

Information and Communication Gaps in the UK [March 2020]

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

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Background

The Patient Experience Research Centre (PERC) at Imperial College London are developing research to explore and understand people's views about, experiences of and behavioural responses to the new 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 sought rapid, early insight from members of the public and aimed to establish a network for ongoing community engagement.

Between 6 and 15 March 2020, we distributed an online feedback form, hosted on Qualtrics, to existing public partners who support our research at Imperial and the wider general public via email, WhatsApp, social media (Twitter) and via VOICE-global. The online form comprised three main sections that aimed to 1) guide our research priorities and design; 2) capture the public's priorities, preferences and unmet needs, and 3) shape our ongoing community engagement and involvement activities, by exploring people's experiences of the outbreak and opinions on research. Questions were piloted and adapted following discussions and input from 7 members of the public known to the research team prior to distribution.

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 smaller numbers of health care professionals, researchers and students. Respondents included a range of ages and backgrounds; one third reported living with a current or long-term health condition or disability; one third had caring responsibilities.

This extract report highlights some of the key information gaps raised by respondents between 6–15 March and shares their suggestions on what good communication should look like. While some points have been superseded by more recent measures and content, many still remain relevant.

Full and summary reports available here: <https://www.imperial.ac.uk/mrc-global-infectious-disease-analysis/covid-19/report-14-online-community-involvement/>

Summary of insight highlighting communication and information gaps

The leading issues raised by respondents were:

- Ineffective communication, including poor access to information and information overload;
- Conflicting guidance and misinformation;
- Lack of detailed bespoke practical guidance; and
- Lack of trust and transparency in the UK government's decision-making.

Respondents' described feelings of concern, confusion and, in some cases, panic as a result of these communication and information challenges. Others shared their frustration that there was nowhere to post their concerns or questions, which was not limited to those considered to be most "at risk". Respondents wanted 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 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. 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.

Further detail of responses can be found in the sections below.

KEY UNANSWERED QUESTIONS

- Should we be wearing face masks?
- Exactly how is COVID-19 spread?
- Who is actually at risk? Why does it affect some people worse than others?
- Why doesn't it affect kids?
- Why are some medical personnel dying from the virus?
- Is herd immunity possible here, on what evidence?
- Are there any long-term consequences of contracting the virus, e.g. can it remain dormant in the lungs, cause long-term ill effects etc?
- What qualifies as a pre-existing condition - especially info on the pre-existing conditions of people who have suffered most so far?

SUMMARISED PERSPECTIVES RELATING TO EFFECTIVE COMMUNICATION

i.e. how to develop and deliver accurate, clear and consistent information that I can access, understand and follow

- Ensure everyone can access the information and guidance
 - Available in multiple languages and/or use of visuals to improve universal access
 - Appropriate for visually impaired 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 health 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 is demand for more public engagement (e.g. more surveys, 'on the street' when possible)
 - 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

SUMMARISED INFORMATION GAPS:

1. ABOUT COVID-19

i.e. I would like to hear more about the latest research around 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-term 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?

2. 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? How to plan and prepare for self-isolation?
 - 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?
 - I would like to know more about disinfection measures I can take at home so that a vulnerable person I am living with is less likely to get infected.
 - What's 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?

3. ABOUT THE UK'S RESPONSE

i.e. what, why, how and when of 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 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?
 - Conflicting guidance: I don't know if it's the right stuff, so I don't know if I should go further or follow it to the letter
- 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?