

Information and rational decision making: explanations to patients and citizens about personal risk of covid-19

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## Abstract

In a pandemic, there is an urgent need for public information and action. Two sets of information given to patients during the covid-19 pandemic are examined. The first is information given to patients who were advised to 'shield' in March 2020. The second is of information given to patients who underwent swab testing for suspected covid-19 in the initial stages of the pandemic. These communications are found to contain greater certainty than the evidence supporting them, which may have led to adverse consequences. Recommendations are made for consideration in future communications.

## Introduction

On 16th March 2020, the UK government published 'Guidance on social distancing for everyone in the UK' (1), which asked people in particular groups to be "particularly stringent in following social distancing measures". These groups included all over 70s, and under 70s with particular health conditions. People offered flu vaccines were part of this cohort (which includes people with heart disease, chronic respiratory disease, obesity, and major mental illness) as well as people with chronic kidney disease, multiple sclerosis, and learning disabilities (2). Subsequently, on the 21st March 2020, a subgroup were identified as recommended to 'shield', which entitled them to food deliveries, priority for supermarket deliveries, and social care support if necessary. (3)

Testing for the presence of covid-19 in the UK was initially limited and undertaken only in hospital settings for patients with suspected disease. Subsequently government expanded this to include any symptomatic person in the UK over the age of 5. On the 2/4/20, the government set a target 100,000 tests per day. (4) Patients booked appointments online at a drive through centre and the result was communicated by text message (5).

Strikingly, communications from government to patients and citizens in these scenarios contained several definitive statements. For patients identified as being in the high risk group, they informed they were at 'very high risk of severe illness' (6) from covid-19. For symptomatic patients having a test for current infection with covid-19, the result by text for negative test results read "A negative result means you did not have coronavirus when the test was done" (7).

These claims were examined as they came to attention during routine work in general practice in the early stages of the pandemic. The shielding information caused distress and confusion in some patients. The COVID-19 results were incidentally and retrospectively noted to be at odds with clinical presentation, leading to concerns about the potential for false reassurance. These pieces of information are assessed against the evidence claimed and the quality of the communication to patients.

## Key points - shielding identification

On the 21st March 2020, the UK Government published "Guidance on shielding and protecting people defined on medical grounds as extremely vulnerable from COVID-19" (3) It stated "This guidance is for people, including children, who are at very high risk of severe illness from coronavirus (COVID-19) because of an underlying health condition, and for their family, friends and carers....This includes the extremely clinically vulnerable people living in long-term care facilities, either for the elderly or persons with special needs." This removed some people on the flu vaccine list, or whose only risk factor was age, but kept others.

These letters were sent to over 2 million UK citizens. The "extremely vulnerable" group included people with organ transplants, haematological cancers, severe asthma and chronic obstructive airways disease. They were advised to shield, which meant staying at home, avoiding face to face contact with anyone else, for 12 weeks. (8) The duration was subsequently extended in each nation and paused at the end of August 2020 (16/8/20 in Wales). People with terminal illnesses and in 'special circumstances' were advised that they may choose to decide not to shield and could discuss with their GP or specialist. The 9 page letter to patients stated that "We know

that this is a very worrying time, especially for patients with significant underlying illnesses” and shielding “will help to protect you from coming into contact with the virus, which could be very dangerous for you.” (9)

Patients were identified at being at high risk of death from covid-19 were identified initially via by prescribing patterns, and hospital databases in the first instance (10,11). General practitioners were subsequently asked to identify further patients who should be added and removed from the list. (12) This decreased the group of shielded patients by over 100,000. (13) GPs were advised to carefully consider who should be added to the list, given the burden incurred by those advised to shield. Confusion was reported by patients on professional websites, social media, and on newspapers and in television, both in the identification phase, and in the later phase, when some people were contacted by text message to tell them that their shielding status had been lifted (14). Some charities produced advice in the identification of high risk groups which was later withdrawn or altered (15).

This created distress for many people, both for some who were told they were at increased risk, and some who were not. It created workload for primary care teams at a time of increased stress during the covid-19 pandemic. However it also created a great deal of uncertainty regarding the identity of the highest risk groups. The first iteration included, for example, in people using home oxygen for any reason. However this included people who use oxygen occasionally for the treatment of cluster headaches, which is not recognised as being a high risk condition. The information that they were in the ‘extremely vulnerable’ category therefore was incorrect. This is understandable, given the need for swift decision making, for an entire country, in a rapidly evolving situation. However there are useful learning points which could be incorporated for future communications.

The category of shielded patients was initially based on the risk of morbidity with seasonal influenza. But there are important differences between this group and the patients at greatest risk with covid-19. International research published on April 25th 2020 found that, in comparison to seasonal flu, patients admitted to hospital with covid-19 were more likely to be male and with heart disease (ethnicity was not reported.) (16) On May 7th 2020 UK research identified higher risk factors being male sex, older, with uncontrolled diabetes, severe asthma, or being black or Asian. (17) Of these, only severe asthma was included on the shielding list. However, there was no change to the categories of people advised to shield.

At the end of May 2020, some patients on the shielded list in England received a text message communication informing them they should stop shielding and that food deliveries would be stopped (Box 1). This was apparently due to the realisation that some groups (for example, those with liver disease and some cancers) were not at very high risk. General practitioners, including the NHS medical director of primary care had no advance notice (18) with some civil servants also appearing to have had no preliminary information (19). Patients reported having little or no explanation on the rationale for change. This was accompanied by reports of patients distress, both because of potential unnecessary shielding, and, in the belief that they were at high risk, fear of no longer being supported in shielding.

#### **BOX 1 - TIMELINE OF SHIELDING ADVICE**

16/3/20 Government publishes list of conditions where people told they should be ‘particularly stringent’ to avoid covid-19

21/3/20 Government publishes list of conditions where people should ‘shield’ for 12 weeks and begins to send letters to 2 million people

9/4/20 GPs contacted and asked to check lists of shielded patients and add/subtract people by 14/4/20

5/5/20 GPs reported to have removed 107,000 patients from shielded patient lists

28/5/20 Reports of patients removed from list with no consultation

8/6/20 Shielding extended to 31st July in Scotland and Wales and 30/6/20 in England with review planned

#### **Key points - covid-19 result communication**

Arrangements for public booking for covid-19 testing opened in mid-April 2020 in England and (20) and mid-May 2020 in Scotland (21). Patients booked a test online, giving their name, and phone number. The process was thereafter operated by text message, with patients attending a testing site by car, or requesting a home test. Patients were instructed to take the swab via a 16 page instruction booklet inside their vehicle or home.

Subsequently patients were advised of a negative test result via text message. The initial message to patients read : "A negative result means you did not have coronavirus when the test was done. You can stop self-isolating if you test negative, as long as - everyone you live with who has coronavirus symptoms also tests negative...you feel well - if you still feel unwell you may have a different illness that could spread to other people, so stay at home until you're feeling better". This was subsequently changed, on the 4th June 2020, to "If you get a negative test result, this means you are at low risk of having coronavirus", before reverting to the original wording. Each iteration maintained the advice that a negative test meant that they and their household no longer needed to self-isolate. (22) (Box 2)

However, categorically informing patients with a negative swab result that they do not have covid-19 is problematic. Patients with a false negative test risk false reassurance and a return to the community where they may unwittingly spread covid-19. Further, the Department of Health and Social Care press department, in response to a request for information on estimated false negative rates, wrote on the 30/4/20, " The test is reliable and effective, but like any diagnostic test, there is always the small possibility of a false negative or a false positive result" (personal communication). The Office for National Statistics, on the 10th of May said that there was significant uncertainty in the accuracy of the test: "We do not know the false-positive and false-negative rate of the current swab test for the virus. False-positives and false-negatives could also come from the fact that participants in this study are self-swabbing. We also do not know if all individuals testing positive are still infectious. Some may have had the coronavirus (COVID-19) in the past but still test positive" (23). Estimation has been in the region of a false negative rate of between 2-29% (24). Further, the false negative rate of self testing by lay people risks a greater false negative rate via the ability to achieve a reliable sample.

21/4/20 Prepublication of systematic review of false negative covid-19 testing finds rates between 2-29% (24)

15/4/20 - symptomatic people able to book test for current covid-19 infection online in order to booked appointment at government test sites , mid May 2020 for Scotland

14/4/20 Government test centres send negative results saying "you did not have coronavirus when the test was done"

30/4/20 Department of Health via press department states risk of false negatives is "a small possibility"

4/6/20 - Negative test government testing centres via text message states "you are at low risk of having coronavirus"

## BOX 2

### Health communication, shared decision making, and uncertainty : critical frameworks

Health messaging in the context of a pandemic is a perfect storm. Fear and panic, mistrust of government, the difficulties of communicating complexity, and the tendency of many social media channels to publish 'fake news' means that it can be argued that simplistic messages are the most likely to result in the most good for the most people. However, it is also necessary to consider the unintended effects of such communication (25). In communicating negative results for covid-19 testing, and in the erroneous inclusion of high risk groups for shielding, the certainty of each message from government was striking. This must be set against the harms of actions after an unknowingly false negative test for covid-19, or being told that one is no longer required to shield after information to the contrary.

## BOX 3

Text used in covid-19 communications

Letter to patients being advised to shield

"The NHS has identified you, or the named person you care for, as someone at high risk of severe illness if you catch coronavirus....The safest course of action is for you to stay at home and avoid all face-to-face contact for at least 12weeks"

Suggested text:

The NHS has searched hospital appointment and prescription records to find the people who we think are more likely to be at high risk of getting ill with coronavirus. We are still learning about this virus. Based on what we currently know, we think you are more likely to be at high risk. However the way we have searched means that a few people will have been included who do not need to be. As we learn more about who is at higher risk, we hope that we can tell some people that they can stop shielding. You can discuss this with your doctor or NHS 111.

Covid-19 results communication by text

"Your COVID result is negative. You did not have coronavirus when the test was done"

Suggested text:

"Your COVID result is negative. This means coronavirus was not found on your test. However the test is not always accurate. Please continue to isolate for 7 days from the start of your symptoms."

The challenges in communicating risk accurately to patients has been well recognised (26). The World Health Organization, in January 2019, published a systematic review of the literature on health communications to public audiences, at-risk communities, and stakeholders during public emergency events (27). Searching PubMed revealed no other systematic review addressing communications in public health emergencies were identified. One of the WHO conclusions was that the "Public should receive explicit, consistent, clearly understood uncertainty information speedily from authorities". They also noted "uncertainty information in messages provided by authorities at times of public health emergency events is uniformly associated with desirable outcomes such as reduced uncertainty about health protection actions; reduced reliance on misinformation, rumors, and sensationalized media stories; and improved response to future warnings." In other words, admission of uncertainties may result in more trust and potentially more buy-in from citizens. This has been contested, with a belief that articulation of uncertainty may be politicised and unwanted by the population at large (28). A narrative review of experimental literature, however, has found negative public impact (such as decreased credibility) occur only when uncertainties are expressed as a conflict in science expertise rather than in technical uncertainty. Whereas, expressing uncertainty with error ranges or likelihood margins had no effect, or beneficial results (29). This is demonstrated in an examination of the effect of scientific communications of uncertainty across domains of cognition, emotion, trust and decision making, more communication about uncertainty on breast screening either had no effect or was considered beneficial. In serial experiments on communicating uncertainty in typical news stories, exposing uncertainty did not change peoples 'affective reaction, concluding "A key challenge to maintaining public trust in science is for communicators to be honest and transparent about the limitations of our current state of knowledge" (30). Additionally, Spiegelhalter has written "we cannot assess the quality of risk communication unless the objectives are clear" and recommends that communicators should "Have the humility to admit uncertainty." (31)

In the case of covid-19, where communication is needed to protect individual and community life and health, public trust in information is essential. Additionally, it should be considered essential to state the degree of uncertainty of communications such that rational understanding of the limits of information can be garnered.

## Conclusion

Two key messages sent to patients instructing significant undertakings by government in the context of COVID—19 did not contain any reference to their uncertainties. Yet the advice given was not based on highly certain evidence (that they and their households return to work, in the case of negative covid-19 tests, or for some patients who were recommended, and then not recommended, to shield). In the context of a fast moving, dynamic, stressful situation, it is understandable that policy makers may wish to err on what they regard as the side of cau-

tion. However, caution applies both ways. Evidence based policy means that policy and public advice should change as better evidence emerges. If apparently inexplicable changes to advice follow, these risk incurring a loss of trust and the public referring to less reliable sources. This problem is likely magnified by over-confident, but under-evidenced recommendations. Further, basic medical ethics requires honesty and openness about the extent and limitations of current knowledge. We recommend that future public communications about risks in the context of covid-19 carefully includes of uncertainties and caveats, We also recommend that admissions of uncertainty in such communications is regarded as a strength of communication and desirable by policy makers.

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