The impact of financial and other targeted support on rates of self-isolation or quarantine [For endorsement by SPI-B: 12 September 2020]

Key points

1. *The effectiveness of NHS TT at reducing transmission of SARS-CoV-2 depends critically upon self-isolation of those testing positive and their contacts*
2. *Current rates of full self-isolation are likely very low (<20%) based on self-report. They are particularly low amongst the youngest and the poorest, thereby contributing to inequalities in the impact of COVID-19.*
3. *These low rates would likely increase with the addition of different forms of support and in particular financial support for those with the lowest household incomes.*
4. *These additional forms of support should be evaluated as a matter of urgency to realise the considerable investment already made in testing programmes.*

Executive summary

If a return to normal life is to be achieved for most people in the short- to medium-term in the UK, members of the public 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 sets of support seem most important:

- Financial support which ensures that people are not financially disadvantaged when self-isolating is likely to enable more people to adhere. Financial hardship and lower socioeconomic grade 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.
- Tangible non-financial support 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 best way to help.
- Information 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.
- Support for psychological wellbeing can be delivered in large-part if financial, non-financial and information support is provided. Additional social and emotional support may also be required by some and can be provided by local schemes in addition to more formal mental health services. Reducing emotional distress is likely to further bolster adherence.

UKRI and DHSC should prioritise trials of these four sets of support, to identify the most effective support package, taking into account that a one-size-fits all approach is unlikely to be optimal. A validated measure of self-isolation, ideally using objective rather than 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 objective, rather than self-report, measures. 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 (3 March 2020), 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 of 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 (9 March 2020). 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.

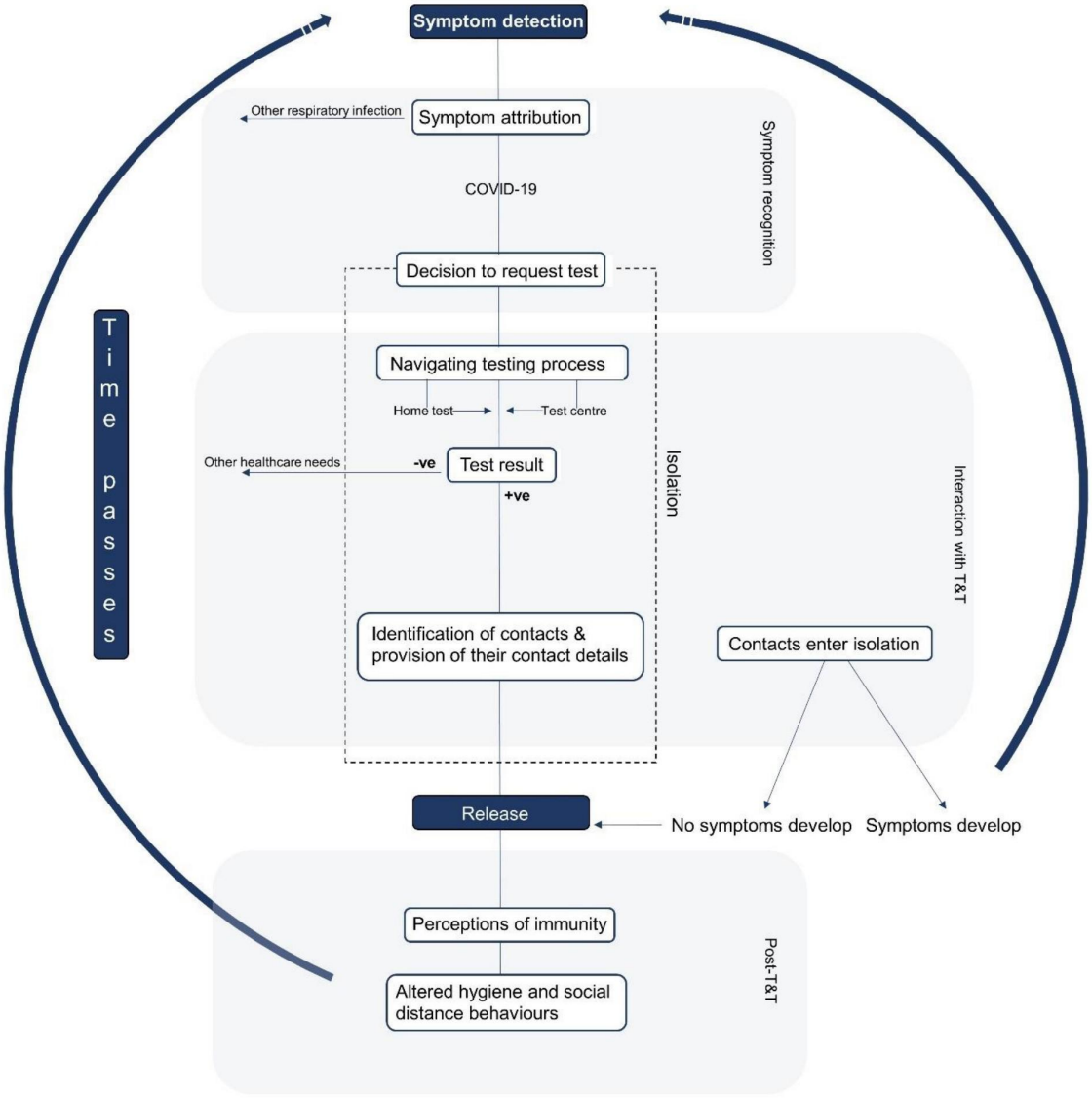
Adherence to self-isolation is essential to preventing a resurgence of the pandemic

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 prevent the resurgence of the pandemic while allowing a return to a more normal life for most people. 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 and in this paper we refer to both using the current terminology of 'self-isolation.'

Achieving self-isolation is the 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 report details of close contacts, and enter self-isolation either immediately (for index cases) or when asked to by a contact tracer (for close contacts). These steps, and the broader test, trace and isolate system, are illustrated in Figure One.

At each of these stages, adherence is a key limiting factor [1]. If 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 any barriers, increase adherence and reduce transmission.

Figure 1: The patient journey through the test, trace and isolate system.
[Image credit: Charlotte Robin]



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 whose household member 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]. This identified 1,939 people who reported having high temperature / fever, cough, or loss of sense or 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 have 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 methodological points 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).

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 strategy differs between the three studies and none is ideal. 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 define adherence as remaining 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 those 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 self-isolation 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 the UK population, self-reported ability to self-isolate was three times lower in those with incomes less than £20,000 or savings less than £100 [11].

Recommendation

Currently, amongst those in the England entitled to statutory sick pay, 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. 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 related leave taking 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].

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].

To be most effective, existing evidence suggests financial assistance is more likely to be effective if it:

- ensures that those affected by self-isolation have no drop in weekly income;
- is provided rapidly;
- is easy to obtain.

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

Evidence

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 on 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 from the NHS volunteer service, local council or charitable sector to identify the individual needs of people who are self-isolating may help. Given the role of boredom and frustration in non-adherence to isolation, identifying ways to combat this may also be productive. For example, for younger adults / teenagers, 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 also 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 are 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 supportive accountability [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 reduced distressing 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 insufficient 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 and clinical support 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.

Proposed next steps

Based on the observational evidence, provision of targeted support seems likely to increase rates of self-isolation. While some financial and other support is already provided, it may not

be at the scale or with the consistency needed to achieve high rates of self-isolation across social groups.

Various forms of support are possible and likely needed. The effect size of each type of support, singly or together is unknown. However, the evidence for the use of additional support is sufficiently compelling to progress to trials of these interventions to estimate the effect sizes of providing different types of support. This should be taken up as priority by UKRI and DHSC. Such a trial should ideally:

- Use a stepped wedge design, in which local areas all begin in the control condition with interventions introduced progressively and in random order;
- Use an observational, rather than self-reported measure of adherence;
- Use a measure of adherence that can distinguish between different levels of adherence according to the risk of transmission to other, rather than viewing adherence as a binary variable;
- Ensure that the interventions tested are developed in partnership with the target population, including local community leaders;
- Consider separately the needs of different groups within the population, rather than assume a 'one-size fits all' approach to support.

In producing this report, it has also been apparent that there are very limited data available on adherence to self-isolation across the UK. Given how central this outcome is to NHS Test and Trace efforts, a review of these data by ONS and NHS Test and Trace is recommended. It will not be possible to evaluate the success or otherwise of the system in the absence of such data. Where possible, objective, rather than self-report, data would be beneficial.

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