# Report 14: Online Community Involvement in COVID-19 Research & Outbreak Response: Early Insights from a UK Perspective

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## Background

As part of the Imperial College COVID-19 Response, we are developing research to explore and understand people's views about, experiences of and behavioural responses to the 2019-novel coronavirus (COVID-19) outbreak, in the UK and elsewhere. To guide that effort and to help inform COVID-19 research and responses more broadly, for example in mathematical modelling and policy, we launched an online community involvement initiative that sought rapid, early insight from members of the public and aimed to establish a network for ongoing community engagement.

From previous outbreaks (SARS, pandemic influenza, Ebola) it was clear that early engagement with communities is an essential part of outbreak response. Limiting the impact of a new infection like COVID-19 includes several interventions that depend on people changing their daily routines. First steps are to try and contain the spread through isolating those with the infection and quarantining their contacts who may be at risk. These restrictions may be required by the authorities or be voluntary. Further steps to reduce spread include 'social distancing'* (reducing contact with those you don't live with) and promoting preventative behaviours, such as good hand hygiene practices. Understanding how the public are feeling and responding to the outbreak can inform how authorities frame and deliver public health messaging. Involving local communities in the development and delivery of preventative behavioural measures could improve acceptance and adoption.

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*The World Health Organization are now advocating the phrase 'physical distancing' in place of 'social distancing' to better highlight the need to physically separate yourself from others, but still remain socially connected.

## Methods

Between 6 and 15 March, we distributed an online feedback form, hosted on Qualtrics, to existing public partners and the wider general public via email, WhatsApp, social media (twitter) and using VOICE-global, an online platform for public involvement in research established by Newcastle University. The online form comprised of three main sections that aimed to 1) guide our research priorities and design; 2) capture the public's priorities, preferences and unmet needs, 3) shape our ongoing community engagement and involvement activities, by rapidly exploring people's experiences of the outbreak and opinions on research (see **Appendix 1** for outline and purpose of questions asked and the outcomes achieved). The form included 44 questions with a combination of multiple-choice responses and free text boxes. Questions were piloted and adapted following discussions and input from 7 members of the public known to the research team prior to distribution. Responses have been summarised in simple tables, and open-ended questions grouped into themes using QSR International's NVivo analysis software.

## Results

We received responses from 420 people; over half of these signed up to be updated about and/or involved in our ongoing work. 73% of respondents described themselves as members of the public, with some referencing their work sector (e.g. teacher, retired) or health interest. There were 255 women and 148 men. 88.4% of respondents were White and there was a spread across age groups with 4.5% aged 24 or younger and 17.9% aged 65 or older. 94% of responses were submitted by people living in the UK, with most having been born in the UK. We also had 15 respondents from abroad, including 8 from Europe, 6 from USA/Canada and 1 from India. A third of respondents reported living with a current or long-term health condition or disability. Just over a third had caring responsibilities. Half of respondents had a university degree or equivalent (bachelor's or master's degree) as their highest level of education achieved.

See **Appendix 2** for all summarised demographic and background data of respondents.

### 1. How the public were feeling about the coronavirus outbreak in the UK

Respondents were invited to share how they are currently feeling about the coronavirus outbreak, which could include any concerns or lack of that people had, perception of risk, opinion of the news or response in the UK, or anything else that they wished to highlight.

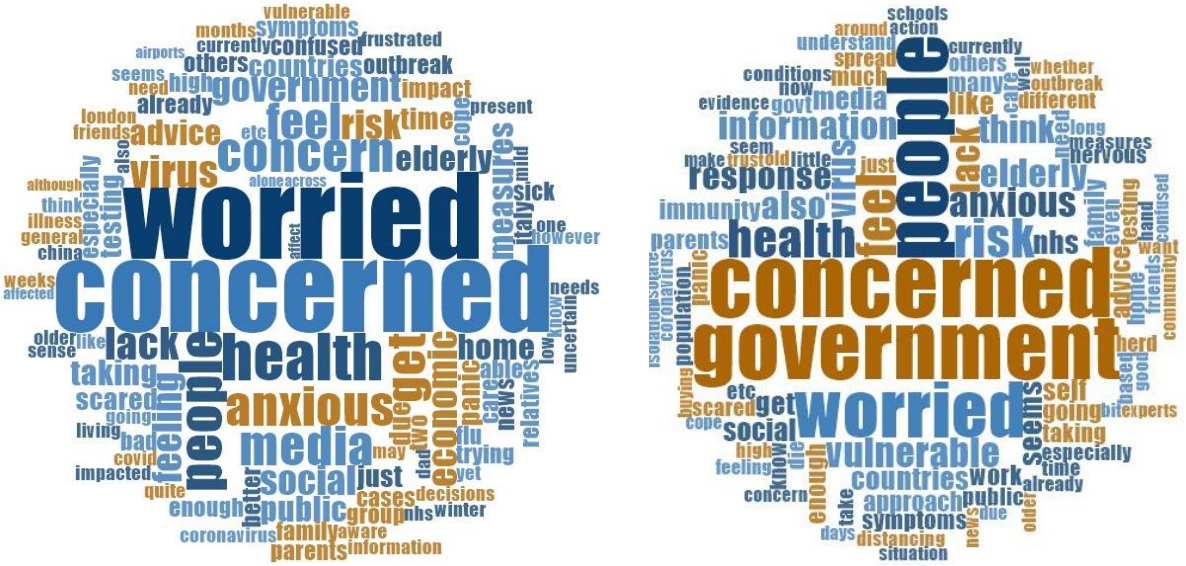



**Figure 1. Word clouds based on all UK-based responses to Q1.1 "How are you currently feeling about the current COVID-19 outbreak?" received between 6–12 March 2020 (left; based on 72 responses), and 13–15 March 2020 (right; based on 305 responses).**

Many responses related to people's reaction to the UK government's response to the outbreak and the role that the media play. This overlapped with answers to several questions asked later in the online form, including: "Do you have any comments or concerns about how the government will respond if transmission of the virus becomes more established in the UK?".

| Q2.7 Do you have any comments or concerns about how the government will respond if transmission of the virus becomes more established in the UK | n (%) |
|---|---|
| Yes | 258 (61.4) |
| No | 109 26.0) |
| Don't know | 39 (9.3) |
| No response | 14 3.3) |

Therefore, we themed and summarised all responses that highlighted how people were feeling about the outbreak and the UK's response, which are outlined below:

## The public do not trust the Government's approach and are concerned not enough is being done to protect vulnerable groups

Overall, most people described concerns about the level and speed of the government's response, had little trust in the decision-making, and felt it was "too little too late". Several questioned why the UK government was taking such a different approach to WHO recommendations. Many highlighted the need to understand why the government was taking the approach that it was and requested sight of the scientific evidence that supports it. This also applied to the government's decision to stop testing, which many people disagreed with and named undetected spread of the virus as a concern.

Several compared the UK government's response to that of other countries, which they perceived to be more effective in 'containment', 'control', 'isolation' (e.g. China, Singapore, New Zealand). Several

also referenced the news coverage of Italy and expected the same to happen in the UK if more wasn't done. People also highlighted the shortage of resources in UK hospitals compared to other European countries (e.g. bed capacity in intensive care units). There was a general demand for stricter measures to be put in place urgently.

Concerns were also raised regarding the government's proposal of herd immunity and the potential risk to lives linked to this approach. Worries about how NHS services will cope with the mounting pressure and forecasted rise in severe cases were frequently raised alongside the feeling that "the UK is very unprepared". This was described in relation to underfunded services, overworked staff and hospitals already at capacity (e.g. bed capacity, ventilators). People are expecting many deaths and suggest that some of these would have been preventable were the NHS better equipped to cope.

Some described a "disregard" by the government towards people and society (particularly vulnerable groups) compared with the economic effects. In this instance, vulnerable groups included the elderly, people living with underlying health conditions, people living with physical disabilities, people facing homelessness, carers, and retired health workers. This was often in relation to the decision by parliament to not take more 'Draconian' measures – some believed this was to avoid any public panic and/or to protect the economy. They perceived this as the government "willing to put vulnerable members of our society more at risk".

### The public are confused about what to think and do

The second strongest theme to emerge throughout this exercise was the lack of clarity and the inadequacy of the government's guidance about what is planned, what to expect and what to do**.**

Confusion was attributed to misinformation, conflicting guidance and an overload of information. Some felt this was due to press coverage and certain social media accounts which they held responsible for sensationalising and scaremongering, some said it was due to "a constant stream of interviews with different experts", while others blamed the official guidance which was either insufficiently detailed, unclear or inconsistent: "Contract it and gain immunity or hide away". We also received reports of elderly relatives or members of society being "so confused by the [government]'s advice" that they were either pretending it wasn't happening or adopting extreme measures of isolation. People with current health conditions reported high levels of anxiety and a lack of clarity about what they should be doing "I don't know whether I am "vulnerable" and whether I should be doing pre-emptive self-isolation".

This seemed to lead to an overall feeling of unpreparedness at all levels and the lack of government leadership meant individuals and organisation were either not preparing themselves for the measures that are now in place, "My employer has not yet taken measures to have us work from home" or people were taking things into their own hands "Everybody I know is making acute small decisions about every aspects of their lives, be they working from home or in healthcare (hardcore decisions), about their kids & their parents, trying to do the best for everyone, in the absence of any transparent gov leadership".

### The public are scared about losing loved ones and worry about the impact on society

In the absence of any known risk factor, respondents were typically not concerned about the risk to themselves but many shared fears about the potential impact on or loss of loved ones who they believe are at risk of being severely affected by COVID-19. Some were unsure about how best to prepare, in particular how to care for those they look after if they were to fall ill themselves.

Several concerns were raised regarding the government's recent announcement of bringing retired NHS workers back to work who they identified as a potentially vulnerable group themselves. The inadequate supply of personal protective equipment and testing of NHS workers was also highlighted alongside worries about the potential impact on health workers' mental health. Others shared concerns about how the outbreak will affect communities socially and economically: the potential disruption caused by the infection control measures, impact of home-working, the psychological impact on children and young people's mental health, the negative impact on the UK economy, businesses (big and small) and on personal finances, and the overall care and support provided to vulnerable groups, including refugees. Some also described concerns regarding cancellation of routine appointments and delays to pre-planned medical care and treatment. Several referred to an expected "collapse" of the NHS which they linked to government austerity and significant years of underfunding of services by government.

### Not everyone is concerned

Around 8% of respondents were not concerned or worried about the COVID-19 outbreak. Some accepted that it should be taken seriously but others felt the reaction is "exaggerated and not normalised compared with pneumonia" and that the "media is blowing it out of proportion". Some reported "no concerns at all", while others shared expectations that they will "catch it and recover" due to their current good health, feeling "confident in the calm, serious, measured and pragmatic approach of the British government", and that the "prime minister and experts are giving the right quality and amount of information based on scientific knowledge". A couple of respondents also suggested that not all older people are as concerned as we may think, either due to them preferring to choose quality of life (i.e. seeing their children and grandchildren) over limiting their risk of infection (i.e. self-isolating), or downplaying the seriousness of the threat, which some highlighted was affected by past experiences "(e.g. other pandemics, war)".

## 2. Public support for research exploring the UK's experience of and response to the COVID-19 outbreak

As a research team, we felt it was important to understand what people thought about our study in the current climate, and not assume that it is important to others just because it is important to us. This insight could help to prioritise the objectives of our research and that of others.

| **Q1.5: Do you think it is an important research question to understand the UK public's risk perceptions, experiences and behaviours during this outbreak?** | **n (%)** |
|---|---|
| Yes | 399 (95.0) |
| No | 7 (1.7) |
| Don't Know | 8 (1.9) |
| No response | 6 (1.4) |

Of the 414 people who responded to this question, 399 (95%) agreed that our research was important, with the main message being that "It's people and not [government] that will determine how things evolve". Of these, 379 (95%) provided a reason, which fell into several broad categories:

| **Proposed reasons why research to understand people's perceptions of risk, experiences and behaviour <u>is</u> important** | **Frequency** |
|---|---|
| Understand and influence planning and impact of current outbreak response<br>➢ Ensure public voice is heard and considered<br>➢ Understand the impact of intervention measures on the public's lives<br>➢ Apply pressure to government<br>➢ Improve design and implementation of intervention measures<br>➢ Improve the assumptions used within models that predict the impact of different interventions | 114 |
| Improve the accuracy, understanding and adoption of information and guidance provided to the public<br>➢ Avoid mass panic<br>➢ Avoid misinformation<br>➢ Improve adoption | 114 |
| Better understand what people think, feel and do and why, which is complex<br>➢ (see section 3 for proposed factors to investigate) | 106 |
| Improve long-term learning and response to future outbreaks | 92 |
| Improve the support provided to communities and vulnerable groups<br>➢ Highlights unmet needs | 13 |

Of the 7 that said 'No', 6 gave a reason, which broadly represented the views that 1) they don't believe understanding risk perceptions will make a difference to how people behave; 2) that we can sufficiently influence people's perceptions and behaviour as needed using current resources available; and 3) they don't believe it will make a difference because scientific research currently has insufficient capacity to influence the current government's policies and decision-making. The 5 that commented on their 'Don't know' response gave similar reasons with the main being a question of "How would it help?" alongside the idea that people need to be told what to do by the government. However, a couple agreed that while it may not make a difference to this outbreak, it may be useful for future learning.

## 3. Important questions we should be asking as part of this research

As well as testing the acceptability of our research, we were interested to learn what other questions respondents thought we should be asking in order to understand the public's response to the outbreak. Six themes emerged from the responses provided by 325 respondents.

**Identify sources of information and their influence over people**

Respondents had previously highlighted several factors that may influence people's understanding and interpretation of guidance and information, such as: education, age, risk perception, social factors, access to information. One pointed out that evaluation of the current outbreak would show how people act in the absence of clear and consistent guidance. Many respondents felt it was important to understand where people go to for health information in order to better understand the effectiveness of key messaging. This included how well key messages were communicated, but also how to create messages that influence the public's behaviour.

Related to this was a desire to explore people's views of official sources of outbreak-related information. This included an assessment of why people trusted certain sources over others and who they deemed to be the creators of this knowledge. Some respondents wanted to understand the role that the public and their peers play in creating and sharing information, or misinformation. Others suggested asking 1) what information people want and need (e.g. More statistics? More testing? Clearer explanations of the UK's response?); and 2) who do the public feel they can trust (e.g. Do they trust the government? Would they prefer interviews with people who have survived this?). One even raised the general question about the public's trust in science.

Finally, misinformation, information overload and media coverage of the outbreak were highlighted as key concerns that need to be fully investigated and addressed.

**Understand people's behaviour**

The second most significant theme was the need to understand people's behaviour, and what influences them to change their behaviour. In sharing why this research is important, a number of key points of interest had been highlighted, such as the influence of socio-economic and cultural factors on people's behaviour (age, perceived severity/seriousness, social norm, access to information, economic pressure, work status, disability, cultural background, political view); the factors influencing risk perception (novel risk vs. known risk, education, age, media); and the influence of media coverage and other countries' stories, experiences and responses.

Some respondents wanted to specifically understand the impact of social-distancing and self-isolation on people's lives, the activities people adopt during these periods and factors that influence whether they can comply. Others suggested investigating shopping behaviours during this time with a particular interest in what drove people to start stockpiling food and goods (e.g. toilet roll) and whether there is a relationship between stockpiling and people's levels of panic. A significant proportion of responses related to understanding issues about people's ability to adopt infection control measures aimed at slowing the spread of COVID-19. Further questions focused on what would encourage people to comply, whether these would need to be enforced, and what people would accept and for how long.

Some members of the public felt it was important to understand why some people were not changing their behaviour. This related to questions exploring the influences over people's behaviour, especially the financial implications of compliance with COVID-19 related measures. For example, respondents raised questions about whether the public could survive without wages, or if there was uncertainty about sick pay and any benefits they may receive.

**Explore people's knowledge, experiences and views**

This theme focusses on the public's experience and understanding of the COVID-19 outbreak and while it complements the previous two themes, it also had some distinct features. This included suggestions to explore people's understanding of concepts such as "herd immunity" and the evidence that should support it, and people's understanding of their risk with regard to catching and surviving the infection. Additionally, some felt it was important to explore what the public felt they needed to know about the virus, including any concerns they may have. Some felt it would be interesting to know why some "Foreigners seem to be more concerned than British nationals", reflecting on possible cultural differences, use of alternative non-UK news sources, lower trust in the NHS and links with people living in other affected countries.

A minor but significant theme related to understanding how the COVID-19 outbreak and the infection control measures adopted impact people's physical health and mental wellbeing. Some respondents suggested that the outbreak could perpetuate inequalities that already exist within society, particularly for those in low income groups. Therefore, collating and capturing the experiences across different demographics was seen to be a way of understanding how to protect people who may be among the most vulnerable. Furthermore, it was felt capturing such experiences would provide rich narratives of the public's relationships and lifestyles during COVID-19 and provide more data on people's ability to self-manage health conditions. A minority of respondents stated it would be useful to explore more about the public's views on life.

**Describe the UK's response and learn from other countries**

Some respondents suggested research exploring and clarifying the government's response to the outbreak, along with capturing learning from other countries. Related to this, these respondents felt it was important to understand how the wider public felt about the government's handling of the outbreak, including the extent to which they trusted the leadership.

In a similar vein, many of the same respondents suggested research exploring public views on testing for COVID-19. This included research investigating how well the public understand the plans and practice surrounding testing, and their views on why there was not more of this happening.

The global nature and influence of the COVID-19 pandemic led some respondents to suggest that we should compare the UK's response with other countries, including looking at how their citizens have mobilised and reacted. A national plan was also proposed in which society play a role in identifying those at risk and jointly coordinating groups and organisations to look after them as they self-isolate, as is being already adopted in other countries.

Two further secondary themes were identified that went beyond the public's response to the outbreak and considered 1) evaluating other groups and 'systems' that are responding to the outbreak (e.g. healthcare system, key workers, community initiatives), how they work, the impact on those involved and what could be improved; and 2) prioritising research that furthers our understanding of the new coronavirus – in particular: the mechanism of disease, the origin of the virus, how it spreads, and how best to protect ourselves. One respondent who was a researcher mentioned the need to explain the differing scientific opinions rather than present the public with a single view about COVID-19.

## 4. Key priorities to be considered by those involved in the outbreak response

Respondents were asked to share what they thought should be a key priority or consideration for those involved in the outbreak response. We received responses from 333 respondents, which covered six themes:

**Develop a vaccine, find a treatment**
By far the most frequently mentioned priority for the public was the need to develop a vaccine, which was mentioned 108 times, followed by finding an effective treatment.

**Save lives**
The second was to save lives by protecting the vulnerable (which many said included healthcare workers and others working on the frontline) and to equip and prepare the NHS for it to effectively manage the most severe cases, including increased provision of intensive care units and oxygen.

**Take action**
There was very strong support to urgently increase the level of the UK's response to the outbreak, with many concerned it may already be too late. Interestingly, improving the coordination of the response across sectors was also mentioned a lot, to include working more inclusively and openly with industry (private medical sector and supply chains), academia, policymakers, public health authorities and experts, health and social care workers, and community groups.

**Understand & prepare the public**
The need for clear, honest, transparent and open communication in order to educate and support the public, and combat misinformation, was a key priority for the majority of respondents. Some felt there should be stricter controls over media coverage of the outbreak who were seen as fuelling "scare-mongering" and "hysteria". Many also highlighted the need to explain why actions were taken and when answers aren't known. Others highlighted the importance of understanding the needs of vulnerable groups to ensure they are adequately supported e.g. how best to support lower income families and pensioners to ensure they are not suffering due to lack of income.

**Research**
In addition to developing a vaccine, and as mentioned earlier, improving our overall understanding of the virus and the outbreak was considered another research priority. This included: tracking the outbreak, better understanding how the virus spreads, who is most severely affected and why, learning more about potential immunity (i.e. do we develop immunity after infection, is herd immunity possible?), and continuing to track the long-term impact, both physically and socially.

**Reflect & Prevent**

Finally, many considered it crucial to document what is happening now and what led to these events, particularly identifying and learning from any mistakes. Several wanted to see more investment in research around preparedness and planning for public health emergencies, highlighting that we must learn from this in order to have an action plan for the next outbreak, or in case this one never goes away. One respondent felt it would be better to prevent it happening in the first place. Another said it would be important to understand how past events had impacted our ability to respond effectively, citing the move away from local NHS Primary Care Trusts that had a more "on the ground approach".

## 5. Which communities should we reach, engage and involve in our research?

The most frequent suggestions were for people who are believed to be at risk of more severe infection because of their age or other underlying health conditions. However, a large majority also outlined people who are vulnerable in other ways (physical or learning disabilities, mental health conditions, living alone, facing homelessness, prisoners), as well as those who are believed to be at lower risk (children, teenagers and young adults).

Other communities put forward included ethnic minorities, migrants and those who have English as a second language – a need that has been reemphasised recently by the Guardian – urban communities and people living in crowded housing, people who live in rural or isolated settings, those who are not online or on social media, subpopulations who may experience racism, renters and landlords, and people who have experienced COVID-19 and recovered.

A number of work sectors were also proposed with health workers being most frequently suggested followed by care homes and carers, gig economy workers, low income groups, teachers and educators, other front-line key workers who maintain contact with the public and unions, employers and business leaders.

Interestingly, we were also advised to include the perspectives of people who think COVID-19 is not a major issue (i.e. "it's only flu"), older generations who may not wish to change their way of life, those who respond by panic buying, science sceptics such as those against vaccinations, religious communities, parents including single parents, people from different political parties, middle-aged men, people who live near the border of Northern Ireland and that of health bloggers and influencers.

For the full summarised list of communities and groups proposed, see **Appendix 3**.

## 6. Information and resource gaps reported by those who responded

It is crucial that communities can access and understand all relevant information relating to the outbreak so that they can plan, prepare and respond effectively. Everyone who took part was asked whether they felt they had enough information about how they should respond to the outbreak. However, regardless of how they answered, they were all then shown a list of additional questions and ideas that other members of the public had previously proposed to us during a pilot exercise of the online form. Respondents were invited to select all that they agreed with and/or add their own ideas in the 'Other' free text box provided.

| **Q2.1 Do you feel you have enough information about how you should respond to the coronavirus outbreak?** | **N (%)** |
|---|---|
| Yes | 187 (44.5) |
| No | 197 (46.9) |
| Don't know | 32 (7.6) |
| No response | 4 (1.0) |

Just under half said they had enough information about how to respond to the outbreak. However, of the 414 people who replied to the next question which asked people "What information or resources are currently missing?", only 45 (10.8%) selected "I don't need any more information". For the rest, the three most frequently selected responses by those living in the UK were: 1) 'What should I be doing to prepare for when/if the UK government steps up its infection control measures (n=198 votes)'; 2) 'I would like to hear more about the latest research around the virus and this outbreak (n=192 votes)'; and 3) 'I would like a dedicated internet portal to access the latest information and trusted guidance' (n=185 votes). The graph showing quantification of all responses is available in **Appendix 4**.

Of the 149 that selected 'Other', all provided a further comment with the majority being requests for either A) bespoke practical information about what to do to protect themselves and their loved ones; and B) more personalised information about the (first-hand) experience of COVID-19 infection (signs and symptoms) and people's risk. But also included requests for, C) more effective communication; and D) more data and rationale behind the UK's response. Other specifics within these categories included a wish for more statistics, plus questions around testing, transmission, immunity and reinfection.

As highlighted within the previous section, there was a strong need for information across all four areas. People being confused about the current guidance and reporting conflicting information was a common theme that came up throughout this exercise. People reported a strong need for clearer, more consistent information and more effective communication that was accessible to all communities, including specific age groups, those who are not online or who have a low level of English. Two respondents made the vital point that people must actively seek and find information – it doesn't come to them. What's more, several respondents described how they read multiple sources and cross-reference facts before coming to their own conclusion – they don't trust one source blindly. If this is the only way to make sense of the COVID-19 outbreak, it's no wonder people are confused. It would also explain why there was such strong support for a dedicated site where people could access the latest independent, scientific information, communicated in a simple and concise way. Expansions on this idea included a rapid response team, hotline or site where people could get answers to specific questions and concerns without burdening 111. As a note, the NHS website was seen as uninformative and politically led. One respondent proposed a daily infographic explaining the UK's strategy and key guidance to follow. Others felt public spaces and GP practices could be better used to ensure information reaches everyone and to act as a constant reminder.

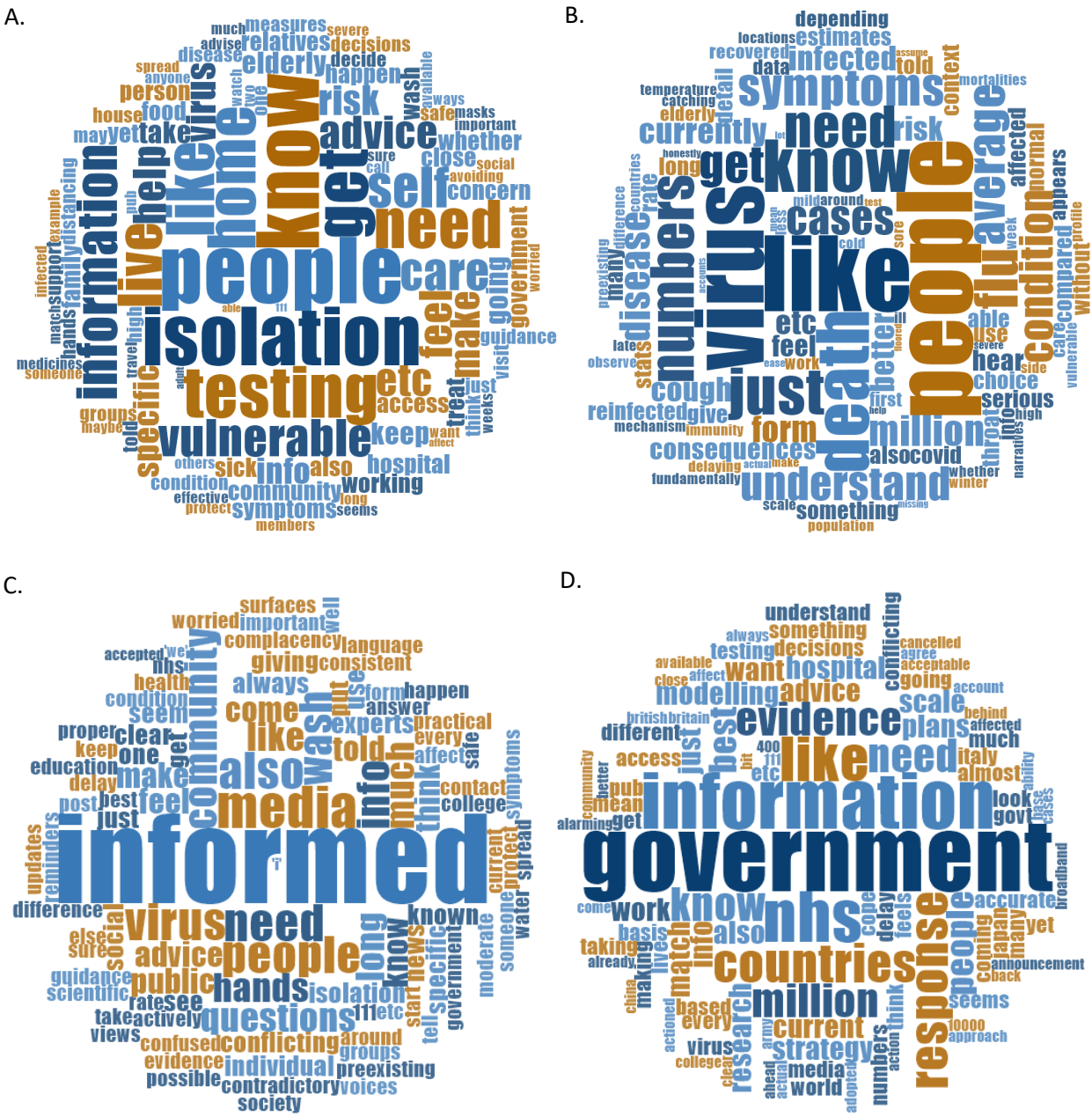



**Figure 2. Word clouds depicting people's requests for A) more bespoke practical guidance; B) more information about COVID-19; C) more effective communication, and D) more information and the UK's response.**

For more information about what information and communication people feel are missing, see **Appendix 5** for the full thematic analysis of responses, including 'Other' gaps and suggestions.

## 7. Accessing trusted sources of information

An important part of research exploring how people think, feel and act during the COVID-19 outbreak, will be understanding how people access information, how they interpret the information and knowing who they trust. We therefore wanted to get some initial insight into the kind of sources people are currently using, and trusting, and the kinds of challenges they are facing. This will help guide how we approach this topic within our research.

| **Q2.3 Which of the following sources do you… for news, information and guidance** (Instruction) | **Access** (Select any) | **Use most** (Select one) | **Trust most** (Select three) |
|---|---|---|---|
| Official websites (e.g. government, NHS, Public Health England, World Health Organization [WHO]) | 341 (81.2) | 62 (14.8) | 194 (46.2) |
| Print media (e.g. newspapers, magazines) | 156 (37.1) | 16 (3.8) | 22 (5.2) |
| Broadcast media (e.g. television, radio) | 272 (64.8) | 54 (12.9) | 67 (16.0) |
| Social media (e.g. Twitter, Facebook, Instagram) | 241 (57.4) | 47 (11.2) | 34 (8.1) |
| Online news | 264 (62.9) | 68 (16.2) | 45 (10.7) |
| Doctor or other healthcare provider | 101 (24.0) | 5 (1.2) | 30 (7.1) |
| Family and friends | 135 (32.1) | 3 (0.7) | 12 (2.9) |
| Work/school/college communications | 148 (35.2) | 3 (0.7) | 27 (6.4) |
| Other | 134 (31.9) | 31 (7.4) | 94 (22.4) |
| Don't know | 0 (0.0) | 6 (1.4) | 28 (6.7) |
| I am not reading information or guidance about the coronavirus outbreak | 3 (0.7) | 0 (0.0) | 0 (0.0) |
| I use/trust them all equally | - | 118 (28.1) | 50 (11.9) |
| No response | 4 (1.0) | 6 (1.4) | 12 (2.9) |

Other sources that people reported using to access information were: scientific journals, universities (online and email), radio, colleagues in the field/medical profession, experts in the field, other non-UK/international online news and sites e.g. Worldometer and EU portal, professional associations, radio, nurseries, alternative media outlets, online training, charities, neighbours, information on public transport.

Three people selected 'I am not reading information or guidance about the coronavirus outbreak', alongside other selected sources, with the primary reason reported being that they were actively avoiding some sources of information due to lack of trust and/or lacking confidence in the official guidance provided.

The other sources chosen to be most trusted included: certain Twitter accounts, Financial Times, medical professionals/experts working in the field, EU portal, scientific journals, professional associations, Sky News and Reuters. A couple of people noted that they don't trust any of the sources either at all or without rigorous fact-checking or cross-referencing with other sources, and a few others made the point that they trust WHO over the government.

## 8. Key challenges and unmet needs shared by those who responded

One of our aims was to identify the challenges and unmet needs of individuals to date in order to propose new focus areas for future research or improvements to the guidance and support that the public receive. We asked whether people had any comments or concerns about a) current or proposed infection control measures, and b) anything else proposed or happening near you.

**Comments in relation to self-isolation:**

The majority of people who took part in our online initiative reported that they would be *willing* to self-isolate. Needing to be convinced that there were justified reasons and the perceived impact of self-isolating (e.g. the potential impact on those they care for or on their mental health) were the main reasons reported by those who said they may not or would not be willing to self-isolate.

| **Q2.4 Would you be <u>able</u> to self-isolate if asked to by a healthcare professional?** | **n (%)** |
|---|---|
| Yes | 243 (59.6) |
| Maybe | 100 (24.0) |
| No | 57 (13.7) |
| Don't know | 9 (2.2) |
| **Q2.5 Would you be <u>willing</u> to self-isolate if asked to by a healthcare professional?** | **n (%)** |
| Yes | 343 (83.1) |
| Maybe | 50 (12.1) |
| No | 16 (3.9) |
| Don't know | 4 (1.0) |

Perhaps unsurprisingly, there was far greater uncertainty about whether people would be *able* to self-isolate. Part of this seemed to be due to the lack of clarity at the time around what self-isolation would mean in practical terms. People were mostly concerned about how they would care for their dependents if they themselves became unwell, including elderly family/relatives, children and other vulnerable adults. There were also practical issues shared around accessing food and medical supplies. At the time, the guidance was only around 7-day self-isolation, where only the person who developed symptoms was to isolate, including away from other household members. This was perceived to be a challenge for people who lived with others.

For all data tables on reported impact and behaviour change, see **Appendix 6**.

**Comments in relation to other measures currently in place or proposed**

| **Q2.6 Do you have any comments or concerns about any infection control measures that are being proposed or have happened near you?** | **n (%)** |
|---|---|
| Yes | 194 (46.2) |
| No | 180 (42.9) |
| Don't know | 20 (4.8) |
| No response | 26 (6.2) |

Reports of school/university/nursery closures was the most discussed community response. Most were supportive of proposed closures, although they acknowledged the increased pressure this would put on working parents; teachers described concerns of teaching remotely. However, some did agree with the decision to keep schools open. Some University students described feeling anxious about inconsistent decisions across campuses regarding closures and exam changes.

A number of comments were made around hygiene practices, either reporting that some people weren't adhering to handwashing advice, raising concerns about hygiene practices in shops or

highlighting the lack of apparent steps being taken to clean and disinfect public areas, in particular trains and other public transport, as had been observed in other countries.

**Comments in relation to stockpiling**

People described the after-effects of stockpiling of hygiene products and observed inaction by either individuals or workplaces (although some described being provided products at work). A few believed that the government should be providing these products to the public. Others described individual changes in behaviour following government guidance to increase handwashing and use of hand sanitizers. Some described concerns of food and medical supply shortages and the need for rationing or control measures to be implemented once guidance and media coverage increased around self-isolation.

**Comments in relation to impact on personal finances**

Several described concerns regarding mortgage repayments, taxes, household bills and loss of income and suggested that the government helps to support people with this (i.e. if they suggest self-isolation this results in not being able to work).

## 9. Ideas for Community Support, Engagement and Involvement

It was important to capture ideas from members of the public about how they would like to be involved with those working on the UK's response to the outbreak. We asked all respondents about whether they would like to be more involved; if they answered 'yes', 'maybe', or 'don't know' they were then shown a list of additional ideas that other members of the public had proposed to us during a pilot exercise of the online form. Respondents were invited to select all that applied and/or add their own ideas in the 'Other' free text box provided.

| **Q3.1 Would you like to be more involved with those working on the UK's response to the outbreak?** | **n (%)** |
|---|---|
| Yes | 134 (31.9) |
| Maybe | 154 (36.7) |
| No | 101 (24.0) |
| Don't know | 27 (6.4) |
| No response | 4 (1.0) |

Over two-thirds (68.6%) of respondents said they either wanted to, or might want to, be more involved in outbreak response. When asked to select how they would want to be involved, the most selected responses were to: 1) "support local communities in responding to the outbreak" (n=156 votes), 2) "help decide what information is shared with the public and how it is communicated" and 3) "capture the concerns and unmet needs of under-represented/vulnerable communities and feed them into the planning" (n=120 votes). See **Appendix 7** for full graph of responses.

Of the 36 respondents that selected 'Other', all provided a further comment with the majority describing individual actions they could take to be involved including acting as NHS volunteers (i.e. at hospitals, with NHS 111 calls), donating blood or sharing their experience of self-isolation. However, one respondent raised concerns of sharing stories of more or less extreme cases that could result in

either panic or people "not taking the virus as seriously as they should." Some described a desire to use their own skills gained through education or work experience from a range of disciplines (including the social sciences, policy, public health and infectious diseases) to help support research and education on COVID-19.

Respondents also provided examples of how the establishment of neighbourhood or community groups could assist with supplying food and essential items to vulnerable groups; providing support; and also, potentially to campaign government for change. A suggestion was made to ask individuals to complete a 'voluntary skills audit' to identify what help and skills could be provided. Others described the need to ensure continuity of care for individuals living with long-term health conditions (e.g. cancer) and disabilities, through the provision of tailored information and support. Further issues raised were regarding waste disposal and ensuring pharmacies have adequate supplies.

Regarding information, respondents reemphasised the need for greater transparency of the government's decision-making. They also called for the government to listen to the concerns of individual's and scientists and share more detail on their efforts to support vulnerable groups (i.e. those on benefits). A few expressed concerns of using social media for involvement purposes, and the need for a 'trusted source', with references to concerns of data management by Facebook.

## Preliminary reflections

It is clear from this work that the public want to get involved and are prepared to contribute their time, skills and experience in order to support the outbreak response. This is further evidenced by the overwhelming response to the NHS volunteering programme that saw over half a million people sign-up to help, also by the thousands of former NHS workers who have come out of retirement to support their peers, and by the number of community support groups that have been established across the nation. Communities are mobilising and will continue to do so, with trust and comradeship being key components of these groups. However, lack of localised insight and guidance, and difficulties in coordinating efforts of this scale and at speed may be barriers that will need to be addressed to optimise these offers of support.

Due to the speed at which we had to create and share the online form, we were not able to create a targeted version for specific groups of interest although it was our intention to do this at a later stage. We therefore adopted a snowball approach whereby a link to online form was shared with known public contacts who were then invited to pass it onto others. We hoped this would help us reach those who are less often engaged by academic researchers. The approach seemed effective at reaching primarily a general public audience, which included teachers, nursery workers, charity workers, and people with specific health conditions. We received responses from every region of the UK, although there was some bias with just under half being from Greater London, most respondents were White and on average had a high education level. However, due to the high volume of responses we were receiving, we decided to close the form to new participants after 9 days in order to be able to analyse the responses. This likely cut our snowball approach short when it was about to reach more diverse members of society. Analysis of the responses has also been slowed somewhat, largely due to nursery/school closures and rapid research activity restricting the research team's time and availability.

Despite this, our online involvement initiative proved to be an effective way to capture deep, varied and meaningful insight into the feelings and experiences of people living in the UK, and abroad, early in the COVID-19 outbreak. We believe this was helped by providing a combination of free text and multiple-choice options, with the latter being based on responses put forward by members of the public during a pilot of the online form. This intended to balance the investment in time and energy needed by respondents to take part, with giving the respondents the freedom to share experiences, opinions and ideas in their own words. Further improvements could be made by consolidating and simplifying overlapping questions, providing a broader range of multiple-choice options (where possible), and offering more accessible versions and different languages. However, we feel the responses received highlight core concerns and unmet needs of a large proportion of society, particularly those that may be most impacted or affected by the outbreak, whether directly or indirectly. A number of aspects of this work, such as sources of information and reported behaviour change (see **Appendix 6**) also closely reflected our findings from the UK Population Survey (n=2,108), which we ran the week after, 17–18 March 2020 (preliminary report findings available here).

## Summary

The Patient Experience Research Centre launched an online community involvement initiative that aimed to rapidly capture the opinions, experiences, preferences and concerns of people in the UK during the early phase of the novel coronavirus (COVID-19) outbreak. By inviting members of the public to volunteer their views and experiences via an online feedback form, we have gained valuable insight across our three core objectives:

**1. Prioritise areas for COVID-19 research**

While vaccine development was considered the most urgent research priority for many respondents, almost all (95%) respondents thought social studies exploring the public's experiences, risk perceptions and behaviours during this outbreak was necessary and important. They described how such research could:

- Help improve the way the current outbreak response is planned and implemented;
- Improve the way information and guidance is provided to and understood by the public;
- Optimise the support provided to communities and vulnerable groups; and
- Improve future outbreak preparedness

Other recommended areas of research included:

- Understanding the role of the media in influencing how people react and respond;
- Furthering our basic understanding of the virus – how it spreads, who it affects the most and why, and whether people achieve and maintain immunity after being infected;
- Critiquing the UK's response to the pandemic against that of other countries; and
- Ensuring lessons can be learnt from this outbreak to better equip us for future outbreaks, and public health emergencies in general.

**2. Highlight key unmet needs amongst diverse communities**

Our online involvement initiative proved to be an effective way to capture deep and meaningful insight into how people were feeling and responding early in the COVID-19 outbreak. It was also successful at highlighting key concerns and unmet needs.

Some comments have now been superseded by the stricter control measures that are in place and community support and action is becoming more established. However, comments around testing and the preparedness of the NHS, safeguarding and maintaining support for vulnerable groups (e.g. elderly, homeless, victims of sexual/domestic violence, child abuse and neglect), the impact of control measures on society, and people's wellbeing and the economy remain key concerns.

Additionally, the two leading issues raised within this theme continue to be reported:

- Ineffective communication, including poor access to information or information overload; and
- Conflicting guidance and misinformation.

Respondents' described feelings of concern, confusion and, in some cases, panic as a result of these communication and information issues. Others shared their frustration that there was nowhere to post their questions or concerns, which was not limited to those considered to be most "at risk". This went alongside their need for more detailed and bespoke practical guidance about their risk and how best to prepare and protect themselves and their loved ones. Almost half (47%) wanted to hear about the latest research on the virus, and 45% wanted a dedicated internet portal where they could access the latest information, statistics and trusted guidance. Making information more accessible to different communities, including those who are not online and those who have English as a second language was also highlighted as a priority.

**3. Engage diverse communities to guide the COVID-19 outbreak response**

The respondents identified a wide range of groups who should be involved in socio-behavioural research looking to understand people's experiences, perceptions and responses to the COVID-19 outbreak. There was also support for more diverse representatives of society to be involved in shaping the public health narrative, the language and communication methods used, the infection control measures proposed and the support that is offered. Our online exercise has already helped inform a YouGov Population Survey that we ran between 17–18 March with 2,108 adults in the UK (preliminary report available here). That survey was important in building the case for greater restrictions and showed the need for more financial and social support for those who were being asked to self-isolate, for example. We are now building on this work to facilitate greater involvement of community members in COVID-19 research and responses to the outbreak.

## Conclusion

The initiative described here highlights the invaluable insights that can be gained from engaging with the public during this COVID-19 outbreak. Our online approach was unique in involving and mobilising communities remotely prior to the UK lockdown on 16 March 2020. Now that restrictions on travel and face-to-face contacts are impossible, such online approaches to involvement are building momentum, but our initiative has shown that much more is needed. Many respondents reported a lack of trust and transparency in the government's decision-making, which was paired with confusion around what was about to happen, what was planned and how they are meant to respond. Such

feedback reveals a need for greater dialogue between UK communities and the government, alongside more effective communication. Online forms and discussion forums offer one way this could be initiated to gain rapid public insight early on in an outbreak, providing accessible versions and alternative languages are also offered. The combination of multiple-choice and free text questions, as used in this exercise, allows for new voices, ideas and suggestions to be heard. And with more than 200 respondents consenting to be contacted, it can also help to build new connections with community members who wish to play a role in shaping ongoing research and engagement activity. However, to really influence a pandemic response, we believe trusted channels for rapid involvement need to already be in place in order to amplify the diversity, speed and impact of community input. This could mean:

- Rapid coordination of existing community or mutual aid groups; and/or
- Establishment of a new network of community champions and "explainers" who assemble during a public health emergency to both support the distribution of public health messaging and guidance, and act as a community spokesperson to capture their concerns and unmet needs in order to guide the ongoing response. This approach would also ensure the perspectives of people who cannot readily access or take part in online activities are captured.

There have already been calls for the views of patients and the public to be included in policy responses to COVID-19. We hope that by sharing the insights from this online initiative, more researchers and policy makers will respond to the concerns of UK citizens and establish wider public and community engagement going forward.
The priority for our ongoing research and community involvement activity is to:

- Engage and mobilise key community representatives (e.g. >70s, <25s, those living with long-term health conditions, pregnant women, people from ethnic minorities, those in insecure jobs, and a range of key workers including health workers) to guide and improve COVID-19 research: influence research priorities, study and innovation design and recruitment strategies, support data collection, analysis and interpretation, assist with sharing findings, and influence policy
- Continue to capture and identify key concerns and unmet needs within communities that can be fed back to those involved in planning and coordinating the current outbreak response
- Provide members of society with a range of ways to rapidly voice their experiences and concerns in order to elevate the human perspective on this outbreak

**We will continue to provide updates about our Community Involvement Initiative via the opportunity page on VOICE.**

**Appendix 1**

| Questions | Purpose | Outcome |
|---|---|---|
| 1.1 How people are feeling<br>1.2 How people have been affected<br>1.3 Extent that people have changed their behaviour<br>1.4 List of behaviours changed and why (triggers)<br>1.5 Perceived importance of research question and why<br>1.6 Other questions we should be asking<br>1.7 Suggested community groups<br>1.8 Any other comments or feedback | Understanding the relevance and acceptance of our research questions, plans and guiding the ongoing design, including the recruitment strategy | • Understanding people's attitudes, experiences and issues during the COVID-19 outbreak has helped to clarify what the biggest issues are that need exploring, which has helped to prioritise our research objectives around social inequalities and how people access and understand information<br>• We were originally intending to recruit four groups into our research: 1) Imperial students; 2) Young adults <25s; 3) Over 25s; and 4) Those at-risk. However, having gained greater insight into the different experiences of this outbreak, we're hoping to capture the perspectives of: >70s, <25s, pregnant women, those with long-term health conditions, people from ethnic minorities, those in insecure jobs and key workers (not just healthcare but also social care, police, supermarket workers, postman, delivery drivers), with a general view target those most impacted by the outbreak and those that were unable or unwilling to change.<br>• Interim analysis of the responses enabled us to rapidly improve the design of a UK Population Survey that we launched a week after this community involvement exercise ran<br>• This exercise has helped to test how people interpret and respond to broad questions with free open text responses. Although improvements could be made, some questions are no longer needed. However, it seems there is great value in capturing in-depth insight early in an outbreak, providing it can be rapidly analysed and shared too. |
| 2.1 Are people receiving enough information<br>2.2 What information or resources are missing?<br>2.3 Sources of news, information and guidance, including primary source and most trusted source(s)<br>2.4 Are people able to self-isolate?<br>2.5 Are people willing to self-isolate?<br>2.6 Comments or concerns about any infection control measures<br>2.7 Comments or concerns about how the government is responding<br>2.8 Key priorities of the public in outbreak response<br>2.9 Any other comments or feedback | Capturing preferences, priorities and unmet needs of the public to inform research plans, outbreak response and guide ongoing community engagement and involvement activity | |
| 3.1 Interest in being more involve in the response, and how<br>3.2 Any other comments or feedback | | |
| 4.1-4.11 Demographic and background questions about the respondent | Understanding the reach of our communication methods and providing context for the responses received | |

**Appendix 2: Demographic and background information of respondents (n=420)**

| Variable | n (%) |
|---|---|
| **Perspective from which the survey was completed** | |
| Member of public | 355 (73.0) |
| Healthcare professional | 36 (7.3) |
| Biomedical/Healthcare-based/Social researcher | 28 (5.6) |
| Student elsewhere in UK | 18 (3.6) |
| Community lead or Public engagement/involvement lead | 17 (3.4) |
| Staff at Imperial College London | 13 (2.6) |
| Student at Imperial College London | 9 (1.8) |
| Staff at Newcastle University | 1 (0.2) |
| Student at Newcastle University | 1 (0.2) |
| Prefer not to say | 4 (0.8) |
| No response | 4 (0.8) |
| **Currently living in the UK** | |
| Yes, I was born here | 322 (76.7) |
| Yes, I moved here from abroad | 74 (17.6) |
| No | 15 (3.6) |
| Prefer not to say | 3 (0.7) |
| No response | 6 (1.4) |
| **UK region of residence** | |
| Greater London | 172 (43.4) |
| South East England | 59 (14.9) |
| North West England | 30 (7.6) |
| East of England | 24 (6.1) |
| Yorkshire and the Humber | 23 (5.8) |
| East Midlands | 18 (4.6) |
| South West England | 16 (4.0) |
| West Midlands | 15 (3.8) |
| North East England | 14 (3.5) |
| Scotland | 13 (3.3) |
| Wales | 9 (2.3) |
| Northern Ireland | 2 (0.5) |
| Prefer not to say | 1 (0.3) |
| No response | 0 (0.0) |
| **Live or work in a city** | |
| Yes | 289 (68.3) |
| No | 105 (24.8) |
| Other | 17 (4.0) |
| Prefer not to say | 3 (0.7) |
| No response | 9 (2.1) |
| **Ethic group** | |
| White (English/Welsh/Scottish/Northern Irish/British; Irish; Gypsy or Irish Traveller; Any other) | 365 (88.4) |
| Asian/Asian British (Indian; Pakistani; Bangladeshi; Chinese; Any other) | 16 (3.9) |
| Mixed/Multiple ethnic groups (White and Black Caribbean; White and Black African; White and Asian; Any other) | 8 (1.9) |
| Black/African/Caribbean/Black British (African; Caribbean; Any other) | 6 (1.5) |
| Other ethnic group | 6 (1.5) |
| Prefer not to say | 12 (2.9) |
| No response | 7 (1.7) |

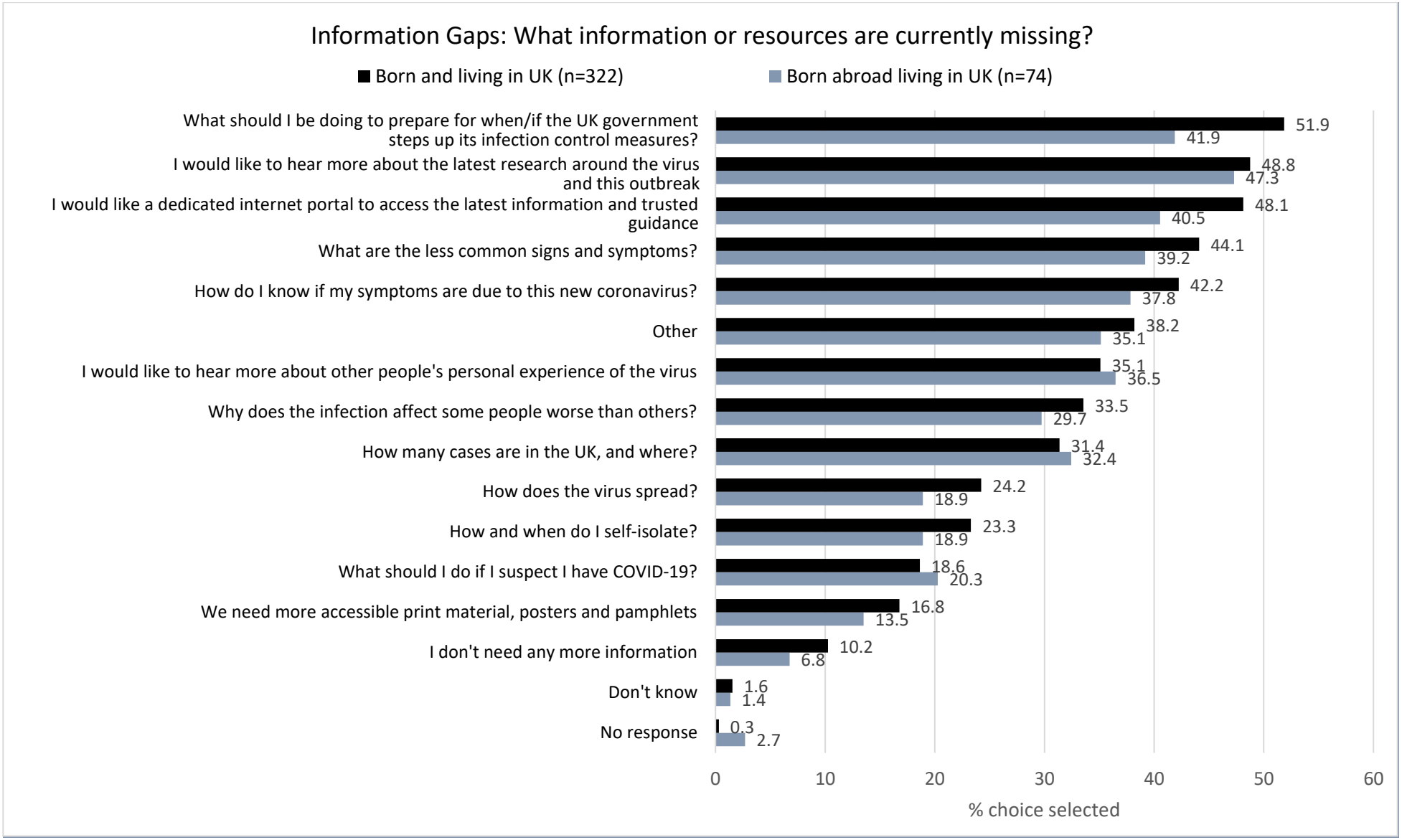
| | |
|---|---|
| **Gender** | |
| Female | 255 (61.5) |
| Male | 148 (35.7) |
| Transgender female | 2 (0.5) |
| Gender variant/non-conforming | 4 (1.0) |
| Prefer not to say | 6 (1.5) |
| No response | 5 (1.2) |
| **Age** | |
| Under 18 | 1 (0.2) |
| 18-24 | 18 (4.3) |
| 25-34 | 61 (14.7) |
| 35-44 | 65 (15.6) |
| 45-54 | 93 (22.4) |
| 55-64 | 96 (23.1) |
| 65-74 | 61 (14.7) |
| 75-84 | 13 (3.1) |
| 85+ | 1 (0.2) |
| Prefer not to say | 7 (1.7) |
| No response | 4 (1.0) |
| **Qualifications** | |
| AS and A levels/ Scottish Highers and Advanced Highers or equivalent | 27 (6.5) |
| GCSEs/National 5s/Scottish Standard Grade or equivalent | 9 (2.2) |
| Professional degree beyond bachelor's degree | 49 (11.8) |
| Doctorate degree | 62 (14.9) |
| Master's degree | 108 (26.0) |
| Bachelor's degree | 112 (26.9) |
| Foundation degree | 11 (2.6) |
| Higher National Certificate/Higher National Diploma or equivalent | 16 (3.9) |
| Other | 15 (3.6) |
| No formal qualifications | 1 (0.2) |
| Prefer not to say | 6 (1.4) |
| No response | 4 (1.0) |
| **Health condition** | |
| Yes | 138 (33.3) |
| No | 272 (65.7) |
| Prefer not to say | 4 (1.0) |
| No response | 6 (1.4) |
| **Caring responsibilities** | |
| Yes | 142 (34.2) |
| No | 270 (65.1) |
| Prefer not to say | 3 (0.7) |
| No response | 5 (1.2) |

**Appendix 3: Suggested community groups to reach, engage and involve**

| | **Frequency** |
|---|---|
| **At-risk groups** | **141** |
| Elderly + Over 70s | 91 |
| People with underlying health conditions | 49 |
| Pregnant women | 1 |
| **Other vulnerable groups** | **75** |
| People with a hearing, visual or physical disability (inc. mobility issues) | 25 |
| People who face homelessness | 17 |
| People with mental health conditions or those who experience mental or emotional distress | 6 |
| Elderly or disabled who live alone | 6 |
| People on benefits | 6 |
| Prisoners | 5 |
| Patients in hospital or due for medical care | 5 |
| People with learning or communication difficulties | 3 |
| People who live in a care home | 2 |
| **Different age groups** | **174** |
| Elderly + Over 70s | 91 |
| Young adults: 20-35s | 29 |
| Teenagers: 13-19 | 23 |
| Retirees + Over 60s | 17 |
| Children: <13 | 14 |
| **Different communities** | **118** |
| Ethnic minorities + marginalised communities (including migrants and those who do not speak English or have low-level English) | 32 |
| Rural communities and people who are isolated people | 13 |
| Anyone likely to experience racism and-or discrimination | 11 |
| All communities | 10 |
| People who are not online or on social media | 10 |
| Religious groups and communities | 9 |
| Parents | 8 |
| Those living away from home: English as second language / countries affected by outbreak | 8 |
| Local authorities, community centres/groups | 4 |
| Different geographical locations across UK | 3 |
| Political parties | 3 |
| People living in over-crowded housing and urban communities | 2 |
| Online communities | 2 |
| Other groups, suggested once: Private renters, People with low levels of education, LGBT communities | 3 |
| **Different work sectors/employment status** | **111** |
| Healthcare workers (inc. doctors, nurses, GPs, support staff, dentists, pharmacists) | 32 |
| Care homes and carers | 16 |
| Gig economy workers | 12 |

| | |
|---|---|
| Low-income groups | 11 |
| Teachers, educators, childcare directors | 9 |
| Employers, Unions and Business Leaders | 8 |
| Self-employed | 5 |
| Charities and Voluntary sector groups | 4 |
| Researcher scientists and academics | 2 |
| Social care services and staff | 2 |
| Media | 2 |
| Other groups, suggested once: Charities working with at-risk groups, Health bloggers + influencers, other front-line key workers (e.g. working supermarkets, delivery people), international students | 4 |
| **Different behaviours** | **24** |
| People who panic buy | 6 |
| People who under-estimate the risk to themselves and or to others (including those claiming "it's only flu") | 6 |
| People who do not access public information + support | 4 |
| Medicine and science sceptics - anti-vax | 2 |
| People who are unable to follow or do not engage with PHE guidance | 2 |
| People who need to be told to wash their hands anyway | 2 |
| Good will groups and communities | 1 |
| **Different genders** | **4** |
| Men, especially over 40s | 3 |
| Women | 1 |
| **Those with COVID-19 and those who have recovered** | **1** |
| **Different countries** | **1** |

**Appendix 4: Quantitative analysis of reported information gaps**



**Appendix 5: Thematic analysis of other reported information and resources that people need**

**BESPOKE PRACTICAL GUIDANCE i.e. What should I be doing to prepare and stay safe?**

- Information for at-risk groups, relatives and carers
    - Information for people on immuno-suppressants or those who are immunocompromised
    - Information for asthma sufferers
    - Information for people with cancer
    - Information for people with rare diseases
    - Guidance issued for the elderly living at home
    - How best to care for others – elderly, dependents, other vulnerable groups
    - Who to go to for help with my vulnerable relatives if I can't help?
- General measures to stay safe and reduce risk
    - Safer ways to get food supplies etc
    - How to travel safely (do's and don'ts) and places to avoid
    - Household guidance e.g. washing clothing, bedding, cleaning
- More guidance on infection control measures:
    - Should I be using a face mask?
    - Social distancing: how close can you get to someone?
    - Self-isolation and household isolation: what does it mean to 'cocoon away'?
    - How and when do I self-isolate?
    - What should I do if I suspect I have COVID-19?
    - How to reduce risk of infection from people who are infected but not showing symptoms
- Self-care advice: how to manage COVID-19 symptoms at home
- When to seek medical advice and how
- Disinfecting surfaces
    - Should we disinfect surfaces or our phones?
    - Disinfection measures to take at home to protect vulnerable people within the household
    - The best way to disinfect surfaces (i.e. kill the virus) – fire, boiling water, bleach, Dettol, do any of these work?
- Financial advice
- How and when to get tested
- How to maintain health and well-being during the outbreak
- What to do (and where to go) if I need medical treatment/care for something else unrelated to COVID-19?

**ABOUT COVID-19 i.e. I would like to hear more about the research explaining what we know about the virus and this outbreak**

- Personal experience: signs and symptoms
    - I would like to hear more about other people's personal experience of the virus – first-hand narratives
    - How do I know if my symptoms are due to this new coronavirus?
    - What are the different experiences? Does it start with a cough? What does the cough

sound like?
    - What are the less common signs and symptoms?
- Personal risk and outcomes
    - Why does the infection affect some people worse than others?
    - Exactly who is at risk?
    - What 'underlying conditions' are the most significant?
    - What qualifies as a pre-existing condition?
    - How would I know whether I'd survive at home or need extra care?
    - Why doesn't it affect kids?
    - Why are some medical personnel dying from the virus?
    - Are there any long-terms consequences of contracting the virus, e.g. can it remain dormant in the lungs, cause long-term ill effects etc?
- Statistics
    - How many cases are in the UK, and where?
    - How many have recovered?
    - What is the current cure rate?
    - Info on the pre-existing conditions of people who have suffered most so far
- Transmission and immunity
    - How does the virus spread?
    - Can it be spread by people who do not have any symptoms?
    - How long on average does the virus survive on surfaces?
    - Can people be re-infected?
    - Is herd immunity actually possible?

**MORE EFFECTIVE COMMUNICATION i.e. I would like to access accurate, clear and consistent information that I can understand and follow**

- Ensure everyone can access the information and guidance
    - Available in all languages
    - Appropriate for visually impaired, the elderly and those with learning difficulties
    - Available to those who are not online (posters, pamphlets, direct post)
    - Increased community awareness (in GPs, in religious centres)
    - Use technology to link communities
    - Targeted messaging to specific groups (e.g. young adults)
- Ensure the information is clear, consistent, concise and understandable
    - One dedicated hotline and site (e.g. UK version of CDC
    - Don't use jargon and don't assume people understand the terms used, e.g. self-isolation, social distancing, epidemic
    - Be more precise with the details
    - Provide clear visual timelines of what's happening, planned and expected
    - Launch consistent public heath campaigns across all communication channels
    - Reduce the number of different voices speaking
- Ensure information is trusted, transparent, up to date, balanced and evidence-based
    - Provide reassurance and transparency and what is planned and why
    - Deliver balanced information that is based on scientific facts
    - Give regular updates delivered by independent scientific experts, not politicians
    - Be clear about what we don't know
    - Demonstrate international and national cooperation
- Involve the public in shaping the narrative

  - There needs to be greater dialogue between citizens and government
  - The public need somewhere where concerns can be voiced and addressed
  - There's demand for more public engagement (e.g. more surveys, on the street)
  - Calls for more positive news in the media (numbers recovered, research findings)
  - Some believe highlighting the risk to the elderly is the wrong message to share

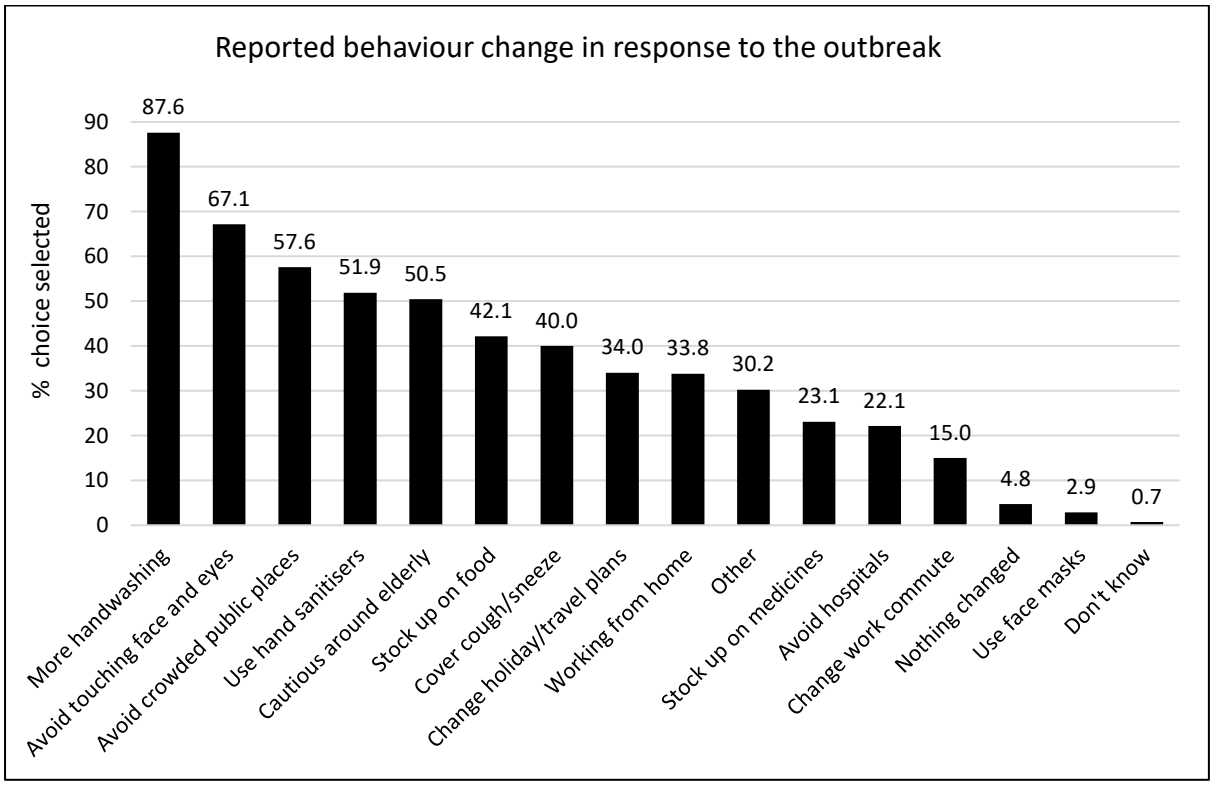
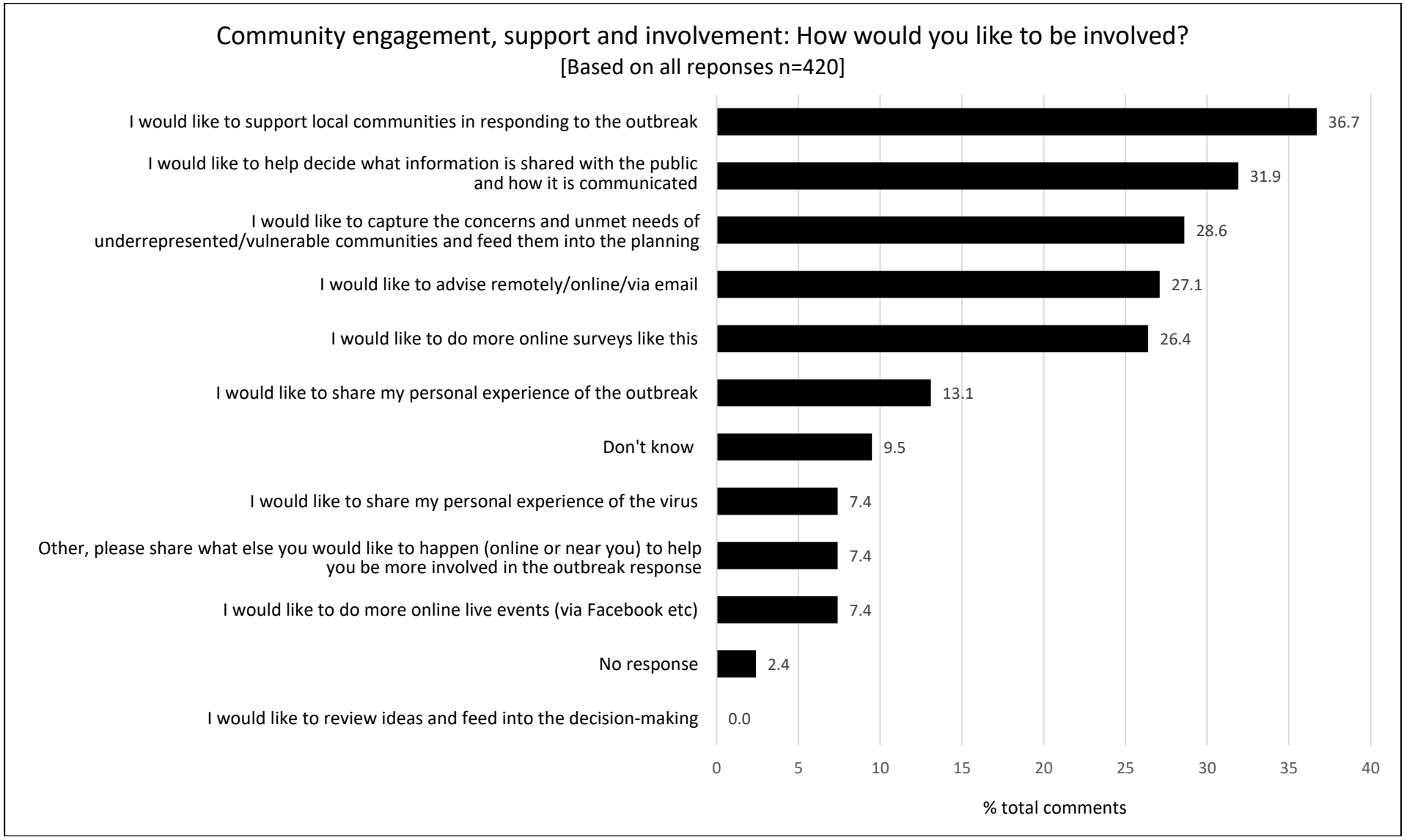
**ABOUT THE UK RESPONSE i.e. I want to understand the what, why, how and when of the UK's response**

- Data and rationale behind the UK's plans
  - The research info & models used by the government to plan the response
  - More of the data and logic behind the current government strategy
  - Why has the government decided to stop testing?
  - How the UK's response compares to other countries' response and experience
  - What is actually happening? And what is about to happen?
  - When will the measures be lifted?
- Greater access to testing and clear reasoning why it was stopped
- How the UK is preparing the NHS, and how to help
  - How is the NHS going to get the resources it will need?
  - How can I support my local community and/or NHS over the coming weeks?

**Appendix 6: Data tables of responses to selected questions (n=420)**

| Variable | n (%) |
|---|---|
| **Q1.2 Reported ways that people had been affected by COVID-19** | |
| Potential exposure to the virus | 164 (39.1) |
| Not affected | 128 (30.5) |
| Self-isolation | 84 (20) |
| Reduced access to healthcare | 64 (15.2) |
| Feelings of worry/anxiety | 29 (6.9) |
| Work/employment | 26 (6.2) |
| Stigma | 22 (5.2) |
| Nursery/School closures | 19 (4.5) |
| Racism or discrimination | 15 (3.6) |
| Social distancing | 13 (3.1) |
| Unable to buy essential household items | 10 (2.4) |
| Cancellation of travel or social events | 8 (1.9) |
| No response | 5 (1.2) |
| **Q1.3 Extent to which behaviour had changed in response to COVID-19** | |
| A great deal | 116 (27.6) |
| Somewhat | 17 (4.1) |
| Very little | 210 (50.0) |
| Not at all | 72 (17.1) |
| Don't know | 5 (1.2) |
| No response | 5 (1.2) |
| **Q1.4 Behaviour change in response to COVID-19 specifically** | |
| More frequent handwashing | 368 (87.6) |
| Avoiding touching face and eyes with unclean hands | 282 (67.1) |
| Avoiding crowded public places | 246 (58.6) |
| Use of hand sanitisers | 221 (52.6) |
| Being more cautious around the elderly | 213 (50.7) |
| Sneezing or coughing into my elbow | 168 (40.0) |
| Stocking up on food supplies | 157 (37.4) |
| Changed holiday or overseas travel plan | 147 (35.0) |
| Working from home more | 142 (33.8) |
| Stocking up on medication | 22 (5.2) |
| Avoiding hospitals and healthcare settings | 93 (22.1) |
| I am not currently doing anything different | 93 (22.1) |
| Changed how I travel to work | 63 (15.0) |
| Avoiding non-essential contact with others | 42 (10.0) |
| Use of face masks | 17 (4.1) |
| More frequent cleaning of surfaces | 8 (1.9) |
| Avoiding public transport | 8 (1.9) |
| Don't know | 3 (0.7) |
| No response | 4 (1.0) |
| **Q2.1 Enough information about how to respond to the outbreak** | |
| Yes | 187 (44.5) |
| No | 197 (46.9) |
| Don't know | 32 (7.6) |
| No response | 4 (1.0) |
| **Q2.4 Able to self-isolate** | |
| Yes | 251 (60.2) |
| Maybe | 100 (24.0) |
| No | 57 (13.7) |

| | |
|---|---|
| Don't know | 9 (2.2) |
| No response | 3 (0.7) |
| **Q2.5 Willing to self-isolate** | |
| Yes | 343 (83.1) |
| Maybe | 50 (12.1) |
| No | 16 (3.9) |
| Don't know | 4 (1.0) |
| No response | 7 (1.7) |
| **Q2.6 Comments or concerns about proposed infection control measures** | |
| Yes | 194 (46.2) |
| No | 180 (42.9) |
| Don't know | 20 (4.8) |
| No response | 26 (6.2) |
| **Q2.7 Comments or concerns about how the government will respond if transmission of the virus becomes more established in the UK** | |
| Yes | 258 (61.4) |
| No | 109 26.0) |
| Don't know | 39 (9.3) |
| No response | 14 3.3) |
| **Q3.1 Would like to be more involved with those working on the UK's response to the outbreak** | |
| Yes | 134 (31.9) |
| Maybe | 154 (36.7) |
| No | 101 (24.0) |
| Don't know | 27 (6.4) |
| No response | 4 (1.0) |



**Appendix 7: Quantitative analysis of ideas for community support, engagement and involvement**