# The impact of financial and other targeted support on rates of self-isolation or quarantine [SPI-B: 16 September 2020]

# Key points

- The effectiveness of the NHS test, trace and isolate system in reducing transmission of SARS-CoV-2 depends critically upon self-isolation of people who may have COVID-19 and their contacts
- 2. Current rates of full self-isolation are likely very low (<20%) based on self-report. They are particularly low among the youngest and the poorest, thereby likely contributing to inequalities in the impact of COVID-19.
- 3. Self-isolation rates would likely be improved with the addition of different forms of support. These include:
  - a. <u>Financial support</u>: Ensuring that those required to self-isolate would not experience financial hardship in doing so.
  - b. <u>Tangible, non-financial support</u>: Proactive outreach is needed, to identify and resolve any practical needs that people have (e.g. access to food, care for elderly relatives).
  - c. <u>Information</u>: Improved communication to the general public explaining how and when to self-isolate, and why it helps, would be useful, in addition to more detailed advice for those self-isolating (e.g. a help-line or SMS service).
  - d. <u>Emotional support</u>: For those who need it, access to social support or more formal clinical interventions delivered remotely if possible.
- 4. Provision of a support package that encompasses these four components but particularly the first should be rolled-out and evaluated as a matter of urgency in order to realise the considerable investment made in testing programmes and the potential of testing and self-isolation to contribute to economic recovery and prevention of disease.

# **Executive summary**

If a return to normal life is to be achieved for most people in the short- to medium-term in the UK, people must adhere to requirements for self-isolation. Although there are important methodological limitations to the data currently available, rates of full adherence among people in the community with cough, fever or anosmia may be somewhere in the region of 18% to 25%. The best available evidence suggests adherence would be increased by targeted support to those asked to self-isolate.

Four forms support seem most important:

- 1. <u>Financial support</u> which ensures that people would not experience financial hardship when self-isolating is likely to enable more people to adhere. Financial hardship and lower socioeconomic position are currently associated with lower self-reported adherence. The roll-out of paid sick leave policies has previously been associated with reduced sickness absence in the USA and lower spread of influenza.
- 2. <u>Tangible non-financial support</u> may be required by many people. At present, leaving the home to shop for food or groceries is the main self-reported reason given for non-adherence. Thirteen percent of people with symptoms report not adhering because of a need to "help or provide care to a vulnerable person" such as an elderly relative. Receiving support from outside the household is associated with greater likelihood of adherence. The type of support needed is likely to differ between households. Proactive outreach should identify the specific needs of each household and the best way to help.
- 3. <u>Information</u> about the principles underlying self-isolation should help people understand why and how to adhere. Multiple studies in the current pandemic and in previous outbreaks have shown that low levels of knowledge, not believing the illness to pose a serious risk and not perceiving a benefit to self-isolation are associated with lower adherence. The importance of making information clear should not be underestimated. A campaign similar to the current #HandsFaceSpace campaign may be helpful, in addition to targeted messages to those who are self-isolating.
- 4. <u>Support for psychological wellbeing</u> will be important for many people. Distress amongst those self-isolating is associated with financial stressors, inadequate access to essential supplies including food and medicines and poor information. Resolving these issues should improve wellbeing. Social and emotional support may also be required by some and can be provided following an initial assessment by local schemes in addition to more formal mental health services (including those delivered remotely). Reducing emotional distress is likely to further bolster adherence.

DHSC should develop a package of support that includes each of these four components (and particularly the first) and ensure that it is available to everyone who needs to selfisolate. A plan to independently evaluate the programme should be developed, to quantify the impact of the package, identify the most effective components within it, and identify any barriers to implementation or uptake. A validated measure of self-isolation, which may require the use of objective as well as self-report measures, should be developed as part of this.

Better quantification of adherence to self-isolation is also urgently required across the UK, ideally using a range of measures include objective, as well as self-report, indicators. ONS and NHS TT should consider how best to provide regular data on this critical outcome.

# Background

This paper has been written in response to the SAGE 52 action: SPI-B to review existing evidence on quarantine compliance in relation to loss of earnings and potential incentives.

SPI-B has previously considered self-isolation as one of several interventions during the Contain phase of the pandemic (<u>3 March 2020</u>), noting that:

- "A number of measures will require Government to rethink existing financial arrangements, e.g. home isolation for those on zero hours contracts who are ineligible for sick pay, people who are in receipt of universal credit or job seekers allowance unable to present themselves at job centres."
- "There could be public frustration if an intervention is perceived to be inequitable or inconsistent, e.g [...] if isolation is impossible for poorer households due to financial constraints."

SPI-B has also given advice on Public Health England guidance to people being asked to self-isolate (<u>9 March 2020</u>). This recommended, among other things that:

- the needs of different groups be considered;
- it is important for people to receive support during self-isolation;
- personalised advice and support, potentially via SMS, should be considered;
- rapid research should be conducted to explore barriers and facilitators to adherence, particularly for people in different economic and at-risk groups.

## Adherence to self-isolation is essential to preventing a resurgence of the pandemic

The isolation of people with symptoms of COVID-19 and the quarantine of people who have been in close contact with them is the cornerstone of the UK's strategy to contain community transmission in order to enable people to resume as many activities as possible. Isolation and quarantine are technically different. Isolation is the separation of people who are ill from others, while quarantine is the separation of people who have been exposed to an infection, but who are not yet ill themselves, from others. In practice, this distinction has become blurred. In this paper use the term of 'self-isolation' to refer to both.

Achieving self-isolation is a key outcome of any test, trace and isolate system. As the system's name implies, there are multiple steps that people must follow in order for this outcome to be reached. People must recognize the symptoms of COVID-19, be willing to report them in order to request a test, be able to obtain a test in a timely and convenient way, complete and return the test, receive the results in a timely way, be willing and able to be interviewed by contact tracers and to report details of close contacts, and enter self-isolation either immediately (for index cases or individuals in their households) or when asked to do so by a contact tracer (for close contacts).

At each of these stages, sub-optimal adherence is a key limiting factor [1]. If the system does not provide people with what they need (e.g. access to testing) or people do not perform the behaviours that are asked of them, the system will fail. Understanding why people are not adhering allows us to identify ways to tackle barriers and add enablers to increase adherence and reduce transmission.

Our understanding of adherence to self-isolation is constrained by two important limitations in the existing evidence base: an absence of validated measures of self-isolation; and an absence of intervention studies that assess the effects of different forms of support on selfisolation. The existing evidence, summarised below, is based largely on self-report in crosssectional studies.

## Self-reported adherence to self-isolation is low

Three studies have assessed adherence to self-isolation in the UK.

In an on-line poll of 2,240 members of the YouGov panel conducted 6-7 May 2020 [2], Smith and colleagues identified 217 people who had either experienced a cough or fever themselves in the past seven days, or where one or more household members had experienced a cough or fever in the past 14 days. Although the definition is not clear cut (some of these people presumably had an obvious, non-COVID explanation for their symptoms), under the guidance at the time most of these people should have been self-isolating. All participants were asked whether they had left their home in past 24hrs. Among those in the symptomatic group, 54 out of 217 (25%) reported that they had not left their home.

The CORSAIR study is an analysis of a weekly series of on-line surveys of adults in the UK, with each survey including around 2,000 people. A recent analysis explored 21 waves of data, including 42,127 responses from 31,787 participants [3]. Data collection occurred from 2 March to 5 August. This identified 1,939 people who reported having high temperature / fever, cough, or loss of sense of taste or smell in the past seven days. Participants were asked what, if anything, had caused them to leave home since they developed symptoms, and were categorized as adhering if they had not left home at all. Only 352 people had not left home at all (18%).

The NHS Test and Trace evaluation team has completed a small pilot survey of index cases (n=95) and contacts (n=66) asked to self-isolate [4]. During a telephone interview, participants were asked how many times they had left their home in the past three days. For index cases, 86% said 'not at all.' For contacts, 89% said not at all. Assuming that the 157 people who did not respond to the survey should be categorised as non-adherent to self-isolation, the team estimated that the lower bound estimate for adherence was 39%. For this study, it is important to note that, even among people who reported adhering, around 70% also reported doing "a final trip" somewhere before they began to self-isolate and in contravention of guidelines.

Five potential limitations should be noted with these studies.

First, all three studies relied on self-reported adherence. Self-report is vulnerable to multiple biases, particularly recall bias (people may be systematically more likely to overlook infringements of the rules) and social desirability bias (people may be disinclined to admit that they infringed the rules). Therefore, actual adherence may be lower than reported.

Second, the studies took a relatively simple approach to assessing adherence. Not all infringements of the rules of self-isolation matter: it is possible, for example, for someone to leave their home carefully for a walk and not come into contact with anybody else. Whether high rates of self-reported non-adherence equate to high rates of risk is unclear.

Third, the sampling frames differed between the three studies. While the Smith and CORSAIR studies attempted to assess adherence in the general population by using market research survey panels to identify people with symptoms regardless of whether they had had a test or not, NHS Test and Trace assessed adherence among people who were already in contact with them either because they chose to request a test for their symptoms or because their contact details were provided by someone who chose to request a test. This difference in sampling may go some way towards explaining the difference in adherence rates –people who have already adhered to one Test, Trace and Isolate behaviour are presumably more likely to adhere to others.

Fourth, all three studies defined adherence as remaining at the home, excluding consideration of self-isolation within the home. Isolation from other members of the household is likely to be lower due to physical and practical constraints. One small survey of people asked to self-isolate during the containment phase found that while most (89 / 92; 97%) reported being able to remain at home, relatively few (41%) were able to isolate from other members of their household [5]. Similarly, a survey of 236 self-isolating members of staff at one London NHS trust found that 57% were unable to isolate themselves from household members [6].

Fifth, the above studies concern people who are self-isolating after developing symptoms or because of their contact with someone else who has symptoms. There is an absence of evidence regarding responses to a request to self-isolate in people who test positive in the absence of symptoms.

## Providing support is likely to improve adherence to self-isolation

A rapid evidence review conducted early in the pandemic [7] identified 14 studies that have explored factors associated with adherence to self-isolation. We are aware of several more that have since been published (relevant studies are cited below). All of these studies are observational, cross-sectional and rely on self-report as a measure of self-isolation in people asked to do so because they are symptomatic, have had a positive test result or have had contact with someone who is a known or suspected case. Although multiple factors were identified, in the sections below we focus on those of direct relevance to the provision of targeted support. In this paper we do not consider enforcement options, but note that a trade-off between enforcement of self-isolation and willingness of people to report their symptoms is potentially problematic [8].

## Provision of financial support

## Evidence

During the 2003 SARS outbreak in Toronto, fear of loss of income was the most common reason given for non-adherence with self-isolation among healthcare workers [9]. The issue was of paramount importance to this group, who requested detailed information about when, how, and how much compensation they would receive during their isolation period. During the swine flu outbreak in Australia, despite good adherence with self-isolation (93%), "a need to work" was cited as a factor in breaking quarantine among the minority of those who failed to adhere [10].

Within the UK, Smith et al [2] found no association between reported adherence to selfisolation and whether participants agreed or disagreed with the statement "If I follow the Government's advice, it will have a negative impact on how much money I have." However, given how few people were self-isolating in this sample, the item on "the Government's advice" may have been interpreted as relating to social distancing, use of face-coverings and other, non-TTI related behaviours.

The CORSAIR study [3] included a composite measure of financial hardship composed of three questions relating to struggling to make ends meet, skipping meals you would usually have, and were finding your current living situation difficult. Greater hardship showed a significant association with non-adherence. Lower socioeconomic grade was also associated with non-adherence, although there was no association with index of multiple deprivation. Among symptomatic CORSAIR participants who had left their home (n=1,939), 11% reported that they had done so "to go to work."

Importantly, these findings do not indicate that willingness to adhere is lower among people with less financial resource. Instead, they suggest that ability to adhere is lower. A cross-

sectional survey of 2,108 people conducted 17 to 18 March found that, while self-reported willingness to self-isolate for seven days was consistently high across all income and wealth groups, self-reported ability to self-isolate was three times lower in those with incomes less than £20,000 or savings less than £100 [11].

Although statutory sick pay is currently offered to people in England who are self-isolating, this is frequently reported as insufficient both in amount and duration for many of the lowest paid to meet the basic expenses of daily living. Paid sick leave has been judged an effective intervention to reduce transmission of SARS-CoV-2 across OECD countries [31]. However, it does not include all workers such as those on casual or zero-hour contracts or gig workers [12]. In addition, payment level and duration vary considerably across countries with the level most often below gross pay. When paid sick leave policies were mandated in Washington DC and Connecticut in 2008 and 2011, respectively, significant decreases in the rates of illness were observed, as sick workers stayed at home and transmission of infection was reduced [13]. Sick pay policies also appear to mitigate the impact of flu epidemics [14].

#### **Recommendation**

Provision of financial support to safeguard incomes would likely have the single largest effect in achieving equitable self-isolation policies, in other words self-isolation that benefits the social groups with fewest material and other resources as well as those with the most. This is based on descriptive analyses of COVID-19 and other pandemics and epidemics which clearly highlight the difficulties for those who are poorest to support themselves and their families without leaving their homes [15-18]. It also includes a study conducted in the current pandemic in which intentions to self-isolate in a general population sample in Israel increased from 57% to 94% when lost wages were to be compensated [19].

Existing evidence suggests financial assistance is most likely to be effective if it:

- ensures that those in the poorest households asked to self-isolation have no drop in weekly income
- is provided rapidly
- is easy to obtain

Although the poorest households will very likely benefit from financial support during isolation, financial support may also improve adherence among people in the middle-income bracket who would otherwise be adversely affected. We recommend enlisting expertise in welfare economics to advise on the design of a financial support package that adequately covers the relevant sections of the population and that is easy to access, quick to pay out.

Employment protection should also be offered for those needing to self-isolate, including parents who may need to stay at home with a child who is required to self-isolate. Scotland has issued a fair work statement to guide employers and employees including ensuring: No worker should be financially penalised for following medical advice [20].

## Provision of tangible, non-financial support

#### <u>Evidence</u>

During the SARS outbreak, people in isolation in Canada relied heavily on others from outside the home to provide groceries and to take over chores such as providing transport for children or disabled or elderly relatives [9]. In the absence of external support, some people had to break quarantine to do this themselves. Shopping for food was the main reason for non-adherence given by a sample of the public in Australia during the swine flu outbreak [10]. In the UK, receiving support from outside your household "because of coronavirus" was strongly associated with remaining at home while symptomatic [2],

although the cross-sectional nature of these data makes it difficult to determine causality. Among symptomatic CORSAIR participants, the main reasons given for leaving the home was to "to go to the shops, for groceries / pharmacy" (18%). "To help or provide care to a vulnerable person" was cited by 13%.

## **Recommendation**

Access to food and medicines that are appropriate for needs and preferences is a fundamental requirement for those asked to self-isolate. For those who are unable to organise this provision for themselves, it will need to be provided. In other countries, self-isolation is accompanied by official action including provision of food, frequent health checks and encouragement [21]. While internet services will suffice for some people asked to self-isolate, others do not have access to the internet, do not have the experience needed to confidently navigate online shopping, or do not have the financial resources to shop online. This will be exacerbated if a resurgence of the pandemic leads to a high demand for online services.

Similarly, support for chores or duties that might otherwise compel someone to leave their home is likely to help many. In particular, the CORSAIR finding that people with symptoms have left their home to care for others who are vulnerable is alarming – identifying people with this need and finding a solution that does not risk transmission is essential. A proactive, personalised offer of help to identify the needs of people who are self-isolating may be beneficial. Given the role of boredom and frustration in non-adherence to isolation, identifying ways to combat this may also be productive. For example, a partnership with the entertainment industry to provide free access to online games or streaming services could be considered. Beyond mitigating the negative impact of isolation, room also exists within this area to trial provision of incentives. As one illustrative example, particularly for younger adults and children, a partnership with entertainments or sports industries might identify novel 'money can't buy' activities or products only available to those who have self-isolated.

# Provision of information

## Evidence

Multiple studies have reported that poor knowledge about an illness or about the rules surrounding self-isolation is associated with worse adherence. Six studies are cited in a previous rapid evidence review [7] which reported that, for example: "When five schools in an Australian city were closed during the H1N1 pandemic, a lack of clear quarantine instructions led some of those affected to invent their own quarantine rules, seemingly based on what they thought constituted a visible symptom of the disease, the acceptable degree of contact with those infected and the risk of being affected or of infecting others. Parents in an Australian city who understood what they were meant to do during the quarantine period for H1N1 had significantly higher adherence to quarantine." The same review identified nine studies suggesting that higher perceived risk of the disease, and greater perceived benefit of self-isolation in combatting an outbreak, were associated with greater adherence.

More recently, ambiguity in terms such as 'essential' that appear in official guidance have been cited in UK focus groups (run on 28 March and 4 April) as problematic for people making decisions around self-isolation [22]. In the CORSAIR study, greater knowledge of Government guidance and of the symptoms associated with COVID-19 was associated with higher likelihood of adherence to self-isolation [3], although this was not found by Smith et al. [2]. The need for a clear understanding of the reasons for and principles underlying self-isolation is also apparent in the reasons given by symptomatic CORSAIR participants for leaving their home, which included "my symptoms got better" (16%), "my symptoms were only mild" (14%) and "I don't think it's necessary for me to stay at home" (13%).

#### **Recommendation**

People who are self-isolating may benefit from receiving daily contact using SMS or telephone offered as part of a support package [23]. We are aware that a trial of SMS / telephone support is currently underway [24]. More generally, information provided to people who are asked to self-isolate needs to include a clear rationale for self-isolation including its effectiveness and the protocol to be followed. It is may also help if this is disseminated in advance to the general population, using a similarly clear format to that currently used for the #HandsFaceSpace adverts.

## Provision of support for psychological wellbeing

## Evidence

A rapid evidence review of 24 studies conducted in February 2020 found consistent evidence that self-isolation can be a distressing experience for those involved [25]. This does not necessarily reflect mental illness but can be seen as a normal response to an abnormal event. The same review identified multiple factors associated with distress. These included: longer duration of isolation; fears about being infected oneself or spreading infection to family members; frustration and boredom; inadequate supplies (including food and medication); receiving insufficient or confusing information; financial loss as a result of isolation; and stigmatization from others.

The psychological burden of self-isolation is sufficient justification to seek ways to resolve these stressors. Yet there is also evidence that reducing distress may also improve adherence: Smith et al observed an association between believing that the lockdown had made your mental health worse and being less likely to remain at home when symptomatic [2]. Symptomatic CORSAIR participants also reported "I was too depressed or anxious" (11%), "I was too lonely" (10%) and "I was too bored" (9%) as reasons for leaving their home.

#### **Recommendation**

Many of the stressors that contribute to the psychological impact of self-isolation relate to financial impact, lack of basic supplies, boredom and frustration, and inadequate information. The provision of support to remove these stressors, as outlined above, is likely to have a beneficial effect on mental wellbeing.

Beyond this, social support and clinical intervention might also be beneficial for some. This may include connecting to local schemes for social support such as COVID-19 health champions in Newham, London [26] or schemes set up for specific communities targeted for mass testing such as universities. Providing access to a national mental health service, delivered remotely and providing evidence-based care [e.g. 27, 28, 29], may be also be required.

## Proposed next steps

Based on the observational evidence reviewed above, provision of targeted support is likely to increase rates of self-isolation, particularly amongst those with fewest financial, social and other resources.

Given that self-isolation is the cornerstone of reducing community transmission of SARS-CoV-2, the evidence is sufficiently compelling to begin implementation of a support package that encompasses the four areas outlined in this paper, as one important step towards to increasing the current likely very low rates of self-isolation. This should be taken up as priority by DHSC. We encourage the following:

- ensure that the interventions tested are developed in partnership with the target population, including local community leaders and the BAME community, while ensuring that this does not unduly delay the implementation of the support package;
- consider separately the needs of different groups within the population including the BAME community, rather than assume a 'one-size fits all' approach to support.
- set up systems to allow rapid and ongoing qualitative and quantitative feedback to allow the support package to be refined where needed;

In parallel, an independent evaluation of this intervention should be commissioned. This should be prioritized by UKRI. The evaluation might include the following:

- a discontinuity analysis or comparison to historical controls to allow some causal inference of the impact of the intervention
- a validated outcome measure based on a range of indicators of adherence likely comprising both observational and self-report

In producing this paper, it has become apparent that there are very limited data available on adherence to self-isolation across the UK. Given how central this outcome is to the effectiveness of NHS Test and Trace, a review of these data by ONS and NHS Test and Trace is strongly recommended. It will not be possible to evaluate the success or otherwise of the system in the absence of such data. A range of complementary measures is likely to be needed. Currently, a variety of self-report measures are used in cross-sectional surveys. There is scope for different forms to be explored which may provide more robust data (e.g. mobile phone data, ecological momentary assessment, and diary studies). These could be collected at an aggregate or individual level. A detailed exploration of these methods is beyond the scope of this paper, but a range of options has been put into practice elsewhere, often based on mobile phone systems [30]. Backwards contact tracing, to identify if new cases are linked to people who should have been self-isolating, is also possible. Clearly such options raise important ethical issues that must be considered in detail. We outline some options here simply to generate much needed thinking on this crucial topic.

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