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

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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 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'[1] (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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[1]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 2020, we distributed an online feedback form, hosted on Qualtrics, to existing public partners who support our research at Imperial (see Imperial Patient Experience Research Centre) and the wider general public via email, WhatsApp, social media (Twitter) and through VOICE-global, an online platform for public involvement in research established by Newcastle University. 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.

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 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.

We have summarised responses into three main areas: priority areas for research, unmet needs of communities, and recommendations for involving a diverse range of communities in the outbreak response, including who should be reached and engaged. More details are provided in the full report.

Priority areas for COVID-19 research

While vaccine development was considered the most urgent research priority for many respondents, almost all (95%) also agreed that 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.

Key unmet needs amongst communities

The leading issues under this theme were:

- Ineffective communication, including access to information and 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 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". 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 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.

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.

Conclusions

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 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.

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