions about the process of getting a test [Medium confidence]. In general, making the testing process as straightforward and easy to access as possible, and demonstrating to people that this is the case, should improve uptake.

5. Some population groups are likely to have particular needs in relation to symptom recognition [High confidence]. This includes parents of young children, people with comorbidities, people from minority ethnic groups, people from lower socio-economic groups, men and people who are receiving less information about the pandemic in general. Targeting such groups may be particularly beneficial. Evidence on the impact of public health communications for [minority ethnic groups](#) and for [young people](#) are provided elsewhere.

6. Fears of stigma and discrimination may delay responding to symptoms by booking a test [Medium confidence]. Public health interventions should address stigma and discrimination targeted towards individuals affected by COVID-19 by changing attributions made by the public to develop more acceptable attitudes towards individuals affected by COVID-19. This could minimise delays to help-seeking behaviour.

Research gaps

1. The research we identified has focused on the general population. There is relatively little known about how specific groups respond to the presence of potential COVID-19 symptoms, including people from ethnic minority groups, people with medical co-morbidities or parents (with respect to children's symptoms). Additional research with these populations would be beneficial. This includes research that identifies ways to increase control beliefs in minority ethnic groups and strategies to provide culturally grounded explanations and illness perceptions that increase knowledge of symptoms and timely access to testing. For children, further work is needed to understand sensitivity-specificity trade-offs in excluding or including common cold symptoms (sore throat, runny nose) in COVID-19 definitions, as these are most difficult for parents. Further work is also required to understand the interaction between symptom recognition, causal attributions and help-seeking behaviour to identify culturally appropriate help-seeking strategies for service providers to implement.

2. We did not identify any prospective studies that have assessed behaviour among people who develop symptoms. Such a study would be valuable in understanding the relative importance of factors that are associated with seeking testing and entering isolation.

3. Similarly, with the exception of one vignette-based study assessing intentions, we did not identify any experimental studies assessing interventions to improve how people respond to the presence of possible COVID-19 symptoms.

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