

# Centering communities in pandemic preparedness and response

Background paper 10 The Independent Panel for Pandemic Preparedness and Response

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### 1. Summary

The COVID-19 pandemic has once again emphasized the importance of community engagement in tackling disease outbreaks. There is ample evidence that community engagement is vital for containing epidemics as the recent Ebola outbreak showcased. Inadequate community engagement can lead to fear, mistrust, and a lack of compliance to public health measures by communities. As the pandemic progressed, governments began prioritizing risk communication and community engagement (RCCE) efforts as part of their pandemic response. In April 2020, only about 36% of countries reported having a community engagement plan and by October 2020,<sup>1</sup> 90% of countries reported having a national RCCE plan.<sup>2</sup>

Community involvement during the COVID-19 pandemic ranged from passive actions to active engagement, either under government directives or voluntarily. Overall, communities played a critical role in supporting the clinical response to the pandemic, particularly through helping in surveillance, testing, and contact tracing efforts. Communities also took on the responsibilities of developing and distributing essential medical equipment such as masks. Communities supported members in need and linked people to services that address the larger societal aspects of pandemic management. These efforts were especially important and impactful when governments did not provide basic services. Challenges to community engagement during the COVID-19 pandemic included the lack of sustainable government commitment and top-down approaches to community engagement, limitations in engaging marginalized groups and youth, and balancing efforts to contain the virus with human rights.

There are four lessons for future preparedness and response efforts that came out of this analysis:

- 1. Communities need to be central in pandemic preparedness and response. The pandemic has made it clear that communities can play a critical role in tackling pandemics especially if they are empowered. For the best results, communities and civil societies should be partners early on in the design, planning, implementation, and assessment of such efforts on the international, national, and local levels.
- 2. Community engagement is not a one-time effort. To be successful, community engagement efforts should be ongoing prior to, during, and after pandemics. This requires clear structures and sustained funding for community engagement at all times not just during pandemics. Sustained community engagement efforts make communities more likely to trust governments in times of vulnerability and uncertainty such as during the COVID-19 pandemic. Earning and maintaining trust is a long-term project that does not begin during pandemics.
- **3.** Risk communication is necessary but not sufficient for successful community engagement. Effective risk communication and providing communities with actionable, timely, and credible information online and offline is essential to maintaining the trust of communities and engaging them. However, risk communication alone is not enough for community engagement. There is a need to establish bi-directional communication channels with communities to understand their concerns and incorporate their feedback.
- 4. Embracing a community resilience approach is needed to tackle future pandemics. COVID-19 has shown that there are structural inequities in access to resources, pre-existing health and economic investment. Community resilience refers to the ability of a community to both mitigate adverse effects and recover from a disaster. Adopting a community resilience approach has been helpful for

addressing large disruptions, e.g., natural disasters, affecting societies. COVID-19 now provides a clear case for aiming to adopt such an approach for addressing disease outbreaks.

### 2. Introduction

Communities are defined by a common set of social relationships that formulate a shared identity amongst members of a community. There is no specific checklist for what defines a community, and communities may or may not be identified by shared geographic space such as a village or an urban neighborhood, in contrast to an ethnic group that may not have a specific geographic boundary.<sup>3,4</sup> Oxford Dictionary of Public Health defines communities as

"A group of people; e.g., a neighborhood, village, or municipal or rural region or a social group with a unifying common interest or trait, loosely organized into a recognizable unit; a vague but useful term. There is often a sense of belonging, mutual self-interest, and perhaps activism that may lead to collective community action on issues and problems of concern. Elected or otherwise identifiable community leader(s) may represent, advocate on behalf of, and decide issues of importance to the community when it interacts with other groups or persons."<sup>4</sup>

The term community engagement is often used to describe the "process of developing relationships that enable people of a community and organizations to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes".<sup>5</sup> There is ample evidence that community engagement is vital for containing disease outbreaks as the recent Ebola outbreak showcased. Inadequate community engagement in designing, planning, and implementing interventions can lead to fear, mistrust, and lack of compliance to public health measures by communities.

This paper reviews existing evidence on community engagement in the context of disease outbreaks, examples of community engagement during the COVID-19 pandemic, successes and challenges of these efforts, and the lessons learned to strengthen community resilience during future outbreaks.

### 2.1 Methods

This analysis utilizes a multi-methods approach. Resources that contributed to this paper included deskbased literature reviews, specialist interviews, case studies, expert roundtables, and panel members discussions.

Desk-based reviews were conducted to capture historical examples of community engagement activities during disease outbreaks. These were then used to examine and categorize community engagement examples during the COVID-19 pandemic. Semi-structured interviews, based on the seven overarching questions were carried out with more than 25 individuals from a wide range of institutions, including members of the WHO secretariat, UN and other international organizations, journalists, social media platforms, scientific institutions, and non-governmental organizations. Interview guides were used for all interviews.

Two roundtable discussions also provided more examples highlighting the impact and challenges of community engagement during the COVID-19 pandemic and provide potential recommendations for the Panel to consider. These discussions helped strengthen the recommendation section of this paper.

# 3. Themes from successful COVID-19 community engagement

The COVID-19 pandemic has once again emphasized the importance of community engagement in tackling disease outbreaks. In fact, as the COVID-19 pandemic progressed, governments began prioritizing risk communication and community engagement (RCCE) efforts as part of their pandemic response. In April 2020, only about 36% of countries reported having a community engagement plan and by October 2020,<sup>1</sup> 90% of countries reported having a national RCCE plan.<sup>2</sup> Furthermore, the pandemic showcased that countries increasingly understand the importance of shifting from solely focusing on providing information to communities to establishing two-way communications and accountability systems to allow for stronger community engagement at the country level. Among the 64 countries the World Health Organization (WHO) considered a priority, 81.2% reported establishing a feedback mechanism to allow for stronger engagement with communities.<sup>2</sup>

Community involvement during the COVID-19 ranged from passive actions to active engagement, either under government directives or voluntarily. Overall, communities played a critical role in supporting the clinical response to the pandemic, particularly through helping in surveillance, testing, and contact tracing efforts. Communities also took on the responsibilities of developing and distributing essential medical equipment such as masks. Communities supported members in need and linked people to services that address the larger societal aspects of pandemic management. These efforts were especially useful when governments did not provide basic services. This section highlights the emerging themes from successful community engagement efforts during the pandemic. A more extensive list of examples of community engagement efforts during the found in Annex 1.

### 3. 1 Building on prior experiences and existing structures

During the COVID-19 pandemic, many successful community engagement efforts expanded on existing structures that aimed to tackle prior outbreaks. In Africa in particular, existing community engagement efforts that were used to address prior outbreaks were used by governments to mobilize community engagement during COVID-19, including the government of Liberia mobilizing community engagement channels utilized during the Ebola outbreak in their COVID-19 response strategy.

**Example**: To tackle the COVID-19 pandemic in northwest Syria, local health authorities adopted a system established to reach all households in the region for vaccination following a polio outbreak in 2013. The system links a task force in Turkey that worked with diaspora medial networks, a central field coordination mechanism in Idlib, with a wide network of volunteers. Because of the lack of capacity, the initiative focused on preventive measures. Volunteers raised awareness about COVID-19, worked on hygiene and disinfection campaigns, and referred community members to medical care when needed. The network used social media platforms (Facebook and WhatsApp) to deliver context appropriate and up to date information from diaspora medical professionals to volunteers and to train health workers.<sup>6</sup>

**Example**: In Nigeria, the "community informer model", which was a key pillar in polio eradication programs, was utilized for COVID-19 surveillance leveraging the vast network of trusted informers conducting house-to-house surveillance and sensitizing and supporting contact tracing in the communities.

### 3.2 Invoking civic mindedness

Disease outbreaks and pandemics can trigger fear, a sense of helplessness, and panic, which can lead to actions of self-preservation, such as the "panic-buying" that happened in many parts of the world when COVID-19 containment measures were first announced. People may also exhibit optimism bias as they believe they are at less risk of being affected by an infection compared to other members of their communities e.g., refusing to wear masks. Such actions driven by self-interest can undermine the measures implemented to contain the pandemic. On the other hand, a culture of civic mindedness invokes a sense of responsibility towards the community. In such cultures, individuals and collectives feel empowered to do the right thing and strive, through good behavior, to achieve more public good with the ultimate goal of societal betterment.<sup>7</sup> In places such as in Japan, Taiwan, and China civic mindedness was promoted—as well as social norms that show signs of consideration of others such as wearing masks when one is unwell—well prior to the COVID-19 pandemic. The culture that everyone has a role to play led to high levels of voluntary compliance with government guidelines to contain COVID-19 without the need for much law enforcement\_in these countries.<sup>7</sup>

**Example**: The government of Vietnam adopted a strategy that evoked patriotism and bravery for compliance with recommended measures to tackle COVID-19 and urged for solidarity, with messages such as "stay home is to love your country", "staying at home is patriotic", and "the virus is your enemy". The government also commissioned artists to produce public service announcements in the form of songs and videos with similar messages. This strategy capitalized on a cultural belief of national unity against 'foreign invaders' and resulted in higher trust among the citizens. According to an independent survey, 94% of the Vietnamese citizens trust their government's COVID response.<sup>8</sup>

### 3.3 Engaging community health workers (CHWs)

The utilization of CHWs as part of healthcare systems has increased over the past few decades, particularly in resource-limited settings. CHWs continued to prove useful during the COVID-19 pandemic in countries of all income levels. Because they are often known members of the community, CHWs can contribute to the prevention, detection, and response to disease outbreaks through acting as trusted educators and mobilizers, contributing to surveillance systems, and filling the gaps in the provision of health services. CHWs can also contribute to social protection efforts to address the social and economic impact of an outbreak, especially due to their knowledge of their communities. India is one of the countries that has utilized CHWs well before the COVID-19 pandemic. Annex 3 expands on a case study of how CHWs were central to the COVID-19 response in Kerala state in India.

**Example**: During the first wave of the COVID-19 pandemic in New York City, CHWs connected people in need to food distribution sites and pantries, they also enrolled people in government programs that provide assistance for food, and organized food drivers and tables with community and faith-based organizations. CHWs provided other services such as connecting people to vocational training to help them access the government system for unemployment and housing benefits.<sup>9</sup>

### 3.4 Communities initiating preventive measures

There is a long history of successful community-led interventions to contain disease outbreaks and other threats. Communities often know what they need the most and when empowered with knowledge, training, and material, they can initiate interventions that support governmental efforts. Communities, especially marginalized communities, can also design their own interventions when there is limited support and guidance by governments.

**Example**: During the early days of the COVID-19 pandemic, Yemen suffered like many other countries to secure personal protective equipment (PPE). In April 2020, local government collaborated with the local women association and international agencies to train women in a rural district to produce masks and PPE. By May 2020, those who were trained produced over 1,500 and 500 masks and PPE, respectively.<sup>6</sup>

**Example**: When the number of cases surged in Arizona state in the United States between May and June 2020, several Native American tribes in the State—who were already vulnerable to COVID-19 and received limited support by the federal government—closed the borders of their reservations, instituted checkpoints for non-residents, and some tribes instituted shelter-in-place measures. Following these self-imposed measures, the number of COVID-19 cases in these tribes decreased by June 2020.<sup>6</sup>

**Example**: In Pakistan, volunteers came forward to set up COVID-19 quarantine wards, manufacture and provide free PPE for medics, and to distribute food to those in need.<sup>10</sup> This is particularly important because it is estimated that about 25% of Pakistanis cannot afford eating two meals per day. Pakistan is one of the few Muslim majority countries that mandates the traditional volunteer Muslim charity tax (Zakat). Zakat is based on the concept that the least fortunate are entitled to a share of everything owned by a community. As lockdown measures forced more people into hunger, communities in Pakistan also voluntarily increased their share towards Zakat to help to address hunger among the many that lost their earnings during COVID-19.<sup>11</sup>

### "I am answerable if any of my neighbours go to bed hungry. How can I have an overstocked pantry while one of my neighbours is in need?"

This is not surprising as a study prior to COVID-19 found that 98% of Pakistanis either give to charity or volunteer their time.<sup>12</sup>

### 3.5 Innovative use of technology and social media

The advancement in technology and ability for mass communication, particularly through social media, over the past few decade made the COVID-19 pandemic unique compared to prior outbreaks. Over the past year, creative (mainly social media-based) techniques were developed to facilitate COVID-19 response and to link people to services and resources. Social media also provided voice to people and connected communities within and across countries.

**Example**: District health authorities used "route maps" to trace and test contacts of COVID-19 cases.<sup>13</sup> Maps detailing places visited and modes of transport used by COVID-19 cases were prepared and released through social media including Facebook and WhatsApp. People were encouraged to share the route maps and to report to health authorities if they have been at the same place as the identified cases during the specified time. When this was initially rolled out in Kerala, one family that tested positive was found to have had contacts with over 300 people since arriving from Italy 4 days earlier. By tracking the exact locations of positive individuals, many people voluntarily came forward to get tested.<sup>14</sup>

**Example**: In the United States, a group of volunteers from GISCorps developed a mobile-friendly public Testing Site Locator application and visualization of geographical location of centers to facilitate testing center-related data collection and dissemination at the national level.<sup>15</sup> This helped the public to locate their nearest and available testing centers and the health system to plan and distribute the centers better.

### 3.6 Institutionalizing RCCE in country preparedness and response

The WHO, and other relevant organizations, advocate for risk communication and community engagement as integral components for preparedness and response to disease outbreaks and have continued to do so during the COVID-19 pandemic. Effective risk communication allows for feedback and cooperation channels to be established, trust to be fostered, and reaches the entire population. Communication efforts can keep communities informed about changing circumstances while also empowering community members to be part of the solution. Some countries that were particularly effective in implementing risk communication strategies during the initial COVID-19 outbreak were Thailand,<sup>16</sup> Vietnam,<sup>17</sup> and South Korea.<sup>18</sup> All of these countries prioritized both the communication of information to their populations, and clearly outlined methods through which community members can manage risks within their own communities through compliance with measures such as staying at home. In various contexts in Western Africa, communication channels for health information that were used during the Ebola outbreak were utilized for COVID-19 response, ensuring that relevant information could reach communities in local languages.<sup>19,20</sup> Lessons from the Ebola outbreak about the importance of communication channels were successfully applied in Kilimanjaro, Tanzania, where public announcements, mass health education, and radio shows disseminated information about the COVID-19 pandemic.<sup>21</sup>

**Example**: Thailand rolled out a 'stay home, stop the virus, for our nation' campaign urging people to refrain from stepping out of their homes and practice physical distancing at the beginning of the pandemic. Thailand had a well-designed risk communication plan including a) risk communication unit for public health emergencies; b) with clear command structure and clearly defined responsibilities; c) all hazards risk communication plan; and a focused budget. This ensured coordinated communication between national level and Thailand's 76 provinces. In addition, extensive network of Village Health Volunteers, who served as interface between health systems and population, engaged in dialogues with village community, which fostered trust and prevented panic.

**Example**: South Korea established a Korea Centre for Disease Control and Prevention which contains an Office of Communication that is mandated to "perform communication in the emergence of infectious diseases" drawing from the MERS outbreak management in 2015. Even before the first case was reported in South Korea, the office of communication began sending messages through multiple channels. The communication office also acted as a single focal point of communication of all technical and scientific information on COVID-19.

### 3.7 Utilizing existing trusted organizations

A rapid survey of 175 civil society organizations in 56 countries found that the majority of the COVID-19 response work done by these organizations was independent of their governments.<sup>1</sup> Grassroot organizations are often well organized, familiar with the needs and challenges of their communities, quick to reach those who are hardest to reach, and have the trust of their communities. During the COVID-19 pandemic, many local and community-based and grassroot organizations strove to both contain the virus and address the consequences of the pandemic.

**Example**: In many parts of India, community engagement helped support quarantined people. Women's self-help groups known as Kudumbasree with more than 4.3 million members helped run community kitchens throughout the state of Kerala in India. The group helped distribute food to people during the lockdown through a volunteer network called "Arogya Sena" (Health squad). Contact details of the Sena members were shared with all residents of the locality so that they can contact them if they are in need of food.

### 3.8 Mobilizing community leaders and influencers

Identifying the right actors is critical to the success of community engagement to tackle disease outbreaks. These actors can range from local leaders (e.g., chiefs and religious leaders) and activists, local health officials, local administrators, students, local media, and educators in the community. Importantly, mobilizing community leaders builds on the trust these leaders have in their community, which governments might not have. **Example**: Following the confirmation of the first COVID-19 case on March 20, 2020 in Abuja, Nigeria, the initial contact tracing strategy depended on passive case detection. Following the implementation of a lockdown on March 31, the government shifted to a community surveillance contact tracing approach. The approach relied on engaging community leaders to ensure they have the needed information and understand the strategy. Community leaders then worked with community members to attend COVID-19 testing. At the testing sites the government held daily meetings with community members to address their questions and concerns and community leaders helped manage the crowd, distribute masks and sanitizers, and enforce physical distancing. Community surveillance was a success and represented 42% of the collected samples and 49% of confirmed cases. Using this strategy improved COVID-19 detection and demonstrated that the area had intense community transmission of the virus.<sup>22</sup>

**Example**: The Moshi municipal authorities in Tanzania held meetings with market leaders to discuss infection control measures including physical distancing in marketplaces. Municipal workers went around the central market, collected trader recommendations and discussed implementation strategies in a participatory manner. This resulted in a positive approach by the market traders, and hand-washing mandate implementation was followed at all four gates of the central in the middle of town, with traders themselves reminding customers. The positive attitudes of traders towards handwashing and locally appropriate strategies, such as engagement of the market leaders, both official and unofficial, were essential to ensure compliance. This was particularly important as the political leadership in Tanzania did not implement any measures to tackle the pandemic.<sup>21</sup>

### 4. Challenges to community engagement during COVID-19

### 4.1 Level of government commitment to community engagement

Countries vary greatly in their efforts to incorporate community engagement in their pandemic preparedness efforts. The latest WHO joint external evaluation of the International Health Regulations (IHR) core capacities of a sample of member countries found that of the 5 indicators measures relating to Risk Communication and Community Engagement (RCCE) for disease outbreaks, indicator 5.4 ("community engagement with the effected communities") had the second lowest average score out of the 5 indicators relevant to RCCE. In fact, there was not a single country that scored a 5 in this indicator - suggesting that there is still a need for firmer advancement for centering community engagement interventions in preparedness efforts for to disease outbreaks.



# Figure 1: Joint External Evaluation (JEE) of International Health Regulations (IHR) Core Capacities Report Scores for Risk Communication and Community Engagement (RCCE) Indicators<sup>23</sup>

This is consistent with the lack of systematic efforts to sustain community engagement during "peacetime" and locating community engagement as part of risk communication efforts which, while critical to successful community engagement, limits communities' capacity to be informed. Such an approach in isolation does not allow communities to be empowered or to be active participants in pandemic preparedness and response.<sup>6</sup> Further, despite increasing political and operational commitment to community engagement, funding for community engagement is often limited, supporting ad hoc reactionary interventions rather than sustained action.<sup>24</sup>

### 4.2 Top-down approach to community engagement

Communities are often not consulted on primary discussions to design, plan, and implement interventions to tackle disease outbreaks. In an accompanying analysis by the Panel of the pandemic responses of 28 countries, the majority of countries did not have a formal community engagement plan that expanded beyond communication efforts to delivering messages to communities without concrete plans on how to directly engage communities. The COVID-19 pandemic is not unique in that regard. The pandemic highlighted that community engagement efforts are often framed as one directional effort by governments to inform communities rather than empowering communities to proactively engage and be part of the plan to contain the pandemic.

People are more likely to work towards common goals and engage with public health advice if they feel empowered and that they are part of a collective effort<sup>25</sup>— which is part of what makes community-based responses so effective. When empowered, communities can support and advocate for their needs on behalf of themselves, a function that is vital to successful emergency response.

### 4.3 Limitations in engaging marginalized groups

Community engagement efforts during pandemics would benefit from having clear focus on how to reach and engage with marginalized groups. Communities are not equal in their access to resources, and

the biggest casualties from the pandemic have been marginalized groups-raising clear concerns about the equity of responses to the pandemic in many countries. One of the more salient marginalized groups highlighted by mayors from different cities across the world are communities that are hard to define and reach (e.g., the homeless and undocumented immigrants).

Difficulty around defining communities creates challenges for efforts that aim to engage them. In Singapore, for example, the living conditions and needs of migrant workers were not adequately considered when the country was initially designing its COVID-19 response plans.<sup>26</sup> As such, despite the overall good performance of Singapore during the pandemic, cases and fatalities were high among this population group. Due to their closely-confined living arrangements in many cases, transmission was inevitable especially without guidelines that could be reasonably adhered to. In the United States, there were no systematic efforts to engage Africans Americans in vaccine trials, and only 3% of people enrolled in COVID-19 vaccine trials were African American although African Americans represent 13% of the United States population and account for 21% of deaths due to COVID-19.<sup>27</sup>

### 4.4 Balancing efforts to tackle the virus and human rights

International human rights law permits<sup>28</sup> restrictions on civil liberties, notably freedoms of movement, right to family and private life and freedoms of peaceful assembly and association, to protect public health so long as those restrictions are proportional, grounded in law, and applied in a non-arbitrary and non-discriminatory way. Without attention to these human rights limitations, public health responses can exceed<sup>29</sup> constraints under human rights law, with digital surveillance<sup>30</sup> and criminal law approaches to compliance raising particular human rights concerns. Further, increasingly authoritarian governments have exploited emergency laws to clamp down on civil liberties and attack political opponents during the COVID-19 pandemic.<sup>31</sup>

### 4.5 Limitations in addressing the unique impact on youth

While young people are less likely to be physically affected the virus, the COVID-19 pandemic has had a great impact on youth including interruptions in their education, employment opportunities, increasing domestic violence, and strain on mental health. For example, among Organisation for Economic Co-operation and Development (OECD) countries, the low-paying jobs that were most affected by the pandemic were mainly held by young people. About 35% of those aged 15-29 are employed in these jobs compared to 15% among middle aged employees.<sup>32</sup> Moreover, the long-term social and economic consequences of the pandemic will most likely disproportionally affect young people and potentially exacerbate intergenerational inequities. However, gaps remain in efforts to engage young people and address their issues.



Figure 2. Youth express greatest concerns about mental health, disposable income and employment impacts of the COVID-19 crisis. Source OECD<sup>32</sup>

# 5. Lessons learned for future pandemic preparedness and response

The COVID-19 pandemic has highlighted a number of areas to improve community involvement in pandemic preparedness and response. These lessons include:

- 1. Communities need to be central in pandemic preparedness and response. The pandemic has made it clear that communities, especially if empowered, can play a critical role in tackling pandemics. For the best results, communities and civil societies should be early partners in the design, planning, implementation, and assessment of such efforts on the international, national, and local levels.
- 2. Community engagement is not a one-time effort. To be successful, community engagement efforts should be ongoing prior to, during, and after pandemics. This requires clear structures and sustained funding for community engagement at all times and not just during pandemics. Sustained community engagement efforts make communities more likely to trust governments in times of vulnerability and uncertainty such as during the COVID-19 pandemic. Earning and maintaining trust is a long-term project that does not begin during pandemics.
- **3.** Risk communication is necessary but not sufficient for successful community engagement. Effective risk communication and providing communities with actionable, timely, and credible information online and offline is essential to maintaining the trust of communities and engaging them. However, risk communication alone is not enough for community engagement. There is a need to establish bi-directional communication with communities to understand their concerns and incorporate their feedback.
- 4. Embracing a community resilience approach is needed to tackle future pandemics. COVID-19 has shown that there are structural inequities in access to resources, pre-existing health and economic investment. These structural components need to be addressed in order for community engagement to actually result in some degree of post-emergency resilience. Without sustained investment in these communities, any form of engagement is likely to serve only as a band-aid rather than as a sustainable framework for future community empowerment and recovery. Adopting a community resilience approach has been helpful for addressing large disruptions, e.g., natural disasters, affecting societies. COVID-19 now provides a clear case for aiming to adopt such

an approach for addressing disease outbreaks. Community resilience refers to the ability of a community to both mitigate adverse effects and recover from a disaster. To build resilience, there is a need for:

- Effective risk communication through the ongoing provision of information on preparedness, risks, and relevant resources to the public before, during, and after an outbreak. This area is increasingly important in the age of social media and mass misinformation
- Fostering a culture of social connectedness and **investment in civic mindedness**. This occurs through the empowerment of individuals and communities to assume responsibility for preparedness and response, which will also requires promoting participatory decision-making in response and recovery efforts.
- Integration and involvement of communities in planning and leadership: through strong partnerships between governments and community-based entities to **co-design interventions** that address the specific needs of the local community
- Investment in social and economic well-being, and in physical and psychological health. Community resilience is strongly impacted by existing levels of social protections as well as access and utilizations of health services. The COVID-19 in particular highlighted the need to invest in population psychological health.

Embracing a community resilience approach to pandemic preparedness and response presents a paradigm shift from the traditional efforts that mainly focus on immediate actions during pandemics rather than investment prior to pandemics. Such approach can help address some of the challenges identified in community engagement efforts during the COVID-19 pandemic.

# Annex 1: Community engagement examples during the COVID-19 pandemic

Based on the key findings from the review of historic community engagement efforts to tackle disease outbreaks, this review examined examples and case studies of community engagement efforts during COVID-19. Overall, communities played a critical role in supporting the clinical and larger societal aspects of pandemic management, either directly or indirectly. This ranged from passive actions to active engagement, either under government directives or voluntarily. Based on prior community engagement efforts during disease outbreaks, paper uses the following areas to categorize different COVID-19 community engagement efforts: design and planning, trust building, behavior change, risk communication, surveillance, tracing and monitoring, administration, provision and logistics (figure 1). A brief narrative on these activities with some specific examples is given below.



Figure 1<sup>a</sup>

### **Design and planning**

There are a few examples of engaging communities in the response design and planning efforts during this pandemic. The Moshi municipal authorities in Tanzania held meetings with market leaders to discuss infection control measures including physical distancing in marketplaces. Municipal workers went around the central market, collected trader recommendations and discussed implementation strategies in a participatory manner.<sup>b</sup> This resulted in a positive approach by the market traders, and hand-washing mandate implementation was followed at all four gates of the central in the middle of town, with traders themselves reminding customers. The positive attitudes of traders towards handwashing and locally appropriate strategies, such as engagement of the market leaders, both official and unofficial, were essential to ensure compliance. This was particularly important as the political leadership in Tanzania did not implement any measures to tackle the pandemic.

<sup>&</sup>lt;sup>a</sup> https://gh.bmj.com/content/bmjgh/5/10/e003188.full.pdf

<sup>&</sup>lt;sup>b</sup> https://www.panafrican-med-journal.com/content/series/35/2/146/full

Design and planning efforts must be coupled with actions to successfully improve outcomes. An example of is the lack of proper implementation of the co-production of knowledge and recommendations by the Black, Asian and Minority Ethnic (BAME) Communities Advisory Group in the UK on the Social Care Sector COVID-19 Taskforce.<sup>c</sup> These recommendations highlighted the importance of placing BAME service users and carers at the centre of policy consultations and learning exchanges within the health and social care sector. BAME communities have had disproportionately worse outcomes during the COVID-19 pandemic.<sup>d</sup> While there have been several reports that directly point to the importance of engagement and co-production of knowledge with BAME community members and supporting community resilience,<sup>c,d</sup> government action on these recommendations has been marginal.<sup>e</sup> This is exemplified in BAME overrepresentation in COVID-19 intensive care units. Despite being 14% of the population, BAME constituted 35% of people in intensive care units in April 2020, by September 2020, the percentage decreased slightly to 33.9% despite the recommendations.

### Surveillance, tracing, and monitoring

Communities can support disease surveillance through reporting of suspected cases, voluntary disclosure of exposure, facilitating testing and screening of symptomatic, and contact tracing. WHO has identified community level surveillance of influenza-like illness and severe respiratory illness as a serious knowledge gap in tackling the COVID-19 pandemic.<sup>f</sup> Communities can complement health systems in case detection and surveillance with trusted and respected community informants working directly with authorities on detection and reporting of suspected cases.

There are several examples of community engagement efforts for Surveillance, tracing, and monitoring. The "community informer model" has been adopted for COVID surveillance in Nigeria leveraging the vast network of trusted informers conducting house-to-house surveillance, and sensitizing and supporting contact tracing in the communities.<sup>g</sup> The model was a key pillar in polio eradication programs in many countries that depended heavily on "community informers" to identify cases of Acute Flaccid Paralysis.<sup>h</sup> Similarly existing community surveillance systems for Lassa fever, Ebola, and TB community based case finding were used in Nigeria for community screening of COVID-19 and contact tracing.<sup>i</sup>

As part of COVID-19 response, many states in the United States engaged community volunteers to support a variety of activities. For example, Massachusetts state recruited a network of 1600 volunteers who supported COVID-19 contact tracing by local health departments.<sup>jk</sup> These volunteers gathered

<sup>&</sup>lt;sup>c</sup> https://www.gov.uk/government/publications/social-care-sector-covid-19-support-taskforce-report-on-first-phase-of-covid-19-pandemic/bame-communities-advisory-group-report-and-recommendations

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/892376/COVI D\_stakeholder\_engagement\_synthesis\_beyond\_the\_data.pdf

<sup>&</sup>lt;sup>e</sup> https://www.theguardian.com/world/2020/sep/20/bma-chair-act-now-stop-further-disproportionate-bame-covid-deaths

<sup>&</sup>lt;sup>f</sup> https://www.who.int/publications/i/item/report-of-the-who-china-joint-mission-on-coronavirus-disease-2019-(covid-19)

<sup>&</sup>lt;sup>g</sup> https://www.afro.who.int/news/community-informants-employ-mobile-data-collection-tools-strengthen-covid-19-surveillance

<sup>&</sup>lt;sup>h</sup> https://www.who.int/polio-transition/documents-resources/best-practices-active-surveillance.pdf?ua=1

<sup>&</sup>lt;sup>i</sup> https://www.ajtmh.org/view/journals/tpmd/104/4/article-p1179.xml

<sup>&</sup>lt;sup>j</sup> https://www.mass.gov/covid-19-relief-volunteer-opportunities-requesting-volunteers

<sup>&</sup>lt;sup>k</sup> https://www.nashp.org/massachusetts-enlists-volunteers-state-contact-tracing-model-to-curb-covid-19/

relevant epidemiological and health data of the contacts through phone calls which helped in making decisions regarding testing and isolation. However, the true impact of this initiative is yet to be fully assessed. Even in countries with very high testing rates, such as Australia, the Integration of trained community volunteer networks into existing surveillance and contact tracing teams—supported by digital tools and software—assisted efforts to identify mild cases of COVID-19.<sup>1</sup>

Community engagement has been shown as an effective strategy in contact tracing of COVID-19 cases in India. District health authorities used "route maps" to trace and test contacts of COVID-19 cases.<sup>m</sup> Maps detailing places visited and modes of transport used by COVID cases were prepared and released through social media including Facebook and WhatsApp, and people were encouraged to share the route maps and to report to health authorities if they have been at the same place as the identified cases during the specified time. When this was initially rolled out in Kerala, one family testing positive had been found to have had contacts with over 300 people since arriving from Italy 4 days earlier.<sup>n</sup> By tracking the exact locations of positive individuals, many people voluntarily came forward to get tested.

In the south Indian state of Kerala, volunteers formed a group to help identify hidden deaths due to COVID-19.° The group had physicians and data experts who scanned newspaper reports and matched information with the official death data. The team releases the data through a publicly available spreadsheet.<sup>p</sup> This increased the pressure on the government which led to strengthening of the death audit process. Subsequently, more and more deaths were officially included in the COVID-19 death tally.<sup>q</sup>

On the other hand, some countries have encouraged citizens to report violations of physical distancing norms. For example, the Mayor of a suburb in Montreal, Canada asked residents "to keep an eye out"<sup>r</sup> and to inform public security people congregate, a local city in Ontario instituted a telephone line and email to report violations like non-closure of non-essential businesses,<sup>s</sup> gathering in large groups, and individuals not following self-isolation orders, while an Indian state used a WhatsApp number for the public to alert the government regarding quarantine violations.<sup>t</sup> If such actions are proportionate, transparent, and fair this may be useful in an otherwise stable governance system.

### **Rick communication and Behavior change**

It is important to understand the media sources used by different communities, in order to effectively communicate the risks of COVID-19, and there are several examples where risk communication channels

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<sup>&</sup>lt;sup>1</sup> https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7887417/#CR19

<sup>&</sup>lt;sup>m</sup> https://indianexpress.com/article/coronavirus/covid-19-route-map-geo-tag-screening-how-a-kerala-district-didit-6358361/

<sup>&</sup>lt;sup>n</sup> https://www.technologyreview.com/2020/04/13/999313/kerala-fight-covid-19-india-coronavirus/

<sup>°</sup> https://www.bbc.com/news/world-asia-india-54985981

https://docs.google.com/spreadsheets/d/1DSZXgc7pfJOb3YT1r3iI5AfMOYOVb39IjC\_an2a1WVc/edit#gid=1246791 462

<sup>&</sup>lt;sup>q</sup> https://www.medrxiv.org/content/10.1101/2021.01.06.20249030v1.full

<sup>&</sup>lt;sup>r</sup> https://montreal.ctvnews.ca/in-ddo-social-distancing-violations-being-called-in-but-police-say-no-fines-yet-1.4872289

<sup>&</sup>lt;sup>s</sup> https://london.ctvnews.ca/london-unveils-snitch-line-for-covid-19-rule-violations-1.4871449

<sup>&</sup>lt;sup>t</sup> https://www.newindianexpress.com/states/kerala/2020/may/21/how-kerala-mastered-the-art-of-contact-tracing-to-fight-covid-19-save-lives-2146294.html

have been effective. In many countries, channels of risk communication for COVID-19 have been both traditional (such as radio or tv announcements and press briefings) and non-traditional (such as social media campaigns).

Volunteers in Singapore were deployed during the circuit-breaker period at the start of the pandemic to educate seniors living by themselves about the COVID-19 and relevant precautionary measures they could take. For many seniors, visits from community members played an important role not only in risk communication, but also in lessening the effects of social isolation that have intensified during circuit-breaker events.

Black health leaders in the US work towards building trust in the COVID vaccine among African Americans through the Black coalition against COVID.<sup>u</sup> The coalition consists of major African American medical groups and leaders from the four historically Black medical schools. The coalition conducted outreach through informational town halls online to address particular concerns of African Americans and worked with community health groups, local churches, and advocacy groups at the grassroots level.<sup>v</sup> Later in the pandemic, despite being disproportionately affected by COVID-19, African Americans' participation in the COVID-19 vaccine trials was low due many factors including historical mistrust in the research system.<sup>w</sup> To overcome this hesitancy, Black community leaders including heads of Historically Black Colleges and Universities (HBCUs) came forward to enroll themselves and have urged members of their communities to consider enrolling.<sup>x</sup>

In Tanzania, community engagement was successful in reducing the community spread of COVID in Kilimanjaro through improving the knowledge and awareness of the community.<sup>y</sup> Market opinion leaders, religious leaders, public announcements, and radio shows engaged with the Institute of Public Health (IPH) and Moshi Municipality to conduct mass public education sessions with the COVID-19 response team and conducted mass public health education through the engagement.

Social media as a channel for risk communication is also key as more and more of the world is connected digitally. Among a sample of college students in China, individuals who found mainstream information sources on social media to be trustworthy had less health anxiety - highlighting the importance of these communication channels. The willingness of communities to accept and absorb information through risk communication channels needs to be highlighted in effective community engagement strategies.

In London, United Kingdom, for example, people reported a significant difference in adherence to social distancing norms with change in perception of normative pressure from friends, with the odds of not adhering increasing by 47% when there was a perception of support from friends, and increased by 12% when there was higher perceived normative pressure from neighbors.<sup>2</sup> These results - particularly pertaining to the perceived support from friends - suggest a strong role to be played by an individual's perception of what is considered inappropriate behaviour by their immediate social environment.

<sup>&</sup>lt;sup>u</sup> https://blackcoalitionagainstcovid.org/

<sup>&</sup>lt;sup>v</sup> https://www.cnbc.com/2020/12/11/black-health-leaders-try-to-build-trust-in-the-covid-vaccine-among-african-americans-.html

<sup>&</sup>lt;sup>w</sup> https://www.businessinsider.com/covid-19-vaccine-black-americans-phase-3-trials-2020-9

<sup>&</sup>lt;sup>x</sup> https://www.cnn.com/2020/09/18/health/hbcu-presidents-covid-19-vaccine-trial-trnd/index.html

<sup>&</sup>lt;sup>v</sup> https://www.panafrican-med-journal.com/content/series/35/2/146/full/

<sup>&</sup>lt;sup>z</sup> https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-021-10379-7

### Administration, provision, and logistics

In the United States, a group of volunteers from GISCorps developed a mobile-friendly public Testing Site Locator application and visualization of geographical location of centers to facilitate testing centerrelated data collection and dissemination at the national level.<sup>aa</sup> This helped the public to locate their nearest and available testing centers and the health system to plan and distribute the centers better. Massachusetts state created 36 Medical Reserve Corps (MRC) of medical and non-medical volunteers to support the state health department in COVID testing and healthcare facility staffing support (long-term care, rest homes, etc.) and later as vaccination clinics volunteers.<sup>bb</sup> In Wuhan, China the community was engaged at the grass-root level in a city-wide temperature monitoring program during the COVID-19 pandemic.<sup>cc</sup> Community volunteers were recruited to manage monitoring stations and conduct door-todoor health checks.

To address the overwhelming issue of social isolation, stress, and mental health issues in older adults during COVID, a Telehealth program involving phone calls by trained volunteers was rolled out in late 2020 in Montreal, Canada.<sup>dd</sup> The community volunteers provide friendly conversation and social connection; provide information about COVID-19; and connect older adults with services and resources in the community to ensure that the necessities of daily living (e.g., food, shelter, medication, etc.) are met.

In India, managing the dead bodies and safe burial and or cremation was difficult for the overwhelmed health system.<sup>ee</sup> Community volunteers and organizations helped provide a dignified cremation or funeral of COVID positive bodies.<sup>ffgg</sup>

### Efforts to mitigate the social and economic impact of the pandemic

In New York City, community engagement efforts focused on a number of intermediary social determinants due to the pandemic, through utilizing CHWs.<sup>hh</sup> These included connecting people to food distribution sites and pantries, helping them enroll in government programs that food provided assistance, and organizing food drives with community and faith-based organizations. Other services included addressing the rising unemployment through connecting people to vocational training, educating community members and helping them navigate resources and the system for unemployment. CHWs also helped people transition out of shelters and other congregate settings. For those who were undocumented, CHWs provided help navigating relevant resources.

In many parts of India, community engagement helped support quarantined people. Hand sanitizers were distributed, food, and other goods were also provided as part of COVID-19 relief efforts. Women's

<sup>&</sup>lt;sup>aa</sup> https://www.giscorps.org/new-ongoing-projects/

<sup>&</sup>lt;sup>bb</sup> https://www.mass.gov/covid-19-relief-volunteer-opportunities-requesting-volunteers

<sup>&</sup>lt;sup>cc</sup> https://jtd.amegroups.com/article/view/42860/html

<sup>&</sup>lt;sup>dd</sup> https://www.frontiersin.org/articles/10.3389/fpsyt.2020.598356/full

ee https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7889837/

<sup>&</sup>lt;sup>ff</sup> https://www.newindianexpress.com/good-news/2020/jul/21/we-dont-charge-a-single-rupee-these-volunteers-have-buried-over-100-covid-19-victims-2172960.html

<sup>&</sup>lt;sup>gg</sup> https://thewire.in/rights/india-covid-19-deaths-burials-volunteers-municipal-authorities-help

<sup>&</sup>lt;sup>hh</sup> https://www.nejm.org/doi/full/10.1056/NEJMp2022641

self-help groups known as Kudumbasree<sup>ii</sup> with more than 4.3 million members helped run community kitchens throughout the state of Kerala in India.<sup>jj</sup> The group helped distribute food to people during the lockdown through a volunteer network called "Arogya Sena" (Health squad). Contact details of the Sena members were shared with all residents of the locality so that they can contact them and order food for the next day. Various cultural organizations and artists started online performances to entertain people during lockdown to help alleviate boredom and motivating people to engage in creative ventures.<sup>kk</sup>

In Pakistan, the communities came forward to set up COVID quarantine wards run by volunteers, manufacture and provide free protective suits for medics, and to distribute food.<sup>II</sup> Communities also increased their share towards obligatory almsgiving that helped to address hunger as many lost their jobs and earnings during COVID.<sup>mm</sup>

<sup>&</sup>lt;sup>ii</sup> https://kudumbashree.org/pages/826

<sup>&</sup>lt;sup>jj</sup> https://indianexpress.com/article/india/kerala/keralas-43-lakh-strong-women-self-help-network-powercommunity-kitchens-during-coronavirus-lockdown-6334845/

<sup>&</sup>lt;sup>kk</sup> https://journals.sagepub.com/doi/full/10.1177/0020731420967630

<sup>&</sup>lt;sup>II</sup> https://www.npr.org/sections/coronavirus-live-updates/2020/03/30/823783027/as-the-coronavirus-rips-through-pakistan-volunteers-rush-out-to-help

<sup>&</sup>lt;sup>mm</sup> http://www.bbc.com/travel/story/20200331-the-law-of-generosity-combatting-coronavirus-in-pakistan

# Annex 2: Historic examples of community engagement efforts to tackle disease outbreaks

In the context of disease outbreaks, community engagement is often initiated as a collection of techniques to involve communities in efforts to stop outbreaks. Community engagement, in different forms, has proven to be important in tackling a number of historically successful efforts to tackle disease outbreaks. Recently, the Ebola epidemic provided important lessons on the importance of community involvement to tackle disease outbreaks.<sup>nn</sup> A key component of this research has been to examine historical examples of community engagement during disease outbreaks. his review provides examples from a number of outbreaks including Ebola, COVID-19, Dengue fever, H1N1, and Zika Virus. It also includes few examples from efforts to tackle Chagas disease, Cholera, Malaria, Marburg virus, Monkeypox, Polio, SARS, Scabies, and Multiple diseases. The review reflects experiences from Sierra Leone, Liberia, The United States of America, Canada, DRC, Thailand, Guinea, China, India, Congo, Dominican Republic, Ethiopia, Kenya, Malaysia, Mexico, Myanmar, Singapore, Sudan, Tanzania, Uganda, and Vietnam.

The following themes emerged from the analysis of successful community engagement interventions:

- 1. Social and behavior change through communication/risk communication. This is the most common theme of community engagement in tackling disease outbreaks. Engaging the public in pandemic planning can provide vital information regarding local values and beliefs that may ultimately lead to increased acceptability, feasibility, and implementation of pandemic plans. Successful examples range from allowing people to take an active role in understanding how to improve their health
- 2. **Case detection and surveillance.** Trusted and respected community informants working directly with authorities on detection and reporting of suspected cases are important for successful community engagement. For example, following the Ebola outbreak in Sierra Leone, authorities engaged local residents and Okada drivers (commercial transportation) to obtain vital mapping and village population data through installing an open-source application on their self-owned Android smartphones.
- 3. Community trust building. Recruiting community-based key informants, who are respected in the community to deliver messages is critical to the success of interventions. In Guinea, to reduce fear around coming forward for having Ebola, survivors communicated with other community members about their positive experience that in Ebola treatment centres (ETC). Authorities provided free transportation for relatives, mobile phones for patients to communicate with their families, and new clothes in ETC. They were cared for with humanity and dignity and local languages were spoken in ETC. This in turn improved the community perception of both the ETC and partners activities to tackle Ebola, which helped improve community compliance with contact tracing and case identification.
- 4. **Design and planning of interventions.** Community consultation is one method that has been implemented engage communities in the design and planning of interventions. During the Ebola outbreak in Liberia, the government engaged in active exchange of information between health officials and communities, where community members advised on planned interventions and local health-related decision-making.
- 5. **Psychosocial support.** There is abundance of evidence of the population mental health toll linked to disease outbreaks and the measures often taken to tackle these outbreaks. As such, efforts to provide psychosocial support to affected community should be central to the response to

#### The Secretariat for the Independent Panel for Pandemic Preparedness and Response

<sup>&</sup>lt;sup>nn</sup> https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5199179/

pandemics. In Canada and in efforts to address the mental health issues related to the COVID-19 pandemic, Trained volunteers, voluntary medical and paramedical teams engaged in 1–2 times/week friendly phone calls to the elderly. Volunteers Inquired about the person's general wellbeing, provided information about COVID-19, and assessed basic needs. Volunteers would then refer clients to community resources and services (e.g., grocery or medication delivery, hotline) counselling, peer support, and social networking when needed.

- 6. **Support with logistics administration.** This includes engaging communities directly in efforts to reduce the spread of the outbreak. The most recurrent examples are for vector control efforts and for safe burial efforts. For example, in Sierra Leone during the Ebola epidemic community leaders and Imams facilitated safe burial and community members who received proper training were allowed to participate in local burial teams.
- 7. Direct patient care/medical treatment support. In limited resource settings, community members can sometimes take part in direct patient care or medical treatment support. much of the patient care and treatment support is often done through community health workers (CHWs). For example, in Liberia during the Ebola epidemic, community volunteers transferred sick patients from treating centres in remote villages to centralized Ebola treatment unit to receive specialized treatment

### Barriers to successful community engagement

- Lack of trust in authorities is a consistent reason for poor or no community engagement. Lack of trust can be triggered by lack of proper, understandable (using relevant languages), and consistent communication by authorities or political instability and violence
- Lack of training and follow-ups in the existing system, especially when recruiting communities for surveillance efforts.
- Developing pandemic response plans without consulting and including marginalized communities, who have some unique needs and characteristics. This often means that locally relevant issues were not ethically and adequately addressed in the response.
- Financial investment or lack thereof in both health systems and other basic needs is important for shaping community responses. Communities with unsatisfied needs can opt to poor or lack of engagement during outbreaks and pandemics. To that end, insufficient resources for Interpersonal communication and understaffing of healthcare facilities contribute to lower community engagement.
- Later engagement leads to less cooperation by communities.

### Key lessons for successful community engagement

- Community sense of ownership and involvement, especially marginalized groups, in the design and planning of interventions is an important factor in successful community engagement. This requires transparency from governments.
- For efforts to succeed, governments and health officials should appreciate and recognize the importance of community engagement. To that end, supportive supervision by relevant authorities enhances the quality of community engagement.
- While community engagement efforts can be organic, governments taking proactive measures to engage communities makes a difference.
- International health NGOs should be transparent and clarify their intervention objectives to reduce resistance by communities, especially when the issue relates to sensitive matters such as burial rituals.
- Community leaders play an important role in trust building and authorities should rely on them for community engagement.

- The communication skills of community volunteers are important, and the government should invest in improving these community skills.
- Flow of communication between different teams in the field during an outbreak is very important; if the communication system between authorities and communities is broken, that will create confusion among teams on the field and the community involved.
- Cyclical dissemination of information is essential for sustained interest among communities to engage in prevention and response efforts.
- Training and a small remuneration and proper coordination can ensure a long-lasting community engagement.
- Existing health system issues such as understaffing can affect community engagement during sudden outbreaks. As such, investing in health systems prior to pandemics is critical for successful community engagement during pandemics.

# Annex 3: The role of Community Level Workers in COVID-19 control activities: A Case Study from India

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More than 65 percent of India's population lives in rural areas with the highest overall burden of disease. The Indian rural health care system is composed of three-tier system comprising Sub-Centres, Primary Health Centres, and Community Health Centres with considerable shortfall in health facilities at different levels - 18 percent at Sub centre level, 22 percent at PHC level and 30 percent at CHC level (as of March 2018)<sup>1</sup>. Workforce shortage is also substantially high despite expansion of infrastructure. Rural India has 3.2 government hospital beds per 10,000 people. Many states have a significantly lower number of rural beds than the national average. The state of Uttar Pradesh has 2.5 beds per 10,000 people in rural areas. Rajasthan and Jharkhand are at 2.4 and 2.3, respectively. Maharashtra, which has seen the largest number of cases, is at 2 and Bihar is at 0.6. It is against such a scenario that the participation community health care system is not adequate and prepared to contain COVID-19 transmission in the rural areas, especially in many North Indian States because of the shortage of doctors, hospital beds, equipment, especially in densely populated underserved states. It is important that training is a priority area not just for professionals but even for paramedics on PPE usage, hand and environmental hygiene.

The real facts and figures of the epidemic in rural areas are not known yet except broad distribution patterns. The course of events with respect to preventive strategies to control COVID-19 especially the experiences in states like Kerala which has comparatively well-developed health infrastructure are important as a lesson for managing future emergencies.

It is a wakeup call and what is important at this moment is to use the lessons of this pandemic in the rural areas where the health care systems have to be improved considering the huge population in rural areas, untrained staff in caring and handling of patients during an outbreak of infectious diseases, and a huge shortage of beds, and equipment.

Kerala with historic and internationally acclaimed achievements in the health sector have become a victim of this transition. Despite the positive image of the health and social sectors and considerable investments in the health sector and establishment of modern care institutions, Kerala society is facing a crisis largely due to the emergence of new diseases such as chikungunya, Dengue, fevers and other viral infections in epidemic proportions especially during and after the monsoon season. Changing lifestyles of the Keralites, the new food culture and the large migratory population in the state have also played a significant role in the new epidemiological profile of the state. This new epidemiological scenario exists in the backdrop of all-round commercialization of health care and the retreat of the public health vision. All these factors need to be understood through empirical studies which only could provide an evidence-based public health policy framework as against an eminence-based decision making which is rampant with regard public health programs

The health service is a socio-technical institution shaped by a number of actors and a multitude of interests. Despite the dominance of a techno-centric approach to public health universally and nationally, there exits an alternate vision to public health which considers health services as a social and cultural institution. Community Level Workers form part of this institution and it is during the pandemic that the importance of such workers has been felt both by the civil society and the government. Workers such as

ASHA and other frontline health workers have a great role and responsibility in the pandemic control apart from maintaining the routine health activities. In many countries, they have been used mainly for community preparedness, health maintenance and educational activities. It is now known that many such workers have faced great personal risks without adequate personal protective equipment to combat the pandemic (Behera et al, 2020). In a country which is facing severe shortage of health manpower, this is a serious matter of concern. It is important to understand how they performed their roles and how the community received it in order to devise suitable emergency governance in future. In several countries, the primary care workers played an important role in health promotion activities and community preparedness.

The state of Kerala in India had a favourable history of maintaining better health of the population as well as in containing sporadic small episodes of new illnesses. Initially, the availability of a committed medical force certainly helped in containing the virus to some extent but due to probably the behaviour of the people and arrival of foreign returnees. The role of primary care workers in containing the virus is not small and it is important to document their experiences and trajectories especially from the state of Kerala which saw the first arrival of COVID-19 case and which went through a favourable history of health development.

**Methodology**: In the present case study, the responses and experiences of the frontline health workers including ASHA workers towards the pandemic are documented from the state of Kerala in India. For this purpose, we selected three different districts from the state, namely, Thiruvananthapuram from the southern part, Alappuzha from the mid-region and Kozhikode from the North. The frontline health workers were qualitatively interviewed using a checklist prepared in advance and content validated using expert validation method. Apart from this, selected secondary data sources were also used to complement the primary qualitative data.



### WORK TRAJECTORIES

### **Thiruvananthapuram District**

This is a district which initially saw considerable surge in cases but now although the number of cases have come down, the number of deaths have gone up compared to other districts. Thiruvananthapuram is the 4th district which contributes to the increase in the number of COVID cases after Ernakulam Kozhikode

and Malappuram. As per official records, the total cases reported in the district is about 1,03,054 out of which 20164 are active cases, 99967 recovered and 834 died.

Most frontline workers mentioned that fieldwork is the heavy work and felt really cumbersome during the pandemic period. Contact tracing is another tedious issue as people are not willing to share information in many instances. In containment zones, this is more difficult as cases might infect the health workers and therefore health workers revealed that they do this through telephone. Many workers revealed that normal responses from the people were lacking. Most workers revealed that they were involved in the preventive activities almost most of their working time.

"There were situations in which we were not able to get into our own house, we were so busy. People in our houses also kept us at a distance".

Social isolation was one of the important phenomena felt by most workers as they were not allowed to enter many houses for classes and instructions.

"People also interacted with us differently as everyone talked to us from a distance. But we managed this isolation"

According to some workers in the district, routine activities such as immunisation and RCH programs were affected to some extent as people were reluctant to come forward. However according to one ASHA worker, 'we were also doing the COVID activities and contacting the people over phone. But this reluctance slowly subsided as the pandemic became a daily affair. Now there is heavy rush for immunisation".

Training was felt as extremely useful by the workers as this enabled them to answer questions, handle situations and give proper instructions.

"Initially, people were very scared and they used to listen to us. But, now they do not listen to us as they feel that they result will affect their work".

One ASHA worker told "we got the required training to identify the cases much before the infection spread. That was most useful for us to handle the situation. We used to contact the people who returned from foreign countries and give the required advices. They also listened to us also at that time. Now they do not listen to us when we tell them to undergo tests when we identify the symptoms as they are not that scared now about the disease. Now people see us as routine machines".

Fieldwork by the health workers is an important dimension of pandemic control activities. According to a Health Inspector, ASHA worker performed to the fullest potential during this period especially to detect positive people and to provide all the help to them. But these activities according to health workers were not very smooth. Despite a high health literacy some places in the district also faced resistance to home visits. "People sometimes expressed displeasure when we used to regularly visit the homes to enquire about their health. However, we used to handle the situation somehow. House visits are one of the most tedious tasks".

One ASHA worker said, 'It was difficult to do fieldwork during this period. But I completely involved myself in home visits as much as I could although personally I have difficulties. I also have a family and a small child. Therefore, I also need to be careful and take protections myself"

"Tribal areas in the district needed special attention as we were not sure how they will respond to the situation. But they somehow managed it well due to natural isolation"

Another ASHA worker, said, "In some areas, I faced bad behaviour when I went to enquire about a COVID case. The people insulted me and said I am spreading the disease as a health person"

A Junior Health Inspector told, "most workers have to cover at least 50 houses which is difficult given the current situation and since we are also given multiple activities like family planning, sanitation, ticks control apart from attending all the meetings".

Misinformation regarding the infection through the social media was certainly an important problem which negatively influenced the preventive work including vaccination. "When we get the information regarding such cases, the local NGOs and other organizations are contacted and the issue is sorted out to some extent".

### **Alappuzha District**

This is a district which witnessed considerable surge in cases after 3<sup>rd</sup> August but the number of cases has come down at the moment. Alappuzha is now trying to stabilize with 2532 cases. As per official records, the total cases reported in the district is about 78915 out of which 75994 recovered, 364 died and 2532 are active cases.

An ordering of routine activities and prior training seems to have helped to streamline the activities during the pandemic. One ASHA worker said that prior activities like sanitation etc. certainly helped in containing the virus to some extent. She said, "there is a competition among us to come up front and such a healthy attitude helps us to show better performance". One JPHN said "I need to be updated each and every time then only I can clear the doubts of others. Although the work load is increasing day by day, I try to complete it as soon as possible..."

"All the Health workers and ASHA workers used to do the vector study and this helped certainly. Each subcentre covers three wards and this may become too much workload as we have to cover more than 500 houses. And this is too much work. The current situation considerably increased our workload. We have to take care of everything including quarantine etc.".

Community organization prior to the pandemic helped in sustaining and promoting COVID control activities. "We have a volunteer for every25 houses, they are also a part of this awareness mission. They mainly come under NCD project, for the check-up of BP, Sugar and body weight, even though all the project workers work in COVID since last year. Now they are not that much active because of lack of remuneration, even for ASHAs. We have a committee in each area, which includes caste representatives, Musaliyar, Christian priest and manager of the library. These people inform us whenever a person breaks the COVID protocol. We use local resources like sanitation committee, Ayal koottam, ADS, Kudumba Sree and angan waadies for the awareness classes".

One Junior Public Health Nurse said that routine activities like NCD clinics have been affected. "I am really worried about the children and their problems. The NCD clinics shows that the eye problems and weight gain have increased compared to last year. They are blaming the COVID for that. Apart from this, the RCH works are like an Ocean, and all those works are computerised now. We need to complete the targets in according to the time. Now we are actually doing the double work after the COVID -19. I do the paper work after mid night".

One health worker said, "although we have this much work load there is no increment or added benefits for us. Even today I do all these without pending since this is my passion. I love to do community services. Those smiling faces give me the completeness".

"When we go and ask people who are infected to go on quarantine, they ask us who we are to ask them. That is the situation now. We do all the work and we face all the bad mouth. Even there are some in the non-infected who do not listen to us". "They tell us that it is difficult to follow this life pattern always. Some people shouted at us but the police helped us to maintain the protocol"

Misinformation certainly exists due to the spread of social media. According to one JPHN told, "it is easy to resolve misinformation if We have strong connections (Including ASHA, Anganwaadi teachers) in the community and we always inform them about those persons. We have formed a 'COVID Jagrutha' committee for that purpose. The Panchayat Member is the chairman of the committee"

### Kozhikode District

Kozhikode had reported high number of cases during the pandemic period. A total of 121157 cases out of which 117039 got cured. The current active cases are 36 36 and the death rate is 456. On 4<sup>th</sup> March 2021 Kozhikode district had reported 345 COVID positive cases in which 3 cases are reported among health professionals. Kozhikode district had already faced a Nipah outbreak in 2018 and the spread of infection was contained at that time. The district was fully prepared to withstand a future outbreak of the disease as they had set up an organized team to evaluate and monitor any onset of infection.

Probably, this prior experience helped the 1712 ASHA workers and the Rapid Response Team in handling the situation. Except some online sessions, no special training was given to the workers. "A social media group of ASHA workers also helped in understanding the situation well. I was also able to detect the symptoms due to this interaction".

One ASHA worker mentioned, "non-COVID health work was seriously affected during this period. We somehow carried out pulse polio program by arranging it in a nearby school. But still parents were very cautious and not ready to come. Almost for two months, no other health programs were carried out. In some cases, even immunization programs were stopped".

Another worker informed, "misinformation regarding the pandemic certainly existed in many places. We used to handle this by giving correct information by house visits and vehicle announcements about the infection. Giving correct information and awareness to the people was always a challenge as information available to us was not complete".

One health worker said, "we stand near the gate or entrance and tell the instructions"

Some workers also faced unpleasant situations during their work. One ASHA worker narrated her experience- "I was worried and sad when a young boy had beaten me for telling him to wear the mask. My family got tensed about my job due to this experience. The incident also made me depressed. In another incident, I faced violence and a group of guys had called abusive words. This was a major problem during the pandemic period but most of the ward representatives stood by me".

Many ASHA workers felt happy that their work is being recognised now and that they are needed in the community. "People didn't much know about ASHA workers before, during COVID time people came to know about us and recognised our work".

Personal trajectories also matter to many community level workers as many of them are young, married and have small children. "My role in community is tough, but I am supposed to do my work, have to deliver medicines and give proper information. I am worried too about my family as I am always exposed to all kind of infection. Phone calls at midnight and sleepless nights were so common during COVID-19 lockdown period. That was the main problem I had faced during COVID time".

### **Conclusions: Health workers and Encounter with the Pandemic**

Based on the narratives as well as observations, we could identify interlinked and dominant trends apart from minor and specific-context related issues.

### **Training Deficit**

We could identify a training and facility deficit in some cases as proper emergency training and handling of PPE was missing. Most of the training was carried out through social media and there was no quality check on such a process. Training is most important as most of the information that the workers gathered are through self-training and internet. This was necessitated owing considerable demand from the people through raising questions and doubts regarding the infection. This is also necessary to counter misinformation which was abundant in many places. Training should also include human management in order to counter unpleasant human interactions. Apart from information, training in **Primary Emergency Health Care** need to be imparted to the primary level workers and supervisors on a periodic basis.

#### **Trust Trajectories and Transactions**

It is surprising that even in a so-called health and politically conscious society, one could identify a number of instances of violence against primary health workers. It is due to a deficit largely because of the emergence of dominant private sector and alienation of the government health workers. A number of instances highlighted here show the sudden salience of the government sector in pandemic control. It is important to **reinvigorate the medical loop and preventive protocols** in health programs to strengthen the health service system at the village level especially an increase in trust between the two entities. Largely, the instances encountered in this case study referred to adhering to specific practices and other emergency measures such as quarantine and undergoing tests. Emergence of misinformation is also due to the trust deficit apart from the dominance of social media.

#### **Community Protocoling**

It is known that health workers could not adequately prepare the community due to lack of information and paucity of time. Given the fact that for many health workers, this was the first encounter with a pandemic, it is possible to give more focus on programmatic components in order to handle emergency care in future.



### Figures

### **Volunteer Activities in COVID Control Activities**



**Health Volunteers by Gender** 



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# Annex 4: Relevant Independent Panel exchanges

### Youth Exchange

### Themes emerging from the discussion

**Theme 1:** Inequitable access to education will negatively impact the labour market in the long-term.

• Millions of youths have been impacted by school closures around the world, with insufficient support from educational institutions

**Theme 2:** Youth mental health has suffered during the pandemic. The pandemic is testing young people's resilience and contributing to mental health challenges through:

- Isolation from peers, friends, family members, and community.
- the stress of unemployment and loss of economic and educational opportunities.
- high levels of uncertainty and insecurity

**Theme** 3: Mainstream narratives about youth apathy on COVID-19 are disconnected from the reality of young people's experiences.

- People are not prepared for multiple rounds of lockdowns.
- Medical students have been stepping up to support the healthcare system.

**Theme** 4: High rates of unemployment and precarious employment among youth are concerning in the short and long term.

- Young women and gender diverse persons are working in the informal sectors and engaging in underpaid and unpaid care work.
- The tourism and service industries have been hit hard; industries where youth are overrepresented in the labour force.

**Theme** 5: While there has been an increase in remote work and learning opportunities, these are not accessible to everyone because of the digital divide and lack of investment in critical infrastructure.

### Areas for action proposed by participants

- Diversify decision-makers (including women and other underrepresented groups) at all stages of preparedness, response, and recovery, including design, implementation, and evaluation.
- Meaningfully engage youth and ensure their perspectives, insights and experiences are not tokenized but shape policies and programming
- Youth services should be essential components of aid and recovery package/response:
  - Accessible and quality mental health services for youth
  - Rental assistance
  - Unemployment/Re-employment programs
  - o Childcare
  - o Education
  - $\circ$   $\;$  Invest in high-speed internet access to enable remote work and learning where possible

- Short- and long-term investments in healthy populations and societies, centering the needs of marginalized populations. Including LGBTQIA+2 community, gender and sexually diverse persons, Indigenous communities, forcibly displaced persons (refugees, IDPs, etc.), migrants, ethnic minorities, low-income populations, and rural and remote communities.
- Address institutional trust and distrust among youth through relationship building
  - o Invest in communication and relationship building with local communities

### **Mayors Exchange**

### Themes emerging from the discussion

Theme 1: During the COVID-19 pandemic, mayors managed unprecedented emergencies with overstretched resources to tackle both the outbreak and the consequences of the outbreak. Cities were "shocked," seeing things they had never seen before.

Theme 2: In some contexts, decisions at the global and national levels around tackling COVID-19 often failed to recognize the reality of city life. For example, in Sierra Leone, the national government-imposed curfews for transport. In reality, 80% of the transport is informal transportation, which result in very close contacts for passengers.

Theme 3: Vulnerable residents were hit hardest by COVID restrictions, and local governments worked on the frontlines to help them.

- The housing crisis that we already had was further exacerbated
- Migrant workers couldn't come in
- Rural areas without acceptable levels of internet access,
- people experiencing homelessness

Theme 4: Some groups fell through the cracks in receiving government assistance.

• Government help was too bureaucratic in some contexts. For the smallest companies and for independent people who didn't have enough money to pay their rent, for example

Theme 5: A critical concern of informality and how to address it.

• For example, in Ghana our physical layout is largely informal: 45% informal. 74% of people are working in the formal sector. These are areas that are directly linked to the spread of diseases

### Areas for action proposed by participants

- Increase collaboration and coordination between local, national, regional and global governments.
- Local governments need more of a voice in informing policy and resources during a pandemic.
- The pandemic has exposed the flaws in our system, and we must use this as an opportunity to promote an inclusive recovery and build back better.
  - Affordable housing has long been a priority, and there is an opportunity now to tackle this
  - We will bridge the digital divide where health and education are being delivered.

- It's an opportunity to confront systemic racism we are going to push for this.
- When mayors are empowered, the country is empowered to perform.
- Governments must decentralize the emergency response in order to reach people at the grassroots level.

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