‘We are subjects, not objects in health’

Communities taking action on COVID-19

Training and Research Support Centre

In the

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Contents

Key messages

This document co-ordinated by TARSC in EQUINET the Shaping health consortium, and with input from co-authors from nine countries provides evidence of practical and affirmative options of people-centred, participatory forms of community organizing and engagement in diverse areas of prevention, care and wider social protection in responding to COVID-19. The 42 case studies from different regions intend to inspire, inform and support.

The case studies are unique, diverse and rooted in widely different contexts and histories. In all, the people involved are subjects, full of life, with rights, ideas and rich experience.

They report the creative development and use of social media platforms for action across all areas of response, connecting people within and across communities and countries, giving voice and visibility to community experiences and linking people to key resources and services. They show the role of an ICT that supports problem solving and expression of marginalized voices. Simple tools, norms and standards, and open data facilitate creative community engagement.

The experiences show organization around symptom surveillance, testing, contact tracing and risk mapping, linking people to support and proposing feasible, less harmful ways of organizing risk settings or implementing lockdowns. Community volunteers have produced and distributed PPE and other health technologies; have self-organized medical, care and counselling support; and have organized food and other essentials for those in need, in ways that address psychosocial challenges and cultural and religious beliefs and that overcome stigma and social isolation. The initiatives have linked small scale farmers to household deliveries for food security, provided food through communal gardens, kitchens and 'people's' restaurants and supported access to emergency lodging, benefit schemes and safe water.

They demonstrate that a compassionate society enhances public health. While not without challenges and reversals, they are solution-focused and use their actions to negotiate and lever the resources and relationships that they expect from the state.

Many build on histories, ideologies, structures, organization and relationships that began long before the pandemic, enabling a relatively rapid response to new challenges posed by COVID-19 and with an intention to sustain relevant innovations after the pandemic.

They reach to socio-economically disadvantaged groups within communities, especially where organizing processes were participatory and democratic, strengthening collective organization, investing in capacities and leadership and making links with more powerful groups to address local priorities and negotiate delivery on state obligations.

They build new relationships between communities and producers and between communities and health workers, and solidarity interactions with international agencies and diaspora communities. The relationships built show the value of productive capacities, economic and system interactions that were previously ignored. While some are a response to imposed measures insensitive to community realities, in others the state, especially at local level, provided enabling conditions and resources and was responsive to local initiative, especially where state capacities were decentralized or autonomous. In responding to deprivation or deficit, there was a caution not to take over state duties, nor to be dominated by the state, and an observation from service workers that community organization and advocacy is what makes the state move.

The challenges presented by the pandemic are creating demand and space for innovation, and in many settings communities are rising to that demand. The mobilization of affirmative community effort and creativity needs to be recognized in the story of the 2020 pandemic.

We hope that the case studies inspire the proactive efforts of other organizations and communities. They also carry a consistent message: The response to COVID does not need to generate fear and coercion. It can be inclusive, creative, equitable and participatory. We suggest that co-production and co-determination with affected communities are not an optional 'add-on' to COVID-19 responses. They are fundamental to a successful response.

1. Introduction: Profiling the role of communities in a pandemic

The responses to COVID-19 have brought out the many facets of public health – from top-down command-and-control measures, sometimes militarized, to bottom-up community driven solidarity and support, and some that combine both. The spectrum reflects a long-standing tension in public health between biosecurity- and biomedical-focused approaches that objectify people as 'the problem' and participatory, people-centred approaches, where people are subjects in their lives and play a critical role in determining and taking action. In addition to all the other challenges raised by the COVID-19 pandemic, there is the challenge of (re)claiming public health from a definition and practice that would situate it entirely and globally in the former (Loewenson et al., 2020). While this raises many terrains of action on knowledge and practice, one aspect is making visible the active role of people.

The spread of the global pandemic comes at a time when possibilities of and expectations for improved health and access to health care globally coincides with socio-economic inequalities and prejudices deprive many people of these opportunities for improved health. People expect to play a role in decisions that affect these opportunities and barriers. Social participation in health refers to people's individual and collective power and involvement in the conditions, decisions and actions that affect their health and health services. It can take many forms and levels. It may be initiated from within the community or by outside institutions. It takes place within formal and informal, invited or claimed spaces and within different functions of health systems. It may be ad hoc and transient or sustained (Loewenson et al., 2017). The *Shaping health* consortium of institutions working on social participation or community engagement in health identified as shared insights that participation is integral to health improvement, intrinsic to people's identity, and a reflection of values, rights. equity and social justice. The lived experience and knowledge of communities, community activism and leadership are drivers of participatory practice, but also of more holistic approaches to health and health care. Effective and meaningful engagement of communities has been linked to progress in diverse areas of health, health care and social outcomes, building social capabilities and learning from action that are contributors to meeting health challenges (Loewenson et al., 2017).

1.1 Dimensions of responses to COVID-19

Johnson and Goronga (2020) argue that these insights equally apply in the response to COVID-19, especially as it becomes clearer that it is a sustained health challenge. Without an effective treatment or vaccine yet available, the public health interventions to control the outbreak are largely social, such as handwashing, wearing face masks and physical distancing. Lockdown measures also have significant social impacts and whatever is done demands public confidence for compliance and public trust in government. These public health measures thus depend on social action and an understanding of lived realities that Johnson and Goronga (2020) argue are best understood by the communities who live them. For these reasons they argue that communities should be recognized as vital assets and included in decisions in responses.

Similar views are articulated from a wide range of settings, north and south (Bhaduri, 2020; Marston et al., 2020; Oxfam et al., 2020; Loewenson, 2020; Nyamapachitu-Mago et al., 2020).

Bhaduri (2020) argues that how well communities, their cultures, views, co-operation, and understanding are engaged significantly affects the trajectory of the pandemic, especially given the harms experienced in a prolonged lockdown. Oxfam et al., (2020) outline a spectrum of measures for local community engagement to ensure that affected populations know the risks of COVID-19; how to identify early symptoms and what action to take, how to prevent or mitigate transmission and how to engage with services. A rapid evidence review exploring how community engagement contributed to infectious disease prevention and control during Ebola, Zika, SARS, MERS and H1N1 since 2000 found in countries at different income levels that local leaders, community and faith-based organizations, community groups, health facility or community health committees, individuals and key stakeholders were playing a role in designing and planning interventions, in building trust and communicating information for understanding of risk and social responses, as well as in surveillance and case tracing ((Nyamapachitu-Mago et al., 2020). Similar learning has been drawn from Ebola outbreak responses in Africa (Anoko et al., 2020).

There is a spectrum of possible engagement with communities, from information and consultation through to partnership and collaboration, co-determination and delegated power to forms of citizen control and co-determination. Control of actions in top-down command and control measures reflect power *over* communities, while there is an argument for forms of engagement that provide collective forms of power where people reflect and act collectively in the interests of public health, in collaboration with services and others.

In the initial phases of the pandemic, uncertainties about its clinical and epidemiological trajectory led largely – albeit with some notable exceptions- on the one hand to strong biosecurity-focused, authoritarian responses over populations in some countries, and laissez fare responses leaving people to make individual choices in others (Bhaduri, 2020; ; Corburn et al., 2020; Loewenson et al., 2020). Some countries or states within countries have, however, tapped the assets in their communities to support prevention, care and mitigation of harm, in diverse types of communities and in settings as diverse as Kerala, India, Syria, UK, South Africa and in different Latin American countries (Bhaduri, 2020; Ekzayez et al., 2020; Marsten et al., 2020; Scheepers et al, 2020; Duque-Franco et al., 2020).

In Peru, ancestral values communicated during COVID-19 dialogue on food security options

Millennium Alliance for Humanity and the Biosphere - Stanford University, 2020

As the pandemic has matured and progressed, with expanding knowledge of its nature and course, there is an opportunity (and need) to generate responses that are effective and sustainable in relation to community roles that have coherent links to wider socioeconomic, political and health system objectives.

In the response to COVID-19, the language of community engagement has featured in public health discourse, with guidelines, editorial think pieces and reviews promoting it as a critical pillar of the response. There is, for example, a significant volume of information and guidance on methods for providing information to and gathering information from communities on what people *should do* in response to COVID-19, including some level of consultation. However these information outreach measures do not necessarily integrate communities or their own responses into public health actions in collaborative and partnership approaches, in decision making on issues on or in monitoring and oversight. Further, support for 'community engagement' is often rhetorical, and located in the terrain of 'risk communication'. While this is important, limiting community roles to being informed about and communicating risk to ensure compliance with centrally defined and imposed measures is not sufficient for either effective social participation or effective public health. It ignores the many other ways communities can be engaged and play an active role in the response.

Accordingly the scope of this report and the work we did for it excludes forms of engagement that *solely* relate to information outreach. The forms of engagement specific to COVID-19 that we covered included:

a. **Planning and strategic review of responses directly related to COVID-19,** including public health, social protection, economic mitigation and stimulus measures, and covering community assessments and use of community evidence; outreach for dialogue and co-planning; joint mobilization and co-determination; monitoring and review of interventions, resource mobilization and making rights or legal claims.

b. **Community engagement, action, collaboration, co-determination on key elements of prevention** – including accessing water and soap for handwashing; accessing and co-producing face masks and other essential health technologies for COVID-19 prevention; testing, contact tracing and implementing quarantines or physical distancing measures;

shielding and supporting vulnerable groups; outbreak surveillance, detection and management; risk assessment and prevention in key settings such as workplaces, social institutions; markets and public spaces.

c. **Community engagement, action, collaboration, co-determination within key elements of care and protection-** including outreach to and support for uptake of key COVID-19 related services and in key social groups; avoiding displacement / fallout from other essential services; rational prescribing, oversight and uptake of key therapies; accessing, (co)-producing and quality control of essential health technologies for COVID-19 care and follow up rehabilitation and care.

d. **Community engagement, action, collaboration, co-determination within key elements of wider social protection**–such as on employment security and income support; food security; education services; social support and mental health support.

The experiences covered in the individual case studies cover one or more of these areas above, specifically in relation to COVID-19, with specific concrete experiences to report, rather than guidelines or manifestos. They took place within rural or urban local authority areas; at state or provincial level or nationally. They may have been time limited or sustained, formal or informal and self or externally initiated, self-organized or stimulated by partnerships with civil society, state and other non-state actors. The spectrum is wide, from grassroots activist initiatives to citizen-driven funding. Many were still in process, still building learning from practice in a context of a changing pandemic profile and demands.

Our intention for this document

We aimed to produce an accessible document that provides evidence of practical and affirmative options of people-centred, participatory forms of community engagement in diverse areas of response to COVID-19. We hope that the narratives of specific experiences inspire, inform and support others involved in or seeking to take such actions and that they highlight the spectrum of self-determination and participation that communities *can* implement in responding to COVID-19, as subjects and partners in and not objects of public health and other responses.

1.2 The methods and work implemented to outline community actions

In August and September 2020, Training and Research Support Centre (TARSC) as cluster lead of the 'Equity Watch' work in the Regional Network for Equity in Health in east and southern Africa (EQUINET) www.equinetafrica.org and in Shaping health https://www.shapinghealth.org/ gathered structured case study evidence on meaningful engagement, involvement and action of affected communities in the different dimensions of the response to COVID-19..

Thirteen detailed individual case studies were prepared by volunteering authors responding to an open call on EQUINET's pra4equity list, and the Health Systems Global SHAPES list, both including several hundred people involved in work on social dimensions of health. Authors were also referred in the call to a separate online questionnaire survey that was in progress by 'the Collectivity' to gather information on how countries are innovating and involving community networks to manage COVID-19. That work is not reported here.

The authors of many of the individual case studies came from the organizations directly involved in the work. The further desk review of 29 brief case studies was prepared from keyword searches of online public domain information from Google Scholar and SocArxiv (where notably limited information was found), from grey literature, from online reports, media, blogs and programme and institutional websites, from email lists, from online compendia collating community engagement and support efforts in diverse settings (Mutual aid disaster relief , idealist.org, open government, and Local mutual aid communities), and from key informants. The source material was primarily in English although some was in local languages of the settings covered. We chose case studies that collectively covered all four forms of social participation in COVID-19 outlined in *Section 1.1,* that covered different regions of the world and where there was adequate public domain published information for a case study.

The individual case studies used a common framework for organizing the evidence, combining 1-2 pages of text and open access/ creative commons graphics or those provided by authors with permissions for each case study. Each had a title, identified the location and brief key features of the context, the social setting and groups involved, relevant features of the organization of the response to COVID-19 and the key features of the community engagement and action, in terms of what was implemented, by whom, with what evidence and inputs and through what processes.

The case studies captured the co-ordination of and partnerships built with state and non-state actors in these actions, and the outcomes and reported progress and experience to date. Evidence presented in original sources on factors that enabled / disabled the experience and any insights from it were included, together with reflections from the case study authors. The direct links are cited with the case studies with key references for each, while general materials used are provided in the reference list.

The case studies were key sources of information for this report, together with other brief information from online websites, images, videos and evidence from selected desk reviews on community engagement and social participation. This information were used to prepare this synthesis document. It outlines experiences that indicate the opportunities and possibilities for meaningful community engagement. The findings were used to prepare shared reflections from all authors, integrating the outcome of a discussion on the draft in a remote meeting of authors in September 2020.

This report is not intended to be an exhaustive systematic review nor a theoretical analysis. The scope of case studies was limited by resources and the work was carried out in 8 weeks.

Food support In Andhra Pradesh, India, during the lockdown

Gospel for Asia, 2020

We are aware of the rapid pace of the pandemic, the complexity of situations it has led to, and that much initiative underway in and by communities is not documented, nor posted online. We appreciate given the time scale of the pandemic that the performance or impact of the experiences documented may not have been formally evaluated. We understand that reporting may not be free of a positive bias. We expect challenges from our own experience of community work and did document these where they were noted.

For the individual authored case studies, the authors checked the content with or obtained permission of relevant civil society organizations, or are themselves from the lead organization. This was not possible with the briefs from online desk reviews, where we relied on existing public domain information. Here we needed to assume that these ethical duties had been implemented by the original authors. We hoped to profile the direct voice of the community organizations and where this was possible we do this. However using secondary data does not always make this feasible. Where feasible, each case study provides a direct link to lead organizations implementing the work for follow up by those interested and pertinent references.

Notwithstanding these limitations, we consider that the information on the scope and organization of the work outlined in this text provides important information for those seeking to advocate and implement more effective community engagement on COVID-19. The 42 case studies follow in *Sections 3-6* organized by the four key areas. We also appreciate that there may be many other experiences, and welcome and hope this report will stimulate further documenting of experience, sharing and exchange, within and across countries.

2. The COVID-19 pandemic

We are not able to make direct epidemiological links between initiatives and case and fatality rates, with local evidence often not available and because widely varying testing rates affected confidence in the data. Specific epidemiological findings where available are noted in individual case studies. To locate the case studies, *Table 1* provides the situation in relation the date of the index case, the case, death and testing rates and the trajectory of the pandemic as of September 14th 2020 for the countries covered. Further detail on the pandemic and broad responses for any country can be found in other sources.

Table 1. Overview of COVID-19 epidemiology in case study countries

Country/State	Date of index case	Cumulative cases/million	Cumulative deaths/million	Cumulative tests/million	Current trajectory
Brazil	Feb 25	20 343	619	68 144	
Argentina	Mar 3	12 269	252	34 524	
United States	Jan 13	20 275	599	279 178	
Haiti	Mar 20	744	19	2 253	
Syria	Mar 22	201	9	0	
Yemen	Apr 10	67	19	0	
India	Jan 30	3 528	58	41 395	
Philippines	Mar 8	2 420	42	28 360	
Taiwan	Jan 21	21	0.3	3 770	
Italy	Jan 31	4 777	589	163 185	
Burkina Faso	Mar 14	82	3	Not available	
Cameroon	Mar 6	756	16	5 586	
Ivory Coast	Mar 16	719	5	5 420	
Kenya	Mar 13	670	12	8 925	
Malawi	Apr 5	306	4	42 284	
Mauritania	Mar 13	1 557	34	16 317	
Mozambique	Mar 22	168	1	114 333	
Nigeria	Feb 28	272	5	2 125	
Senegal	Mar 4	850	18	9 483	
South Africa	Mar 5	10 928	260	65 902	
Zimbabwe	Mar 22	505	15	10 403	

Source: Worldometer, https://www.worldometers.info/coronavirus/ September 14 , 2020

3. Case studies of community engagement on prevention

The first three case studies report community initiatives on health technologies for prevention.

3.1 g0v: civil society mapping of mask availability in Taiwan

A decentralized civil society technical community in Taiwan called 'g0v' mapped mask availability at various convenience stores using real-time data reported by civilians and by the National Health Insurance Administration's databases. For further information see: g0v: http://g0v.asia

Taiwan's national health insurance (NHI) provides each citizen with a healthcare card with a unique ID. Doctors use these cards to access patients' medical records online. The country's strong digital systems in healthcare were assets in responding to COVID-19, for medical personnel to track people at risk due to travel data from immigration and customs or those with severe respiratory symptoms to be tested for COVID-19. The country had relatively few COVID-19 cases despite its proximity to China and not applying a lockdown, attributed in part by the Taiwan's Digital Minister to the strength of its digital healthcare information system.

g0v is a decentralized, grassroots community focused on transparency, good governance and bottom-up solutions for information technology (IT) that involve social participation. g0v has about 4 000 participants working on a variety of projects, all of which are open source and initiated and organized by citizens from any background and education level. Its projects are built by "citizens' spontaneous collaboration for the public good," including in annual "Hackathon" workshops where citizens of diverse backgrounds are invited to participate.

g0v Logo and Diagram

Source; screenshot from http://g0v.asia

From late February, when reported daily new cases of COVID-19 in Taiwan were still in single digits, g0v held a 100-person computer event in Tainan city. In response to widespread concern and uncertainty around mask availability, participants developed a crowd-sourced and continually updated online map of convenience stores on the island that had masks in stock and available for purchase. g0v used data collected and updated by local people to prepare and update the map to show where to buy masks. The online map 'went viral' shortly thereafter and was widely used throughout most of urban and rural Taiwan in the initial weeks of the pandemic, easing anxiety on mask availability. People checked the maps less frequently after the initial spike in use as the anxiety declined.

g0v worked with the Digital Minister Audrey Tang and the NHI administration to obtain more rapid extensive data on mask availability from government databases. This partnership eased distrust of the government among some citizens. Tang described the participatory 'mask map' as a way for citizens to govern themselves while also working with and improving relations with government, given the transparency in the design of the project. The mapping began as citizen-led technology, drawing on g0v's way of working that existed before COVID-19. It later received government support and amplification given recognition of its role in increasing community engagement in preventing the spread of COVID-19.

1. Chen, P.-Y., Liu, Y.-C., and Chang, H. (2020). Mask Map - Cooperation Between Government and Community. *Fight COVID Taiwan*. https://fightCOVID.edu.tw/specific-topics/mask-map
2. Jaffe, E. (2020). How open data and civic participation helped Taiwan slow COVID. *Medium.com,* March 27,. https://medium.com/sidewalk-talk/how-open-data-and-civic-participation-helped-taiwan-slow-COVID-b1449bab5841
3. Kimbrough, S. O., and Chou, C. (2020). Taiwan's Tech-savvy Citizens Helped Flatten Its COVID-19 Curve. *Knowledge@Wharton*. https://knowledge.wharton.upenn.edu/article/taiwans-tech-savvy-citizens-helped-flatten-COVID-19-curve/

3.2 Women volunteers producing of protective equipment in Yemen

Female volunteers from six villages in Yemen's rural Mabyan district organized and were trained to produce face masks and personal protective equipment (PPE) suits to accredited standards for medical staff from six different medical centres. For further information see UNDP Yemen

Yemen has been in a war since 2015. Many of its healthcare facilities are no longer able to provide health care, over 100 000 people have died as a result of violence and famine and more than three-quarters of the population need humanitarian assistance. There is thus concern about the impact that COVID-19 will have. By mid-July, there were 1 500 confirmed cases and over 400 deaths, but these numbers were thought to be an underestimate due to limited testing capabilities. The WHO fear that up to half of Yemen's 26 million people could contract COVID-19. Healthcare workers in some facilities lack basic PPE and are thus at risk of contracting COVID-19. Trade embargos and economic sanctions imposed by the US, UK and other countries have restricted the supply of PPE and other supplies and equipment for health services. With a national health system already under pressure and with limited resources to respond to the pandemic, the country's response has relied on humanitarian assistance from UN agencies and the European Union.

In late April 2020, the lack of masks, gowns and other PPE for health workers motivated community members to address the need. Local Village Cooperative Councils in Mabyan district and the local Women's Association led the effort to train women on how to sew face masks and protective suits to an accredited standard, with funding from the Yemen government's Social Fund for Development, the European Union, and the United Nations Development Programme (UNDP). The women initially trained others in the skills learned. The women had by late May produced over 1 500 face masks and 500 protective suits in centres in six different villages.

The demand for PPE and the success of this initiative has sparked similar initiatives in five other districts, according to Social Fund for Development Director Hameed Ai-Names, using funds from humanitarian aid to support these local capacity building activities for community contribution to their services. Cooperation with the local Ministry of Health office in the production of PPE was important to ensure that it was in accordance with local medical standards. The Village Cooperative Councils enjoy autonomy in managing such local support activities and have been successful in recruiting volunteers, with a history of developing such locally relevant projects.

Community women in initiatives to produce COVID-19 PPE

Source; UNDP Yemen, 2020

1. al-Ahmadi, A. (2020). Funding shortfall risks COVID-19 spread in Yemen: UN. *Andolu Agency,* July 15,. https://www.aa.com.tr/en/middle-east/funding-shortfall-risks-COVID-19-spread-in-yemen-un/1911305
2. UNDP (2018). In Yemen, Village Cooperative Councils improve access to basic services. *UNDP Brussels*. https://www.undp.org/content/brussels/en/home/stories/in-yemen--village-cooperative-councils-improve-access-to-basic-s.html
3. UNICEF (2020). As COVID-19 intensifies suffering in Yemen, the EU increases vital support for children and their families. *ReliefWeb*. https://reliefweb.int/report/yemen/COVID-19-intensifies-suffering-yemen-eu-increases-vital-support-children-and-their
4. UNDP. (2020). Empowering Communities to Lead COVID-19 Fight. UNDP, New York

3.3 Producing open-source prevention kits in Cameroon

Mboalab is a small open science initiative in Cameroon supported the training of community members to produce open source, do-it-yourself PPE such as masks and hand sanitizers, and to design public awareness flyers. For further information see: https://app.jogl.io/project/217 and the MboaLab home page https://www.mboalab.africa

Cameroon has more than 200 ethnic groups, with a cultural division between north and south. Most people live in urban centres, while the agricultural sector and informal sector are the main sources of employment. The health system has a shortage of health care workers and inequalities in the distribution of healthcare across the country. During the COVID-19 pandemic, the government provided messaging on regular hand-washing and physical distancing and has isolated tested and implemented contact tracing from initial cases onwards. It has, however, struggled to maintain sufficient testing and tracing and faces shortages of PPE for health workers and community members.

After March 2020, when cases began to rise in Cameroon, Mboalab, a small open science initiative based in the village of Mefou-Assi in Yaoundé, explored the role it could play. Mboalab connects communities with academic research, educates community members and develops collaborative solutions to local problems. Its collaborative projects include a CAS-12 Typhoid project to develop locally produced typhoid diagnostic equipment and scientific capacity among local residents, and participation in the African Open Science and Hardware Summit.

Front page of MboaLab website:

Mboalab. 2020

Building on its prior social relationships and collaborations in citizen science with local communities, in this initiative on COVID-19, MboaLab staff worked with people from the Mbankomo area to develop an effective, affordable and acceptable open-source protocol for producing hand sanitizer, medical visors and face masks. Lab staff ensured that manufacturing procedures were consistent with USA FDA and CDC standards. Mboalab staff met with local community representatives to explore how these open-source prevention kits could be safely and sustainably produced by local residents in the area. Community members were recruited to participate in testing PPE product quality, organizing prevention kits, and distributing the kits to different neighbourhoods and health centres. MboaLab particularly engaged community members that had experienced violence and displacement.

Mboalab workers used the capacity building of local communities to produce PPE for themselves and for local medical personnel. It was also as a vehicle for informing people on COVID-19 prevention measures. Integrating local residents in the planning and co-production of these resources was seen to enable them to better adapt and modify the products in the prevention kits in future pandemics. The success of the effort depended on pre-existing social relationships between Mboalab staff and community members and access to open-source/open-science resources on PPE production and safety standards.

1. Kindzeka, M. E. (2020). Cameroon Doctors Ask for Protection as Attacks by COVID Carriers Increase. *VOA News*. May 18, https://www.voanews.com/africa/cameroon-doctors-ask-protection-attacks-COVID-carriers-increase
2. Tandi, T. E., Cho, Y., Akam, A. J.-C., Afoh, C. O., Ryu, S. H., Choi, M. S., Kim, K., and Choi, J. W. (2015). Cameroon public health sector: shortage and inequalities in geographic distribution of health personnel. *International Journal for Equity in Health*, *14*, 43-43. https://doi.org/10.1186/s12939-015-0172-0
3. UNAIDS. (2020). Dealing with COVID-19 in Cameroon. https://www.unaids.org/en/resources/presscentre/featurestories/2020/may/20200511_COVID19-cameroon

The next seven case studies report initiatives in diverse communities on prevention outreach.

3.4 Community support for prevention in Mangochi district, Malawi

In Mangochi district Malawi, community leaders and members supported the local district administration to engage returning migrants and improve uptake of testing and contact tracing, and to propose and distribute support to families during the lockdown to facilitate adherence to prevention measures. For further information contact Country Minders for Peoples Development.

Mangochi district's 1.1 million people were seen to have a high risk of COVID-19 due to tourism and migrant travel from South Africa and other neighbouring countries. The district has a commercial hub and the lake that generates income from tourism and fishing, and migrants seldom follow formal immigration procedures, raising the risk of imported cases.

After confirming the first COVID-19 cases on 2 April 2020, a Presidential Taskforce on COVID-19 was set up with representation of diverse disciplines including civil society.
Mangochi district recorded its first COVID-19 case on May 8. Initially the district response was top-down, with planning, awareness raising, contact-tracing, and other preventive measures done by the District Assembly and international non-government organizations (NGOs) without meaningful community engagement. The district found it hard to identify, test, quarantine or contact trace immigrants without the engaging community and traditional leaders, area development committees, village development committees, health centre committees, community health workers, community-based organizations (CBOs) and community members.

Map of Malawi,

Worldometer, 2020

The District's Chief Preventive Health Officer noted that some people were hiding new arrivals, or were not coming for repeat tests after the first test. Immigration officials in the district saw that engagement and cooperation of communities living at the border was key for successful prevention. Communication was thus built between the district and the traditional and community leaders and families of returnees on COVID-19 prevention guidelines and measures. In turn they encouraged returnees to go voluntarily for testing together with their contacts. This community led engagement with returnees was more successful and was noted by the district COVID-19 Response Team to be leading to more effective contact-tracing.

With the 'lockdown' measures threatening local economic activities and in turn adherence to prevention measures, government, international NGOs and the district administration engaged and took input from community leaders on the support needed. Community members participated in distributing washable face-masks, hand-washing buckets, soap, emergency seeds, livestock and equipment and take-home food rations and nutrition support for children. Some tailors in the district were given materials and resources and began manufacturing and selling washable face-masks at affordable prices in their communities, providing both timely availability of face-masks at low cost and an economic boost for them and their families. Including traditional and community leaders and communities in the district response has produced positive results, including lower levels of COVID-19 cases than projected.

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3. Mamba K (2020a) "Mangochi Cumulative COVID-19 Cases Now At 22", Malawi News Agency Malawi, Mangochi,15 June 2020
4. Mamba K (2020b), "Mangochi DHSS Stresses On Prevention As COVID-19 Cases Soar", Malawi News Agency, Malawi, Mangochi, 10 July 2020
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3.5 Community health worker outreach to migrant workers in Mozambique

A network of community health workers in Mozambique, supported by the International Organization of Migration (IOM), built on years of community work to connect and support migrants coming from South Africa to southern Mozambique to provide information, track symptoms and support follow up prevention. For further information contact IOM in Mozambique

The southern provinces of Mozambique have both urban / peri-urban and rural populations. With relatively infertile farmland, many local residents travel to South Africa to work in mines and farms, with about 24 000 Mozambicans work in the mining sector and over 80 000 on farms. Public health services are weak. The Mozambique government reacted quickly to COVID-19, closing borders and suspending public gatherings. The country reported few cases in the first few months of the pandemic, as a result of both measures implemented and limited testing.

In late March, notwithstanding the low case numbers reported from Mozambique, but with daily cases above 100 in neighbouring South Africa, more than 14,000 Mozambican workers in South Africa returned to Mozambique over the course of a few days after South Africa declared a lockdown. Community health workers (CHWs) recruited from local communities have been trained and supported through local NGOs by IOM across the southern provinces in Mozambique, with financial support from a number of international agencies. They have worked over the past several years on a cross-border health program in cooperation with the Mozambican Miners Association and Mozambique's Ministries of Health and Labour, Employment and Social Security.

In March 2020, the CHWs contacted migrants by phone obtaining contacts from IOM's registry of active mine workers and from community and traditional leaders and traditional medicine practitioners. They communicated information to the returning migrant workers about prevention methods, COVID-19 symptoms and mandatory quarantine, backed by local radio broadcast information and handwashing stations in resettlement sites initially constructed for people displaced by cyclones in 2019. CHWs informed IOM weekly about any symptoms of migrant workers' who then shared the information with the Ministry of Health.

IOM and CHWs discussing the 16 days campaign.

UN Women/Leovigildo Nhampule,, 2020

With limited access to testing and lack of medical resources, the government and IOM focused on preventive and mitigation measures implemented by CHW cadres close to the community. The focus on preventing spread from cross-border migration in the early stages of the pandemic addressed an important route of transmission. CHWs contacting migrants by phone and symptom checking provided an alternative way of tracking spread given limited availability of tests. That CHWs had been working closely with communities in the southern provinces for many years meant they could build on trust and existing relationships with diverse community stakeholders in the complex effort to track and support returning migrants.

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3.6 Community prevention activities in Dharavi, India

The Dharavi settlement in Mumbai, India has won appraise for its community engagement strategy and testing and treatment methods during the COVID-19 pandemic. Making community engagement central in public health efforts has helped local residents overcome unique challenges the area faces.

Dharavi, Mumbai, India is one of the largest informal settlements in Asia, located in the megacity of Mumbai. With 1.5 million people Dharavi is said to be one of the world's densest urban settlements. While urban areas have slightly better access to healthcare than rural, they contend with dramatic overcrowding and environmental pollution. India is one of only three countries to have surpassed three million COVID-19 cases. Testing for COVID-19 has been lower than it should be. In Dharavi, population density exacerbates virus transmission. While the lockdown imposed during the initial phases of the pandemic was later lifted to stimulate the economy, cases then surged.

In early April 2020, as daily new cases and deaths rose, the Municipal Corporation of Greater Mumbai built quarantine facilities, brought in more medical practitioners, and isolated vulnerable populations, aligned with the government's key priorities of tracing, tracking, testing, and treating. They engaged community members to take part in these initiatives and to promote awareness of public health guidelines. Those who tested positive for COVID-19 and had symptoms were isolated and offered free food and medical care. Community bathrooms and toilets were frequently cleaned. Community members and NGOs helped to maintain a steady supply of goods and essential equipment to the quarantine centres. Public awareness and community engagement were supported and facilitated through media, songs and radio programmes. Masked rappers created a song about adherence to public health guidelines, with information about COVID-19.

These activities enabled exposure or infection to be more rapidly identified. In early June, more than 600 000 people were screened, and 1 830 positives COVID-19 cases detected. In July, the number of positive cases sharply declined, and the curve had flattened in Dharavi. The number of cases was reported to be 2 370—or about 3% of the total number in Mumbai.

Dharavi near Mahim Junction.

A. Savin, 2020

The response in Dharavi has won widespread recognition from outside observers including the WHO Director-General for its effective partnership between government, private sector, civil society, academic and community actors and for generating a sense of ownership in COVID-19 efforts amongst community members. Dharavi was predicted to be devastated by COVID-19, but the response was effective in containing the virus. The experience demonstrates that socio-economic hurdles can be overcome by such collaborative approaches that build on long-standing relationships and networks when a public health emergency hits.

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3.7 Self-organized prevention on Native American Reservations

Many Native American and Alaskan Native tribes have decided to take their own prevention and surveillance measures, independent of the US federal government. They have closed their borders after recognising that surges in cases in the state could disproportionately impact tribal members. When states began reopening, some tribal officials did not relax prevention methods.

Native American reservations in mid-western and western states in the US are recognized as semi-independent political entities with treaties with the U.S government. They tend to be rural with economies that are heavily dependent on gaming and hospitality services, with systemic inequality, higher mortality than for white Americans and limited health care. Treaties are supposed to afford reservations independence and federal support. Pandemic costs have drained funds from tribal governments from healthcare, education and public safety, funded from local economic activities. The U.S. federal government has provided some unemployment and eviction relief to citizens but has not met the needs of Native communities in contrast to treaty provisions. Tribal leaders have voiced concern to the government about inadequate resources to respond to COVID-19. Under treaty policies, the government is supposed to supply resources with tribes having the power to determine how such resources are used. Between April and June 2020, only 4.8 billion of the 8 billion dollars that indigenous tribes are collectively entitled to through the CARES Act had been allocated, far less than the resources needed.

Navajo Council delegate meeting

K Benally, Wikimedia commons

Between late May and early June 2020, reported daily new cases in Arizona, the site of one of these reservations rose from 388 to over 1 000. With their significantly greater vulnerability to COVID-19 and the surge in cases that accompanied the reopening of other states, several tribes closed their borders to non-residents, with checkpoints for non-residents traveling on reservation roads, and some imposed curfews for residents and some to protect their hard-won gains in COVID-19 prevention. Checkpoints reduced the risk of sick people entering reservations. Leaders of the Yurok tribe imposed shelter-in-place orders for residents in order to reduce contact among people and therefore transmission rates. Given inadequate support from the federal government, these self-organizing efforts are reported to have had a significant impact in reducing COVID-19 case incidence in some areas. In the Navajo Nation, the number of new cases declined from May 2020 to June 2020.

These efforts by sovereign tribal governments to self-organize a precautionary local pandemic response contrasted with state-level moves towards re-opening. They have generated some controversy from non-native communities and governments. However, they have also been recognised by many public health experts and local community residents. The latter felt that the restrictions protect their most vulnerable members and also demonstrate tribal sovereignty and governance in response to the pandemic.

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3.8 Active Community Surveillance in Abuja, Nigeria

Nigeria's Emergency Operations Centre, consisting of members from several branches of the Nigerian Government and other multi-national organizations worked with community leaders and through them community members to implement community surveillance methods to encourage testing and tracing of contacts and to ensure tracing of cases of COVID-19 and their contacts.

The Federal Capital Territory (FCT), Abuja is the capital of Nigeria. Abuja is one of the wealthiest cities in Nigeria, however, many community members live in poverty and have limited or no access to phones and internet. The first COVID-19 cases in the FCT were confirmed on March 20 and the multi-sectoral COVID-19 Emergency Operations Centre (EOC) was activated three days later, involving national and international organizations. While the initial strategy was to find cases through calls from neighbours and clinicians, Abuja went into lockdown on March 31.

EOC's initial strategy relied on passive case finding and little engagement beyond local government institutions, with limited testing and inadequate evidence on viral spread. The EOC soon shifted to a community surveillance method. This focused on working more closely with community leaders, who would in turn encourage community members to get tested at the designated client triage and sample collection sites if experiencing symptoms and sometimes without symptoms.

Health outreach in Nigeria

CDC Global, 2020

The community surveillance method aimed to reach community members who had limited access to internet or information about how to get tested and the follow up measures. The initiative included initial meetings with community leaders to make sure that they understood the testing plan and discuss the information and strategies to encourage community members to attend testing. They developed a public awareness drive to inform the community using print, TV/radio, social media and public announcement vans. They also held daily meetings with community members at sample collection points before testing began to address concerns and questions. Community leaders helped to manage crowd flow, dispense masks and hand sanitiser and ensure social distancing.

The campaign led to a significant increase in case finding. Before the shift towards community active surveillance, COVID-19 reports were declining, likely due to a lack of access to updated COVID-19 information as well as greater social isolation because of the lockdown. Program organizers felt that improving the frequency of community feedback and moving beyond existing community leaders to work more closely with community health care providers like traditional and spiritual healers would further increase the impact the program.

Hamisu AW, Ayodeji IH, Furera Z, et al., (2020). Assessment of the Contribution of Community Active Surveillance to COVID-19 Case Detection in the Federal Capital Territory, Abuja, Nigeria. *African Journal of Biology and Medical Research*, *3*(2). https://abjournals.org/african-journal-of-biology-and-medical-research-ajbmr/wp-content/uploads/sites/17/journal/published_paper/volume-3/issue-2/AJBMR_O48YMGC3.pdf

3.9 Community-Driven Reponses in Northwest Syria

The health system in northwest Syria has limited capacity and resources to provide quality care. The ongoing civil war makes coordinating responses to the pandemic extremely difficult. Despite this, COVID-19 prevention is taking place through community engagement and bottom-up governance, supported by diaspora Syrians, use of social media and other online platforms.

Syria has been suffering from a prolonged war that has lasted nearly a decade and decimated much of the country's infrastructure and economy. Prolonged conflict has displaced 2.8 million people out of 3.5 million and has resulted in 83% of Syrians living below the poverty line, with displacement, poverty and a fragile health system. War has raised the risk of rapid transmission of the novel coronavirus. Added to this, there is limited access to health care services, health workers and infrastructure. Northwest Syria, the site of this case study, is isolated from surrounding areas. It is home to several different military factions fighting for control. As a result, efforts to coordinate a COVID-19 response have been difficult.

The Syrian Government has applied a series of lockdowns, curfews and border controls and the health system has worked with international funders and the UN to prepare for the expected rise in cases. While there were only three deaths from COVID-19 reported in Syria in March when this experience was initiated, the poor infrastructure, reported widespread mistrust of the government and under-reporting suggest that the true number of COVID-19 cases is much higher.

In North-west Syria, in response to this situation, local Syrian actors like the White Helmets (or Syrian Civil Defence) created a large campaign - 'Volunteers Against Corona' - to mobilize volunteers from various regions to respond to COVID-19. Volunteers were organized into technical teams and neighbourhood committees and tasked with raising awareness, supporting disinfection campaigns and referring community members to medical care. Volunteers were zoned by their neighbourhoods and took part in protecting high-risk people and linking local communities to a central campaign.

Social media platforms such Facebook, cloud web services, and WhatsApp have been used for communicating among volunteers. The considerable Syrian medical diaspora (largely in France and the UK) has kept the local health system up to date with the latest information on the coronavirus. Platforms such as WhatsApp and Google Meet have been used to provide information and training for health workers.

An Early Warning and Response Network established in 2013 has been used to monitor COVID-19 outbreaks and has also helped to provide PCR testing, supplied from the WHO. Given a lack of capacity, the health system focused on preventive measures. A local NGO has worked closely with neighbourhood and community groups to set up an online platform to support initial self-health assessment to reduce pressure on the health system. The Idleb Health Directorate, a local technical health authority in the area, created a grassroots governance system to increase its legitimacy and trust among local community members.

The response in Northwest Syria demonstrated that effective, creative, bottom-up planning and community collaboration can support prevention of COVID-19 outbreaks, even in the absence of a strong central government or sufficient funding. The initiatives fill, in part, significant gaps in services and resources arising from the ongoing civil war. Local responses to previous outbreaks, including polio in 2013 and the learning from them have been crucial in designing and laying the foundation for the responses to COVID-19, with support from global and diaspora relationships and agencies.

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3.10 Using local radio stations for prevention: learning from Union des Radio et Télévision Libres du Mali (URTEL) in Mali

A network of local radio stations in Mali, URTEL, partnered with domestic and international organizations has enabled information flow to communities even in an area affected by conflict in Gao region, Mali, For further information see URTEL, https://www.facebook.com/urtelmali/

In 2017, Mali had 18,9million people, with Islam the most widely practiced religion (95%). Gao is the capital city of the region of Gao, located on the Niger River. From 2012 to 2013, it was the self-proclaimed capital of the secessionist territory of Azawad. COVID-19 was first reported in Mali on 24 March with 2 640 cases and 124 deaths by August. The Mali government has developed a preparedness and response plan including risk communication and community engagement that intends to cover all regions of Mali. Given the conflict in the region, the Gao government met with the local committees to discuss information outreach to students, populations and security agents on the pandemic, working with international organization like the United Nations Multidimensional Integrated Stabilization Mission In Mali (MINUSMA). One of the organizations that contributed to this discussion and the implementation of national plan in a conflict area like Goa was Union des Radio et Television Libre du Mali (URTEL).

Created in 1991, URTEL is a network of 350 affiliated rural and urban radio stations. It promotes free radio and television broadcasts. In response to COVID-19, the URTEL network provided a means to reach people in an area of conflict where government services are not present. URTEL and its network radio members in Gao worked through their local network to provide daily updates on the progression of COVID-19 in Mali and the actions to respond to it. As part of their partnership with MINUSMA, some radio stations rebroadcast the program "Objectif Santé", a UN radio program, produced with the participation of WHO and Malian health actors on COVID-19.

URTEL representative giving masks to local radio personnel in the Gao region

MINUSMA, 2020

Through its regional and communal councils, URTEL members disseminated video messages from influential community and local opinion leaders and faith based organizations through social networks and radio programs. A program called 'The Voice of Youth and Children', gave voice to local children. Masks were distributed to journalists in conflict regions in collaboration with MINUSMA and government. MINUSMA provided air transport for URTEL journalists and radio hosts to reach all parts of the region.

The existence of a local radio station network and partnerships in the country and with international organizations contributed to the success of this intervention. URTEL's wide network of radio stations provided the possibility of synchronised radio broadcasts through many local radio stations, even in a region affected by conflict. Resources were pooled to enable production of audio-visual information for communication and broadcasting. The collaboration with MINUSMA and local organizations in the region also enabled URTEL's interventions in Gao. Over the years the local radio stations have forged relationships with the Gao population, enabling the journalists and giving legitimacy, Links between the radio stations and local organizations helped to bring materials to journalists and action on the ground.

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3. MINUSMA. (2020a). *À Gao, les radios de proximité et les acteurs de la société civile s'engagent dans la prévention de la COVID19.* MINUSMA.
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4. Case studies of community engagement on care and protection

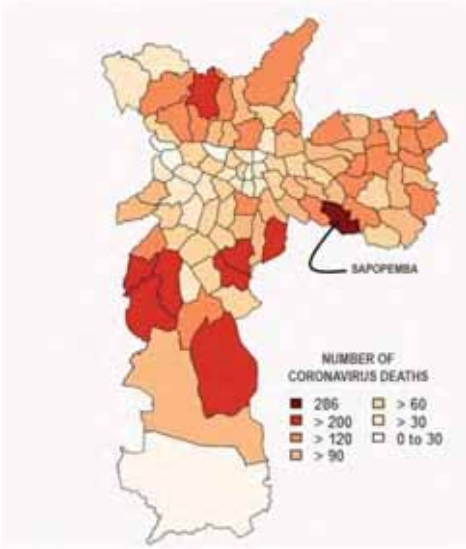
Care and protection have taken many forms, often integrated, as reflected in this first case.

4.1 Social mobilization for health and cross sectoral action in São Paulo

The Sapopemba Life Brigade built on a long history of social movements around local wellbeing to have remote meetings with residents, carry out their own surveys and widen social information and dialogue to engage health, education and other services to implement prevention, promotion and care support in the district. For further information see www.facebook.com/brigadapelavidasp/

Sapopemba district is located in São Paulo, with 284 524 people, about a fifth of whom are below the poverty line and living in slums, where there is often no piped water supply or sewerage. The neighborhood has a long history of social mobilization, and has won significant social welfare improvements, such as daycare for young children and basic education in public schools. Nearly 85% of the territory is served by 16 Basic Health Units, most implementing the Family Health Strategy (FHS), as well as three hospitals and three Psychosocial Care Centers. To date three basic physician visits/year are offered per user in the free at point of care national public health system, termed the SUS. While the SUS is resourced, organized and delivered though co-ordination between federal, state and municipal governments, this coordination has not functioned well during the pandemic. Brazil's president, Jair Bolsonaro, denied the pandemic's severity, undermining federal funding for the response and leaving state and municipal governments to play the central role. In São Paulo, the Municipal Health Secretariat (SMS) proactively set rules for social isolation and partial lock-down and set measures to identify, monitor and treat those infected or suspected of being infected with COVID-19. In Sapopemba, however, persistent vulnerabilities have both undermined their implementation and intensified mortality from the pandemic.

Total number of deaths in the city of São Paulo, per district, august 2020



Source: Mortality Information System - SIM/PRO-AIM/CEINFO, Municipal Secretary of Health of São Paulo

Faced with this crisis, leaders in Sapopemba's longstanding social movements on health, housing, childhood, adolescence and human rights, gathered to identify demands and responses. Inspired by the Emergency Health Brigade (organized in Brazil's Northeast), they aimed to combat the pandemic by defending rights, demanding accountability and supporting the state, while also promoting teaching and learning from the population. Having meetings online gave the welcome surprise of rapid progress. "It seems that we were even able to gather more, each person at their work or at home, discussing and highlighting solutions for this very difficult time that we are experiencing. I was excited; everything was so fast. We started in April and on May 25, we approved the Life Brigade Manifesto." (Francisca Ivaneide, a movement member)

The group aimed to implement Brigades in all 32 sub-districts of the city of São Paulo. The pace and format of the initiative in neighborhoods varied according to the organization and structure of the movements found in each territory. In Sapopemba, the presence of diverse social movements enabled a range of activities aimed at pressuring local authorities to apply preventive actions, as well as facilitating efforts to find locally appropriate solutions to the specific conditions in the district. One of the Brigade's first initiatives, with the help of city commissioners and congressional members, was to hold meetings with different municipal government departments to identify preventive actions. This dialogue was enabled by existing relationships between community members and technical personnel, such as the participatory councils of the SUS.

Citizens and council members were informed by Brigade members on how to connect digitally and invited to scheduled meetings. The first of these held on June 25 involved around 70 people,

including Brigade members, managers and health workers. This meeting called for more transparency and details on data on pandemic cases and deaths in each sub-area of the region.

When provided with this data, the Brigade discussed with personnel in the 16 Basic Health Units to identify and jointly co-ordinate actions and priority groups. One task force handed out protective masks donated by companies on the streets and talked with passers-by and merchants. Black cloths were placed on gates as a sign of mourning for the deaths in the community and a car with loudspeaker was provided by a union to honour victims. By mobilizing people who hold credibility in the region and using appropriate language to publicize the risks and number of deaths in different areas of the territory, this initiative helped to raise public awareness of the seriousness of the pandemic.

Brigade and SUS outreach activities , Sapopemba

E Silvério 2020

The Brigade carried out similarly co-ordinated actions around education. It has organized debates with school communities regarding the return to classes in September, given stark divisions in opinions around this return to school.

Brigade members have called attention to situations where infection risk is high, such as the street markets which remained opened during the quarantine. Their affordable prices make them very popular. They are normally organized in three rows, leading to crowding. The Brigade discussed with the Secretariat of Sub-Districts to rather organize markets in one long line to prevent this crowding, but with action yet taken by the time of writing this.

The Brigade carried out a survey to gain an in-depth understanding on risk factors, the impacts of the pandemic on the lives of residents and the difficulties they experienced in implementing responses. A commission of Brigade members working in different social areas designed the questionnaire and distributed it digitally to educators and families connected to schools and on paper to groups without easy digital access. A second phase survey is being designed for application at Basic Health Units, to survey people's knowledge of the epidemic and their experience during quarantine. Brigade members aim to use such information to identify priorities for action and to give it weight in negotiating for these actions with government.

"When the movement moves, the Secretariat moves." Brigade members and public health managers both say this, showing the support the Life Brigade brings to the SUS. The actions taken show how knowledge of local dynamics and links between social leaders and public managers has helped the work of the local health system and its links to the public. The experience of active citizenship around COVID-19 opens wider discussion on renewing the social participation arrangements in the SUS. In the harsh realities of Sapopemba, the Brigade innovated through promoting more integrated action between health, assistance, education and justice sectors to implement concrete actions in response to COVID-19.

The political relationships and trust accumulated over many years helped the Brigade leaders to link sectors of civil society organized in different areas of social policy, to foster inter-sectoral actions and to value the knowledge of those experiencing the local reality and who are familiar with its residents' needs. This innovative focus, the joint action by the movement with the region's public services and managers enabled a convergence of strategies, knowledge, information and action to support prevention, promotion and rights.

1. Demographic Census (2010). Characteristics of the population and their households: universal results. Rio de Janeiro: IBGE, 2011.
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The next four cases outline experiences of more direct engagement inside medical services.

4.2 Doula Care in Syracuse, New York USA amid COVID-19

Doulas (non-medical support persons who provide support before, during, and after childbirth through comfort measures and education) in Syracuse, NY transitioned to virtual support in accordance with COVID-19 restrictions and urged the state and hospitals to recognize their importance and facilitate their presence, virtually or in person. Contact Village Birth International

Syracuse, New York is a city with over 140 000 people, but with poor economic growth and high economic inequality. New York State has had one of the highest COVID-19 prevalence rates in the United States. Strict lockdowns and social distancing were initiated and hospitals implemented drastic measures to reduce infection, including limiting support of non-medical support from doulas in childbirth.

Community-based doula organizations in Syracuse include Doula 4 a Queen (D4Q) and Village Birth International (VBI). These organizations focus on maternal health, particularly for women of colour. Between 2006 and 2010, Black women in New York City were reported to be 12 times more likely to die from pregnancy-related causes than white women. A 2016 study found that in New York City, black college-educated mothers giving birth in local hospitals were nearly 3 times more likely to suffer severe complications than white women who never graduated from high school.

Screenshot, Village Birth International website,

https://villagebirthinternational.org/syracuse-ny/

As COVID-19 restrictions were put in place, the New York state governor created a task force to develop recommendations for maternal health. These recommendations described doulas as essential, but also stated that "Exceptions [to their exclusion from hospitals] should be made only in limited circumstances and based on clinical guidance, such as availability of PPE." Doulas said that while the governor's stance acknowledged their importance, it left the decision on their presence completely up the hospital. They raised concerns about the implications of COVID-19 for increased medical intervention, C-sections and postpartum care for women of colour.

COVID-19 restrictions prohibited or limited doulas from physically accompanying women during childbirth. VBI thus hosted free virtual doula training for any doula they trained. This enabled doulas to support mothers and families virtually. VBI also hosted a Zoom meeting about "Protecting birth justice during COVID-19."

When the governor released recommendations lessening restrictions, some doulas expressed concern that the governor's new description of doulas as essential was not paired with adequate funding to support their work, nor sufficient measures to ensure their safety when needed. Until in-person doula care could be both safe and supported by the hospital and the state, VBI and D4Q continued their work virtually.

VBI and D4Q rely heavily on grants as they provide care to mothers from marginalized communities who cannot typically afford to pay fees for care. While they used creative measures to sustain their care services virtually during restrictions, they have also been vocal about the need for further resources and protection from the state for their role. A founding VBI doula explained "there is so much more that needs to get done if you are going to make statements like 'doulas are essential.'"

Rivera, M. (August 11, 2020). New York's Virtual Black Birth Workers: A Birth Justice Response to COVID-19. *Blog: Medical Anthropology Quarterly*. http://medanthroquarterly.org/2020/08/11/new-yorks-virtual-black-birth-workers-a-birth-justice-response-to-COVID-19/

4.3 St. Boniface Hospital in Haiti Creates Disease Surveillance Teams

St. Boniface Hospital worked with community leaders in southern Haiti to monitor community members' symptoms. Community leaders also addressed mistrust in official medical information by providing leadership in encouraging COVID-19 prevention methods. For further information see Health Equity International: https://healthequityintl.org

St. Boniface Hospital is located in Fond-des-Blancs in Haiti and is the largest hospital in southern Haiti. Fond-des-Blancs is a rural mountainous area and has a huge infrastructure deficit. Marketplaces make up some of the only economic activity and agriculture is difficult because of a lack of irrigation canals.

When COVID-19 cases started to rise in Haiti after March, the Haitian Government closed schools, businesses and banned gatherings of over ten people. Masks were required in public and a 12pm curfew put in place. Commercial air travel was shut down in response to the pandemic but reopened on July 1 with a self-quarantine for 14 days and three rounds of symptom checks for new arrivals.

Community Health Workers in Fond-des-Blancs, Haiti

Mikaela Raphael, 2020

Health Equity International (HEI), a United States-based organization set up St. Boniface Hospital as part of the non-profit St. Boniface Haiti Foundation. HEI has worked hard to shift away from a visiting medical team model and now has more than 500 Haitian staff members. St. Boniface began with visiting medical teams from the USA, but now 98% of the staff are Haitian. The hospital funded education for local residents and later hired them in both medical and non-medical positions to locally run the hospital.

When the pandemic emerged, St. Boniface Hospital staff met with local religious leaders, school teachers, principals, and other community members to discuss these community leaders' roles in preventing the spread of COVID-19 and helping to address mistrust of official information about the virus. The hospital trained 63 community health workers on COVID-19. Most of them had grown up in the local area. They then worked outside the hospital to train community leaders to provide help with contact tracing and to encourage community members to take the virus seriously. The hospital also created disease surveillance teams consisting of the hospital's community health team and local community leaders. The teams monitored community members for COVID-19 symptoms during the course of their routine community health work and identified those in need of hospital care.

These actions were consistent with the way the hospital was engaging the community before the pandemic. The connections seemed to be crucial to build the trust needed between healthcare professionals and the local community for other measures to be effective. The use of local community health workers, the transition to a hospital staff of local Haitian medical professionals, and the active investment of responsibilities for community engagement in local community and religious leaders have all deepened the engagement between the hospital and the communities it serves.

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4.4 COVID-19 Care network: care support in Kolkata, West Bengal

A self-organized COVID care network of doctors and volunteers, many of whom are survivors or close family of survivors, uses telemedicine to provide guidance and counselling on social and medical issues. The network organized webinars and awareness campaigns to allay anxiety and stigma related to COVID-19. It monitors people in self isolation, refers cases to public services and arranges blood donations. Its registration with government enables effective links with public services. For further information see the COVID care network

Kolkata is a city-district and the capital of the Indian state of West Bengal. It acts as the principal commercial and education hub in Eastern India and is the third largest economy of the country. Kolkata Metropolitan Area has a population of over 14.1 million residents, with over one third living in slums and a constant inflow of migration from rural areas of Bengal.

India imposed a nationwide lockdown on 24 March 2020 that took people by surprise and generated harms for disadvantaged groups, like migrant workers. In this context, West Bengal government used a mix of innovation, sensitivity and debates in its management of the pandemic. The state used drones to monitor the lockdown and collect samples; partnered with a doctor's association, critical of its activity, to better handle the pandemic; announced a scheme offering government jobs to kin of frontline COVID-19 workers and volunteers who died on duty; and its police performed songs and skits on the roads to educate the public on COVID-19 prevention. The state has, however, faced challenges in meeting the demand for testing, with increasing caseloads and instances of admission refusal and overcharging in the private sector.

On 1st July, the COVID care network (CCN) was formed to provide integrated COVID care across the society. The idea was first conceived by doctors and professors at the Institute of Post-Graduate Medical Education and Research and Seth Sukhlal Karnani Memorial (IPGMER & SSKM) Hospital of Kolkata and then widely discussed in professional circles and with COVID survivors and their associates. It aimed to provide psycho-social assistance to COVID-19 patients and their families. There are now over 85 doctors and many more volunteers in the CCN, many survivors or close family of survivors, including in the medical personnel. "We all learned the hard way and so we decided to help people like us, who are facing the problem," said Madhabilata (model, founding member of the CCN).

The CCN registered with the West Bengal government. It largely uses telemedicine, providing assistance through dashboards, online portals and a 24*7 helpline number where experts and volunteers provide guidance and counselling on social and medical issues. It also organizes webinars, awareness campaigns to allay anxiety, fear, stigma and ostracization related to COVID-19.

In an interview, professor Sarkar of SSKM hospital's COVID-19 strategy team and involved with CCN commented, "People can't see the virus, and the infected person becomes representative of the virus….so there may not be physical lynching, but the psychological lynching has been there. The stigma causes guilt and patients are excommunicated and made to feel they don't have the right to live."

CCN team counselling residents about COVID-19 related stigma

Photo credit: CCN

The social support forum responds to the needs of those infected, including those who contact the helpline and those admitted in isolation facilities. CCN members contact them periodically

and monitor their health, providing updates to the state health department and provide them with certificates of completion of their 14 day quarantine to help prevent stigma. The CCN uses algorithms to risk stratify cases to assess their co-morbidity and need for hospital care and then referred as needed for treatment. For home care, CCN members advise people on a range of issues, such as their need for hospital care or home remedies such as taking lemon for vitamin C supplementation for suspected common colds. An MoU between the CCN and the government on counselling enabled CCN to coordinate with mainstream public sector hospitals, ambulances and triage medical care.

The CCN has recently expanded this initiative beyond Kolkata and has started working in Siliguri, a city in the north of West Bengal, after an alarming rise in its COVID-19 cases. The CCN reached out to the communities with the help of local clubs and organizations and collaborated with 105 other voluntary groups. It developed a Siliguri specific helpline support to provide medical consultations. Post graduate students and North Bengal Medical College and Hospital personnel joined the initiative as volunteers. They were trained in line with government guidelines to provide guidance on use of pulse oximeters to alert patients of falling oxygen levels, and notified government if a patient needed a test or admission.

CCN awareness campaign for the Indian railways staff

Photo credit: CCN

Together with Stellablue Interactive Services, CCN jointly developed the MEDePAL app, available for free download. The app has registered doctors, pharmacy and diagnostic laboratories and users can consult doctors by video, organize online delivery of medicines or book tests. Network members have actively participated in blood donation camps held across the city during the lockdown when the blood banks ran dry, the CCN has recently arranged blood donation camps and members have donated plasma for treatment of critical cases.

With costly care and bias in the private sector and an overwhelmed public health sector in the face of an increasing caseload, community initiatives like CCN complement and support public sector care. The CCN involved a diversity of group members, from doctors involved in COVID care to COVID-survivors who have experienced infection first-hand, bringing diverse insights and skills to different areas of need, from physical support to managing the social repercussions. The CCN activities thus allayed anxiety, fear and social ostracism, while also providing medical advice and contextually relevant social support. Volunteers from COVID-survivors provided peer support and hope that the crisis can be overcome. People looking after each other's' diverse needs and fighting the pandemic together, across communities, helped to crystallise that hope.

Acknowledgement for information for this case study is made to Dr Somdatta Satpathi, IPGMER & SSKM.

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4.5 Residents association engagement on healthcare in Paraisópolis, Brazil

The Residents Association in the Paraisópolis community of São Paulo, Brazil set up quarantine centres and trained volunteers to track community members' symptoms and help neighbours access food and healthcare. Similar efforts in other informal urban settlements across Brazil created pressure on the Brazilian Government to allocate more resources for the COVID-19 response in these areas.

Paraisópolis is one of the largest informal settlements in Brazil. The United Nations declared this densely packed urban setting "intolerable," because many residents struggle with food insecurity and lack basic services like running water and sewage. Jobs tend to be low income, require long travel from home, and have precarious conditions of employment. Paraisópolis is surrounded by some of the wealthiest areas in São Paulo. The community is tightly packed and many have no choice but to continue working, raising the risk of infection and outbreaks.

The residents association in Paraisópolis is composed of local community members. It operates independently of the Brazilian government. After the slow government response to COVID-19, the residents association took advantage of private donations through crowdfunding and mobilised community volunteers to deliver a variety of relief efforts. They started a "street president" program, where community volunteers monitor about 50 families each for COVID-19 symptoms. Volunteers were trained to communicate with sick residents remotely. They also took on being first responders to emergencies after they claimed that the local government failed to respond to emergency calls in these areas (government officials challenged these claims).

Crowdfunding campaigns helped to pay for a 24-hour ambulance in areas where emergency responses were insufficient. The residents association worked with city health workers, the NGO *Parceiros da Educação*, and São Paulo's Albert Einstein Medical School to transform local gyms and schools into quarantine centres. The residents held a socially distant march in São Paulo demanding water, food aid, public ambulances and virus testing. Activists from Paraisópolis and other favelas, many through the G10 Favelas Slum Summit, lobbied for a federal stipend for low income and unemployed workers. The government responded with a stipend of $112 equivalent per month for these workers from April to August 2020, extended at half the amount to December 2020. Some mayors have held video calls with residents associations to develop more pro-active responses to COVID-19.

Paraisópolis, São Paulo, Brazil,

https://commons.wikimedia.org/wiki/File:Paraisópolis_I.jpg

The $46.5 billion in emergency income support from Brazil's Congress far exceeded the total amount of private donations. While community efforts and donations filled an initial vacuum in state support, community organizations saw that it was important that it also put pressure on the government contribute to relief plans and provide public utilities and services.

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The remaining cases in this section outline experiences of social engagement on a diversity of areas of care and social protection directly linked to health, nutrition and wellbeing.

4.6 Community Action Networks for community support in South Africa

Community Action Networks in South Africa organize volunteers to provide solidarity support for community needs related to COVID-19. They have provided soup kitchens, held community theatre, provided care packs for the homeless, made masks, and held blanket and winter clothes drives. For further information see Cape Town Together and Muizenberg CAN.

South Africa has high levels of socio-economic inequality and poverty, that have deepened during the COVID-19 pandemic. Seven and a half million people in the country share communal taps and small living spaces, making social distancing difficult. South Africa implemented a strict lockdown on March 26. The government deployed over 28 000 community health workers to the highest-risk communities for active house-to-house case tracing and used contact tracing teams and systems that were previously used for controlling the spread of TB. Bureaucratic processes to access resources from a centralized Solidarity Fund left many poor families still in need of aid.

In mid-March, when COVID-19 incidence began to rise more rapidly Community Action Networks (CANs) began in Cape Town, in a model that subsequently spread across South Africa. The CAN model emerged as part of the 'Cape Town Together' community response to COVID-19, run by community organizers, activists, public health workers and artists.

"We run a community kitchen in Muizenberg to provide healthy food to our community during the COVID-19 crisis.

Photo: Brendon Bosworth.". https://www.muizenbergcan.org

CANs are online platforms and networks rooted in neighbourhoods. They connect diverse people to share ideas and take actions to respond to needs generated by the pandemic. CANs have helped to provide soup kitchens, they have put on community theatre events, put together care packs for the homeless, made masks, and held blanket and winter clothes drives. In Cape Town, there are over 2 000 volunteers in 150 CANS connected to the Cape Town Together network. Members of CANs in Muizenberg partner with local community kitchens. Many CANs use WhatsApp to communicate, and some have weekly video calls. The interactions and activities vary between CANs as they are defined by community members. Local city and provincial governments have sought to regulate CAN activities, such as by requiring that food donations are in line with local standards and monitored by local city authorities.

Dr. Leanne Brady, a health systems activist and member of the Salt River CAN comments: "Recognizing the incredibly stark inequality that we face, and taking on board how hard it would be to organize across race and class lines in a city divided as Cape Town, we wouldn't ever have imagined that so many people would start organizing on their own streets and coming to together to take action." The CANs' nature enabled adaptation to their participants' needs and skills, while also leading to variability in their performance. There are also concerns that CANs complement and do not substitute roles that the state has a duty to provide.

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4.7 Adolescent girls addressing COVID-19 needs times in Vadodara City

In response to COVID-19, SAHAJ, a non-profit organization in India, and community-based partners responded to various issues that emerged from the pandemic in Vadodara, working with young people and local leaders. They made masks, provided safety kits with various PPE, supported access to sanitary napkins and facilitated food distribution in a culturally appropriate manner that reached the most vulnerable families. For more details visit www.sahaj.org.in

Vadodara is one of the three most populous cities in Central Gujarat, with 336 slums housing more than a fifth of people in the city. The slums lack adequate roads and water and sanitation, and the people largely work as construction workers, painters, carpenters, office cleaners, cooks, caregivers and vendors. Gujarat is highly industrialised state providing work to millions of migrants, including from poorer states.

The first COVID-19 cases in the State were confirmed on March 19 and the Gujarat Government closed all educational institutions, malls, multiplexes, and swimming pools across the State for two weeks, and implemented a complete 21 day lockdown from March 24. The state delivered free food packages to isolated elderly persons; launched a mobile app to track home-quarantined persons; provided US$133 cash assistance to card-holding families; a US$800 package for lowest income families and food and accommodation to migrant workers while restricting their travel during the lockdown. In early April, 31 private hospitals across the state were insourced as COVID-19 hospitals. Testing was ramped up, albeit below what was required. Gujarat Government pressed upon industry to increase the production of PPEs and ventilators.

This is the context in within which the Society for Health Alternatives (SAHAJ) and community based partners responded to various issues that emerged from the COVID-19 pandemic in Vadodara. SAHAJ is a non-profit organization that has worked in Gujarat for over three decades on adolescent development and rights in five districts, within an overall goal to advance social justice through nurturing local leadership for comprehensive health and wellbeing.

Masks available in the market were expensive and in short supply. With guidance from the SAHAJ community organizer, the adolescents' girls group 'Akanksha' made 5 328 masks for SAHAJ's frontline workers and peer leaders in urban Vadodara. SAHAJ provided safety kits that included a sanitizer, hand towel, five masks and three pairs of hand gloves for 1 000 frontline workers and peer and community leaders working in five districts.

Girl from Mali Mahollah making masks for volunteers

Photo: Kalpana Mahadik, 2020

PPE kit was distributed to community volunteers

Photo: Alpana Nayi, 2020

During the lockdown, girls and women had difficulties accessing sanitary napkins as the lockdown affected their mobility and supply chains and with reduced family earnings sanitary

napkins were not a family priority. Girl members of the Yuva Working Group suggested to SAHAJ to keep sanitary pads with the Peer Leaders in each *basti* for girls to purchase them in times of emergency. Girls 12 to 14 years of age were educated on 'menstruation', and those who had started menstruating in the last three months were given a packet each. In addition, girl peer leaders from each *basti* conducted a session for first timers in their *basti,* on the appropriate use and disposal of pads, following COVID-19 safety protocols drawn up by SAHAJ.

The two months of lockdown (the national lockdown was extended two further times) was a challenging time for workers on daily wages in the *bastis.* With no means of livelihood, many families had to manage with just one meal a day. Some local external funders came forward to distribute cooked meals in the first week of the lockdown, as the ration distributed by the government was not enough to feed families during the entire lockdown period.

With the assistance of adolescent peer leaders, SAHAJ distributed dry rations consisting of wheat flour, rice, tuvar dal - lentils, oil, sugar, spices (chilli powder, turmeric powder, coriander powder, salt), poha or beaten rice, suji, semolina and tea to the most vulnerable families in the project areas across the five districts. The peer leaders identified vulnerable families in their areas. Targeted distribution is a sensitive issue.

Humanitarian kit distribution by Community Leaders

Photo: Jignesh Jadav, 2020

To maintain the dignity of the vulnerable families and to avoid conflict in the local areas, peer leaders requested a family member to collect their ration kits from the local leader's house at a designated time:
'We asked them to wear masks or cover their mouth and nose with a handkerchief /dupatta when they came to collect their kits. We sanitized their hands before handing them the kits. We delivered kits to the homes of people who were not in a position to come and collect the kit due to their age or disability'.

This work illustrated how different population groups were affected during the lockdown. 'Cookie-cutter' centralized COVID-19 responses provided by states became considerably diluted and distorted in their implementation. Solutions need to be adapted to local contexts. Collectives and local organizations provided a platform for local people to brainstorm workable alternatives. Collectives also provided members with support to deal with challenges and risks involved in their efforts to contain and mitigate the pandemic. External agencies were not able to reach the most vulnerable during complete lockdown. Local leaders were in contrast well positioned to organize relief, education and information dissemination in their neighborhoods.

There were various enabling factors for this community engagement in the COVID response. Local organizations and collectives were present and had been active for many years. There was a history of proven and credible leadership at local level. Authorities and relief agencies could reach out to these local organizations, and had confidence that centrally provided relief through these local organizations would reach the most vulnerable households. Mobile phones and access to internet enabled the use of social media for information dissemination and to collect data.

The examples above also show the agency of young people, as they struggle to overcome the barriers created by restrictive gender norms. The youth showed a sense of solidarity, pride and gratification as they see their efforts contributing to the well-being of others.

4.8 Better Together REACH for Hispanic communities in Lebanon, USA

The Better Together REACH initiative set up a webinar series to bridge a lack of information in Spanish for the Hispanic community on maintaining health and wellbeing during the pandemic and to facilitate participation in discussions from community members in order to address their questions and needs. For further information see Better Together Lebanon

Lebanon, Pennsylvania is home to several primarily Hispanic communities. It has a population of about 25 000 people, nearly half of whom are Hispanic. The Hispanic community in Lebanon is disproportionately poorer than other ethnic groups, more likely to lack health insurance and with higher rates of chronic diseases and poor health outcomes.

Infection and deaths due to COVID-19 has also disproportionately affected Hispanic communities in Lebanon and throughout the United States. Pennsylvania cases spiked in April with higher numbers than similar states but began to level out in May through to August. Pennsylvania has had higher testing levels. After an initial lockdown, there was some debate over the timing of reopening of businesses to take both immediate and longer term economic and health impacts into account.

'Better Together', a non-profit organization, focuses on community outreach for health and wellness in the Lebanon community. The Better Together team was established in 1999 and works on nutrition, physical activity, and diabetes prevention in the community by training community health workers and improving access to healthy food. Better Together had to cease many in-person outreach activities due to the pandemic and shifted focus to online outreach using Facebook and other platforms, with a focus on the response to COVID-19.

Better Together website screenshot.

http://bettertogetherlebanon.com

Beginning in March, the team developed a one-page resource in Spanish to answer questions about emergency lodging, food, unemployment benefits, utility payments, and other non-medical needs arising from the COVID-19 pandemic. They distributed the resource to families picking up meals at local school district distribution sites. Bilingual community health workers trained by Better Together held virtual meetings with Hispanic community leaders where people raised that it was difficult to find reliable information on COVID-19 in Spanish. They determined that many had access to smartphones and internet (major carriers in Pennsylvania offered free internet during the pandemic) so they partnered with Penn State Project ECHO (Extension for Community Healthcare Outcomes) to begin a webinar series in Spanish through Zoom.

The bilingual community health workers discussed needs with Hispanic community leaders for the webinars to focus on the most helpful information and to connect people and organizations to available resources. Topics included diabetes management, mental health resources, keeping children physically active and healthy diets. The series also included opportunities for community members to participate in discussions about challenges they were facing. The bilingual community health workers helped to overcome marginalisation due to language and socioeconomic factors. Receiving input from trusted Hispanic community leaders and having discussions through accessible technology helped to engage people has built learning on approaches that may now be used for other health problems.

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4.9 Community-based responses in Bababé, Mauritania

Community initiatives in Bababé, Mauritania have taken place despite a fragile health system and lack of public trust in authorities. Community leaders have co-ordinated the provision of preventive measures and supplies for basic needs, to promote the use of local services, screen people travelling in and out of town and refer those needing treatment to services, coordinated with local medical personnel.

Bababé, Mauritania in West Africa is largely rural. It has a high level of poverty and a health system that faces challenges in meeting health needs. Despite local poverty, cell phone technology is widely available and used.

On March 15th, 2020, before reported cases or deaths, the government closed borders, established a curfew and quarantine, banned traffic between cities and closed public places. Travellers were screened and quarantined at borders and treatment centres set up in the capital. The curfews limited economic activities and had adverse economic and social consequences for families, with many suffering partial or total loss of income. Local residents were reported to see details of the COVID-19 pandemic to be 'fake news' and to not trust measures put in place by the government. There is also report of weak support for healthcare workers, and some health workers not adhering to preventive measures. When a second COVID-19 case emerged in Bababé, the government sent a small box of medical supplies and provided a training session for only two nurses in the rural area.

In this context, village chiefs and community members worked with local health staff to establish a number of community-driven initiatives to respond to the pandemic. They set up a communication system via WhatsApp for monitoring and early warning of cases of COVID-19. The same system informs people about COVID-19 trends, promotes the use of the local health services which people are reluctant to visit and provided information to challenge rumours and false information. The communication system was also used as a form of community-based surveillance of movement across the nearby border with Senegal, to enable local screening and quarantine.

At local healthcare facilities, Koran schools, and other gathering areas, protective equipment such hygiene kits and single pedal handwashing devices were made available. Community members worked with state officials to support Talibé children, who are young boys who live in local Koran schools and are often forced to beg on the streets. Women in the district created a project called "Faandu Almudo" which provided Talibé children who no longer had access to the streets after curfew with a daily meal.

A triage system was also set up to facilitate the screening of more people coming in and out of town in a more efficient manner, to make referrals to medical attention for the most urgent cases.

Community efforts in monitoring and informing the population have proved to be valuable in detecting cases, tracing contacts and supporting the needs of local residents. Digital technologies through cell phones are sufficiently accessible, even in poor rural areas, to be effective communication media and have enabled public awareness activities. Partnerships between community leaders and local health staff were important, even in the absence of a strong or well-resourced national ministry of health, to support screening and referrals to health services.

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4.10 Cards from the community in the Yale New Haven Health System

Yale New Haven Health System (YNHHS) implemented 'Cards from the Community', a program that shares well wishes through digitalized cards created by school children with patients and healthcare workers.

The north-eastern states of the USA were affected early and intensively by COVID-19 and had some of the strictest lockdowns. Yale New Haven Health System (YNHHS) includes 6 hospitals throughout Connecticut, New York, and Rhode Island, as a non-profit healthcare system that serves both local and national patient populations. While Connecticut is a relatively wealthy state, its local New Haven communities include large African-American, Hispanic and refugee communities who face social and economic barriers to health and healthcare access. As part of broader lockdown measures, YNHHS implemented its own prevention measures, including limiting or prohibiting visitors and requiring PPE to be worn by employees and patients. YNHHS offered a call centre for community members to ask questions about COVID-19 and answered FAQ on their website. Many healthcare staff maintained some isolation from their own families and friends to prevent transmission and few patients in hospital were able to receive visitors. The pandemic restrictions on movement prohibited deliveries in hospitals, such as flowers, gifts or food for patients or healthcare staff. The resulting isolation and loneliness can negatively affect both the physical and mental health of patients, even after release from the hospital.

To address some of these negative effects of quarantine and social distancing, YNHHS started a program called 'Cards from the community'. Cards expressing well wishes for hospital patients and staff during COVID-19 were collected from school-aged children and shared virtually. The cards intended to boost morale of both patients and staff, to create a human connection despite the virtual nature of the interaction. To facilitate digital card sharing, the Department of Patient Experience used word-of-mouth communication through staff members of the hospital on patients in need. Many health staff have school-aged children and the initiative connected Patient Experience staff with teachers and administrators from local schools. Children wrote cards to both staff and patients. Cards were collated by local points of contact - who were individuals or organizations working with the children - and sent to the hospital. Slide shows of the cards were displayed on a TV channel in the patients' rooms, and cards addressed to staff were posted on the internal YNHHS wellness website and included in emails sent to staff about COVID-19 related issues.

Thank you card

Yale New Haven Health newsletter,

By the end of May, over 600 cards had been sent to patients and staff and viewed on patients' televisions almost 1000 times by mid-April. TeleHealth services and Medcalm, vendors of YNHHS televisions, shared this idea with other hospitals and 13 other institutions have since adopted the idea. The program also provided psychosocial support for children. One school principal participating in the program said, "It is extremely gratifying to know that we can help in some way to those working and suffering on the front lines of COVID-19". Health facilities in the USA generally provide few opportunities for community engagement, a disconnect between community and health facility that has deepened with the pandemic restrictions. This simple initiative addressed short-term needs and has potential to be further developed to improve engagement between hospital and community in the longer term.

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4.11 Conference calls with religious groups on COVID-19 in Maryland, USA

In Maryland, community conference calls that were part of an existing medical-religious partnership were held to relay information to the public about the pandemic and to allow community leaders to discuss struggles, concerns and responses to the pandemic in their communities.

This US state of Maryland, in the eastern United States, like other states, has pockets of significant social and economic need. The governor of Maryland began announcing lockdown orders and other measures in mid-March, with a mandatory stay-at-home order coming at the end of March. As a result of these measures and fairly rapid deployment of testing, Maryland managed to avoid the rapid rise in cases seen in New York City, a few hours' drive away. The state government was criticized, however, for reopening earlier than nearby states, with a second wave of infections taking place from June.

Throughout the pandemic, residents expressed a variety of concerns including a call for mental health support, food security, access to face masks, and measures to address social isolation and barriers to health care. Many people did not have the ability to quarantine if they became ill and could not access testing.

In 2011, the Johns Hopkins Bayview Medical Centre established the Healthy Community Partnership with a wide range of leaders from local religious institutions. Medical staff met regularly with religious leaders to offer health education and address concerns and questions among these congregations. Out of this partnership came Medicine for the Greater Good (MGG), a program that built on the insights from these engagements with local religious leaders and trained medical students to better understand social and economic determinants of health.

By the time of the pandemic, the Health Community Partnership and MGG had an established network of over 500 individuals and community leaders in local religious organizations. They initiated a conference call series with this network, held on Monday and Friday of each week. The conference calls were 60 minutes long each and featured updates on a variety of aspects of COVID-19 and included time for religious leaders to discuss concerns and for callers to ask questions. Each call was recorded so that the information discussed was available for reference. If there was not time to answer all questions, the network sent emails and made follow-up calls to people.

Throughout the series, medical experts and representatives from government agencies and community organizations were invited during the calls to provide information and to hear concerns. All calls ended with a meditation that was inclusive of all faiths and traditions.

Surveys were sent out to a sample of 200 community members to assess the effectiveness of the calls, the type of concerns and how easy access was. The surveys found that many people wanted the calls to continue even after the pandemic.

These conference calls engaging religious organizations and health-related services as a partnership were effective in conveying information in a culturally-sensitive manner. They helped to raise the health literacy in communities, to problem solve local issues and to coordinate activities among various health system and community partners. While the calls began as a more information-focused set of interactions, with medical experts providing information to a community audience, they evolved and began to take on a more engaged and two-way problem-solving character.

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4.12 Social bubbles in New Zealand and quarantine pods in the United States

The model of 'social bubbles' or 'quarantine pods', which began in some countries as a government-directed strategy for slowly increasing social contact during the lifting of lockdowns, has taken on its own momentum in many communities in the United States, offering a self-organized approach for balancing social needs and public health priorities.

The initial wave of COVID-19 in the USA began in March and after an initial rapid rise, prevention efforts to 'flatten the curve' were instituted in many places in late March and April, bringing the transmission rate down. These measures were eased in many places in May and a second wave of cases followed in June and July, followed by further restrictions. A third wave of cases is projected as schools and universities open in the third quarter of 2020.

The idea of 'social bubbles' or 'quarantine pods' first gained attention when the government of New Zealand incorporated them into official lockdown guidelines as they eased their initial, very strict lockdown regulations and slowly allowed increased social contact. Social bubbles allow members of a household to interact with a limited number of other individuals or households, usually no more than 10-12 people, without social distancing. The agreement is that all of the members of the bubble will observe strict distancing measures with anyone outside the bubble and when in public spaces. On the basis of modelling, the argument was made that this approach to managing social contact during pandemic could be highly effective.

While social bubble regulations have been part of official guidelines in New Zealand, the UK Canada and elsewhere, they were never incorporated into state or federal regulations in the USA, which focused instead on defining essential workers and control of density and mask use in public spaces and at large private gatherings.

Many US households and communities have however adopted the idea themselves as a new social form for individuals, peer networks, neighbours, families and other small groups of people to balance the need to engage socially with the desire to reduce transmission and protect vulnerable members in their social networks. One poll estimated that up to half of US households have been in a bubble at one point. There are hundreds of online guides for how to set up and manage the delicate politics of social bubbles, as well as numerous online pandemic bubble diaries.

With the opening of the new school year in August, the bubble (or pod) model has recently evolved to address concerns about prematurely returning children to schools. Friends or neighbours in many states have set up independent 'learning pods' and are hiring their own tutors and teachers to offer home-schooling during the initial months of the school year, although like home learning in general, this may be an option less accessible to those on lower incomes, with consequences for social inequalities.

Pandemic responses often entail significant shifts in social relationships. The social bubble model offered a framework for organizing new kinds of social interactions in the context of ongoing cycles of COVID-19 lockdowns and restrictions. Though government mandated in some countries, in the USA this model has been taken up by many households without any state or federal mandate. There are concerns, however, that 'podding', either for social purposes or to manage schooling needs, is only sustainable for those middle class families who live in low-density households, can work from home, and can afford reducing contact and hiring outside support.

Block, P., Hoffman, M., Raabe, I. J., Dowd, J. B., Rahal, C., Kashyap, R., and Mills, M. C. (2020). Social network-based distancing strategies to flatten the COVID-19 curve in a post-lockdown world. *Nat Hum Behav*, *4*(6), 588-596. https://doi.org/10.1038/s41562-020-0898-6

5. Case studies of community engagement on wider social protection

5.1 Farmers' led farm-to-home model during lockdown in Satara, India

With lockdowns threatening farmers ability to sell food and household food security, in Satara Maharashtra key stakeholders—farmers, local administration, community-based organizations, social workers — quickly came together and implemented a solution that guaranteed farmers a market for their produce while also meeting the nutritional requirement of the urban residents. For further information see Satara Farmers' Revolutionary New Model.

Satara is a predominantly a rural district in Maharashtra, India, with 81% of its three million people living in rural areas and small scale farming a major source of livelihood. Maharashtra, with nearly one-third of total cases and almost 40% of mortality has emerged as the worst affected COVID-19 state in India. It went into the nationwide lockdown on 24 March and only essential services were allowed to operate, with rules and physical distancing in public enforced by the police. With only four hours notice, it caught all, including farmers, by surprise. Since June, selected economic activities and services have resumed operation, coinciding with a rise in COVID-19 cases, and a scarcity of ICU beds and ventilators, including in Satara. COVID care provisioning is primarily being handled by the district civil hospital, along with the private health sector. In addition to central and state COVID-19 management guidelines, the district administration has also encouraged innovative solutions.

For farmers ready with their *Rabi* crops, sown in winter and harvested in spring, the lockdown meant a sudden absence of agricultural workers to cut and load the crops in trucks, or truck drivers to transport the produce to the markets. With regular supply chains disrupted, perishable products risked being spoiled, incurring a heavy loss to the farmers. The Pune Agriculture Produce Market Committee also ceased its operations at many market yards to minimise health risks from public gatherings and Satara district falling under Pune administration closed these markets leaving farmers without larger *mandi* (markets) to sell their surplus produce.

While this situation was replicated in many parts of the country, in Satara many stakeholders—farmers, local administration, community-based organizations, social workers — quickly came together to co-determine a solution that guaranteed farmers a market for their produce while also meeting the nutritional requirement of the urban residents. The Satara municipal officials realised physical distancing during the lockdown demanded doorstep delivery of food products. The municipality already had a door to door garbage collection service using a fleet of 40 trucks and thought this was possible.

The Paani Foundation is an NGO engaged in water and environmental management that networks with farmers and villagers across 24 districts of Maharashtra to build collective communitywide action aimed at mitigating the water crisis in rural Maharashtra. A social worker from the foundation connected with a self-help group (SHG) of 38 farmers, Mhatoba Krushivikas Mandal, to explore with them how best to distribute and sell fresh farm produce. They agreed that the farmers could aggregate their produce and themselves distribute their products to the wards under Satara municipality, using hired 'tempo' vans. This would sustain a viable market despite the lockdown and provide consumers fresh farm produce delivered almost at their doorstep, reducing crowding at the vegetable markets. The social worker and a local advocate connected the farmers' collective with the Satara Municipal Corporation and police and assisted the farmers to register and get the necessary permissions.

Satara's innovative farm to home model

Photo credit: Mr. Dayanand Nikam and Paani Foundation

The farmers began with four tempo vans, hired daily, to transport the produce across different locations in Satara Municipal area. On the first day there were no customers as nobody was aware of the service. The next day they announced their arrival using hand-mikes and soon customers started queuing. In time, consumers began trusting the service, sales picked up, more farmers joined in and the number of vehicles supplying vegetables went over a hundred. To avoid duplication and unnecessary movement during the lockdown, each vehicle was assigned specific wards for selling vegetables. The municipality disseminated the list of farmers and their contact numbers and designated wards. Later the farmers started taking orders directly from the consumers over WhatsApp for delivery.

By directly supplying to the municipal wards and having a direct communication channel between supplier and consumer, the initiative helped to maintain physical distancing, secured livelihoods and food security. It also reduced the cost of intermediaries who previously mediated between farmers and APMC markets, reducing costs for farmers and purchase prices for consumers as these intermediaries pocketed high profits. For instance, in one village, prices of watermelons fell fourfold during lockdown using this new model.

Tempos loaded with fresh farm produce for delivery/ distribution

Photo credit: Mr. Dayanand Nikam and Paani Foundation

The success story of the Satara model spread and four more districts of Maharashtra followed the same approach. There were questions about whether it would continue after the lockdown relaxes and routine services resume, but for now the demand has not gone down, and consumers are rather asking for more variety of produce. This demand is driving the collective to diversify their products, providing a core of 15 essential items and informing consumers about the prices ahead. Even though grocery stores have opened, the farmers' still provide lower end prices. The future of the service is thus dependent on responsiveness to the community as consumers.

The experience shows the potential during and after the pandemic of direct, local and decentralised linkages between farmers and consumers. This not only appears to empower and serve local communities as consumers, it also benefits farmers by removing middlemen, and brings fresher products into circulation. This not only enabled the physical distancing required to manage COVID-19, but improved dietary factors in health. Enabling such efforts in the longer term and wider level does require different forms of support, including regulatory support from the government, communications and networking that local civil society groups' can help with, financial support from the banks if needed for trucks or transport, logistical support from local transporters and overall coordination by local self-governments. Yet the Satara model shows that these are all feasible in a decentralised manner.

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5.2 FoodFlow connecting farmers and communities in South Africa

FoodFlow is a nonprofit dedicated to connecting small farmers with families in need of food due to the pandemic and facilitating deliveries through donations. For more information see FoodFlow https://www.foodflowza.com

South Africa has high levels of social inequality, but also has assets in a well-developed large and small scale private sector and good road infrastructure, as well as a strong NGO sector. South Africa implemented a lockdown on non-essential businesses in late March 2020, and has since been opening particular areas of economic activity as COVID-19 cases declined from the peak of 12 584 cases on July 19th, 2020.

Due to the pandemic and the lockdown, farmers have not experienced the usual demand from hotels and restaurants. Meanwhile, families struggle with food security due to the economic impact of COVID-19. FoodFlow was started by two women, Ashley Newell and Iming Lin, with experience in social development efforts and vegetable farming. It solicits private donations through the media and uses the funds to purchase produce from local farmers. The food is then organized into parcels to supply to those in need during the pandemic. The initiative originated in Hout Bay, near Cape Town but it works to connect food producers and communities in need in four South African provinces: Western Cape, Eastern Cape, KwaZulu-Natal and Limpopo.

FoodFlow organizers initially planned to deliver about 150 bags a week, but donations from the first week made it possible to deliver 3 500 bags, each bag providing about 10 meals. FoodFlow has several community distribution partners, many of which are non-profit organizations. Local farms deliver bags to community distribution partners for pickup/delivery to households in need.

Screenshots from Foodflow website

https://www.foodflowza.com/our-approach

The organization plans to continue facilitating the connections between small-scale food producers and local communities in need beyond the pandemic. A distinctive aspect of this project is the focus on working with both small-scale food producers close to communities, often owned and run by black South African farmers, as well as smaller community-based organizations already based in vulnerable communities who handle the distribution of the food. This model uses existing, well-embedded resources within vulnerable communities while also fostering new connections across communities.

Small-scale farmers are often left out of large-scale food aid programs which typically purchase from the large corporate retailers and suppliers. FoodFlow facilitate deliveries between small farms and communities, supporting these farms and bringing fresh food to families in need, instead of canned and dry goods. The strong transport and communication infrastructure in South Africa and its robust NGO sector are factors in the success of the initiative. While was set in motion by middle-class actors and supported by donations from more affluent funders, it makes effective use of existing resources, networks and capacities and has helped to catalyse a form of engagement among them that would likely not have happened otherwise.

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5.3 Kudumbashree- community social protection in Kerala, India.

Community Kitchens, run by a network of over 2.2 million local women volunteers in a Kerala state supported community-driven programme, Kudumbashree, have provided millions of meals to community members in need during the COVID-19 pandemic, provided other key supplies and support and linked by social media, enabled an early, decentralised, participatory state-wide response. For more information see Kudumbashree http://kudumbashree.org/pages/826

Kerala state in India is largely rural, but is also experiencing rapid urbanization. The state ranks the highest in India on social development indicators such as the elimination of poverty, and in high levels of life expectancy, adult literacy, primary education and healthcare. Kerala is a prominent tourist destination with Ayurvedic tourism and tropical greenery as its major attractions. Malayalam is the most widely spoken language. The state has a large diaspora population, while migrants living in Kerala, mostly from Assam and West Bengal, constitute more than 8% of its population.

The first COVID-19 case in India was detected in Kerala, on 30th January and the alert level was raised when cases rose in March. Isolation beds were arranged in 21 major hospitals in the state and a helpline was started in every district. By the middle of March, the Kerala government announced a 200 billion INR package for COVID-19 management and was conducting more than 3 000 telephonic counselling sessions with people with suspected symptoms and around 200 health care workers were deployed for management of COVID-19. The state announced the 'Break the Chain' campaign to spread awareness about the disease. Hand wash bottles and water taps were installed in public places like the entry and exit gates of railway stations. On 23 March, the state declared a lockdown earlier than the nationwide lockdown. By the end of March, the Government with the help of Kerala Start-up Mission developed a YouTube channel and an app for broadcasting information, updates and guidelines for COVID-19 management. Kerala crossed the 1000 cases mark in May. Dedicated COVID-19 hospitals treat severe cases while milder cases receive care at the First Line Treatment Centres. COVID-19 specific cells were established in every governmental department, such as transport, tourism, higher education, and food safety, co-ordinated across departments and districts by the health department. The swift and comprehensive response to COVID-19 was attributed in part to learning on emergency preparedness after floods in 2018 and the Nipah virus outbreak in 2019, and the result has been a lower prevalence and mortality rate from COVID-19 than the national average.

A Kudumbashree neighbourhood group meeting

Photo credit: Kudumbashree

Kudumbashree is a public programme based on community networking across Kerala. Neighbourhood Groups (NHGs) of 10-20 women, one per family and mainly from poor households, are the primary level unit. Special NHGs may also be formed for people who are differently abled, those with HIV and AIDS or destitute families. Area Development Societies (ADS) operate at ward level, and Community Development Societies (CDS) at the local government level. It may be the largest women's network in the world. Its main objectives are poverty alleviation and women's empowerment. Kudumbashree evolved out of years of community mobilisation and civil society initiatives in Kerala and Kudumbashree's formation was reinforced by the distribution of power to the Panchayati Raj (local self-governance) institutions and the People's Plan Campaign.

Although the Nipah experience helped Kerala prepare early, the widespread restrictions from the lockdown resulted in constraints in supply of and access to essential resources like food, medicine, masks and sanitizer, with a price surge due to high demand. Kudumbashree circulated information on COVID-19 across the NHGs who conducted meetings on future courses of action on 21 March, a day before lockdown was declared. Almost immediately, Kudumbashree had formed 300 000 WhatsApp groups with 2.2 million NHG members to spread awareness on

guidelines for prevention and to plan and initiate diverse local COVID-19 management initiatives, collaborating with state enterprises, with proactive participation from volunteers and networks.

In the over 1 100 'Community Kitchens' across Kerala, run by Kudumbashree collaborating with local Panchayati Raj, food volunteers prepare and home deliver food to poor and quarantined families and at Corona Care Centres. The community kitchens include 379 'Janakeeya Hotels', or 'people's restaurants, that provide affordable meals and take away counters have been established in check-post areas for transport department workers and drivers. The government provides a tally on its COVID-19 dashboard of the number of meals delivered.

Kudumbashree members cooking and packing takeaways

Rural India online, 2020

The Kudumbashree 'Snehitha' gender help desk, present across all Kerala districts, offers short stay facilities, counselling and mental support from 360 professional community counsellors and service providers to distressed women and children, especially those who are quarantined, in situations of domestic violence.. Kudumbashree members are also taking part in the 'Sannadha Sena', a volunteer group formed by the Kerala government to coordinate various COVID-19 related activities. In association with UNICEF 2 500 resource persons call families with elderly members once every three days to enquire about their health and needs and ensure that they get food from community kitchens and medical care from Primary Health Centres. Almost all Kudumbashree district teams and farming groups have initiated activities to promote kitchen and vegetable gardens, organic farming, agricultural campaigns, seed distribution programmes and tuber crops cultivation, to respond to immediate needs and prepare for future food-related challenges. The network is also providing support to the students of 270 Institutions and schools for intellectually disabled adults, holding activities for children in all districts and developing an app with the Kerala Book Store to support learning during school closures.

Kerala's experience with a 2018 Nipah outbreak helped to prepare the decentralised planning public mind-set needed to respond to COVID-19, but even more important was the longstanding organization in a wide grassroots network of women and local self-help groups and governance bodies in proactively informing, discussing and identifying innovations that could work and be delivered through state-community interactions. Having village panchayat bodies already involved in management of Primary Health Care and a well-distributed health care, education and state system also helped to facilitate decentralised state support and trust in state practices. Kudumbashree's incubation of democratic leadership and participatory dialogue, action and learning, especially in women built both rapid proactive actions, and communication and information flow that enabled understanding, co-ordination and accountability on performance. The initiatives implemented were thus timely, relevant, decentralised in their local organization, collaborative with local resources and capacities and widespread.

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5.4 Ensuring social protection of homeless people in the Philippines

The Philippines Homeless People's Federation (HPFPI) responded to COVID-19 impacts on homeless people through a network of local community leaders and partners to distribute essentials and food, make washable masks, set up community kitchens and communal gardens and provide relief income for homeless people not registered in the government scheme using their own funds and those from international solidarity.

Philippines has one of the most dynamic economies in East Asia and the Pacific, but with high levels of poverty and inequality. There are around 4.5 million homeless Filipinos with 3 million in Manila, possibly the most in any city in the world.

The Philippines identified its first case on January 30th, 2020 in Manila and was the first country to confirm a death due to COVID outside of China. Due to its close proximity to China, a temporary ban was imposed on workers travelling from China after the COVID outbreak and lockdown measures were imposed in Metro Manila and Luzon island, prohibiting people from going outside except for basic necessities, and affecting over 50 million people. Since then, the Philippines government has mounted a multi-sectoral response to COVID-19 covering a range of information and preventive measures.

The Philippines Homeless People's Federation (HPFPI), with more than 9 000 members in 14 cities and towns throughout the Philippines, brings together community organizations working on land, housing, income, infrastructure, health and welfare challenges. The federation responded to COVID-19 impacts on the communities it covers by identifying vulnerable homeless people across eight cities in the country and coordinating with government and NGOs to set up a communications network to support them. They disseminated information through TV and radio with the help of local communities. With a slower response from external agencies, community leaders distributed daily essentials such as soap and alcohol cleanser and community members made washable masks for everyone and purchased thermal scanners to detect symptoms, using HPFPI funds. They bought food in bulk with the support of the federation and distributed packs with instant noodles, coffee, biscuits, 3-5kg of rice, canned sardines, vitamins, medicines and child essentials to families. They also set up community kitchens and communal gardens.

As a COVID-19 relief measure, the Philippines government had announced payments of 5,000-8,000 pesos for each family. However, many homeless people are unregistered, and the majority are reported to not have received the payment. The Federation and community provided relief to homeless people using funds received from Slum Dwellers International and the Asian Coalition for Housing Rights.

The HPFPI and support from the community has helped to reach out to and protect those that the government has not. Each community provided independent initiatives to serve specific local needs. Amidst lockdown, surging cases, joblessness and lack of resources, each local community came together to form something larger to respond to community needs, supported by the federation and with solidarity from international partners. The revolving community fund, generally used to extend loans to community members, was used during COVID-19 to provide food and medicines to those in need. Similarly, many outside the federation also volunteered for community kitchens and communal gardens for common usage.

The federation's efforts have been recognised at the local levels and have garnered attention and support for local political leaders. Yet the federation also recognises that in the longer term, positive change calls for more sustained government encouragement and support of such initiatives and recognition of groups such as homeless people in social protection plans.

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5.5 Women's self-help group actions on food security in Dewas, India

Samaj Pragati Sahayog (SPS) with its network of community-based self-help groups (SHG), used its longstanding network to work with and draw on the experience of local women to plan and provide appropriate forms of relief assistance and food security support for the most vulnerable families in Dewas and Khargone districts, liaising with relevant authorities. The products for food packages were procured from local Farmer Producer Organisations (FPO) to support their livelihoods. For more information visit http://www.samajpragatisahayog.org/

Madhya Pradesh is the second-largest state in India with many people depending on farming for their livelihoods, including in Dewas, the 15th largest district in the state with 1.6 million people. Dewas is predominantly rural, has low levels of adult literacy, especially in women, and many people from the *Adivasi* (indigenous) population, one of the most marginalised and discriminated groups in India. The pandemic has aggravated this with newspaper reports of horrifying experiences of Adivasis being beaten to death due to lockdown violation.

Madhya Pradesh implemented a four-pronged approach of identification, isolation, testing and treatment (IITT) to arrest the spread of the pandemic, with rapid response teams and technology to augment case finding and broader community-based surveillance activity using SARTHAK LITE, a citizen app that helped citizens with real-time information on collection centres, fever clinics and treatment facilities. A COVID-19 rakshak system involved citizen volunteers to report suspected COVID-19 cases for local administration response, although the shortfall in public health infrastructure limited the treatment response. Patients receive free COVID treatment at the existing public sector hospitals or the contracted private facilities.

The pandemic and lockdown affected livelihoods of unskilled labour, informal sector workers, daily wage labourers working in urban and peri-urban areas, unorganized construction workers, migrant workers, small vendors, internally displaced people and women-headed households. It also harmed the incomes of small producers and small and marginal farmers. The close-knit community life of Adivasis in Dewas made them susceptible to a faster spread of infection, while poverty and severe undernutrition weaken their ability to withstand the disease. Adivasi residents depend on weekly markets for their supplies, but these markets closed with stringent physical distancing norms for pandemic prevention. Government ration shops faced disrupted supply chains leading their food supplies to be erratic and often of poor quality. As traditional livelihood practices of the Adivasis came to a halt in the pandemic, they lost their purchasing power and farmers ran short of cash when they were unable to sell their produce at a fair price.

Samaj Pragati Sahayog (SPS) with its network of community-based self-help groups (SHG), is one of the longest-term and largest civil society initiatives working in Madhya Pradesh and Maharashtra, aiming to improve water security, agriculture and uplift the Adivasi communities. By 2018 SPS had formed women SHGs involving Adivasis, Dalits (Scheduled Castes), landless and displaced people in over 500 villages and 15 towns, as the foundation for their initiatives. Through the SHGs, women run Cluster Development Associations (clustering 15-20 SHGs) and Federations (of around 200 SHGs), participating in crop marketing and improved agriculture and reinvesting income from these programmes in health and education. The Federations collaborate with the government and civil society organizations, bringing their voice in discussions on their development.

During the pandemic, local SHGs and the SPS provided relief assistance to 13 044 of the most vulnerable families in Dewas and Khargone districts. They listed families that would most need income support or monetary relief, and planned to sort them according to their needs. They discovered in the process that providing them with essential kits first was more relevant than monetary relief. While cash transfers would have been easier than procuring, packaging and transporting essentials, the SHG members, coming from the community, knew how difficult it is to access banks or ATMs from these far-flung places, even during regular times.

The process was meticulously planned, starting from the selection of essentials to their delivery, whilst maintaining social distancing norms. The relevant authority was informed of this initiative to ensure its smooth functioning. Three to four local SHG member families helped to prepare the

relief packages, which included a month's supply of oil, cereal, pulses, condiments, and also soaps and detergent to maintain hygiene. The package was prepared keeping the different family sizes in mind to meet their differing needs. They made sure that the purchased products were of good quality and sufficient in quantity. Daily plans were made listing specific families to prevent crowding. Only healthy volunteers from the SHGS were selected to carry out the task. The SHGs and SHG Federation of women delivered essential kits to 11 840 families across 12 locations of the two districts. A further 1 204 families from inaccessible hot spot areas were provided with direct bank transfers of 1000 INR, strictly adhering to the government's pandemic prevention guidelines.

Women receiving the relief packages

Photo: Samaj Pragati Sahayog Community media

The products for the kits were procured from different Farmer Producer Organisations (FPO) to support their livelihoods. For example, wheat flour in relief kits was procured from Ram Rahim Pragati Producers Company Ltd. This company is owned and run by more than 4 800 marginal Adivasi women farmers of that area who are also part of over 300 SHGs promoted by SPS. Ram Rahim Pragati Producers supplied 118 tonnes of flour worth more than three million INR within the stipulated time. This procurement also helped the farmer shareholders of the FPO. This prevented distress sales by providing the farmers with an appropriate value for their produce, even when the supply chains remained snapped and markets shut during the lockdown.

SPS being an interactive platform with a decentralised structure works in consultation with the community and focuses on the issues that the community itself deems important. The professionals who render these consultations are not the typical 'metro educated', but rather local members of the village or community who contribute with their experience and insights. The structure of the organization does not promote bureaucratic, hierarchies in the work, and each initiative is highly collaborative.

The pandemic posed many challenges, not all foreseen, and affecting each community differently. An organization working in such a situation is expected to have flexible decision-making processes and an approach which prioritises and includes the community's rich experience and opinion. The SPS organizational structure with its vast network of SHGs, therefore, proved suitable to rise to the complex challenges unfolding due to the pandemic. Aided by community insight, the help provided was tailored to the local needs to ensure maximum benefit.

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4. Ministry of Tribal Affairs (2019) Annual Report 2018-19. *Ministry of Tribal Affairs*. https://tribal.nic.in/writereaddata/AnnualReport/AREnglish1819.pdf
5. Mitra, P. P. (2014). Madhya Pradesh tribe still shackled to British-era 'criminal' tag. *Hindustan Times*.
6. Samaj Pragati Sahayog (2020). UrgentRelief to Affected Families following COVID-19 Lockdown in Remote Central Tribal India. *Samaj Pragati Sahayog*.

5.6 Operation Mercy Mission in Bengaluru, India

A coalition of NGOs worked with local residents, city officials and police to deliver urgently needed food aid to vulnerable communities in spite of strict lockdown restrictions.

Bengaluru is a large city in southern India known as the 'Silicon Valley of India'. In Bengaluru, COVID-19 support from the central government has been inadequate to meet the needs of what are termed "economically weaker sections' of the city. These communities are not only economically marginalised but also have very little access to information and are reported to be generally distrustful of state authorities. Lockdown restrictions were put into place with very little warning, catching most residents by surprise and leaving them more food insecure than they had previously been.

Twenty NGOs in Bengaluru came together to form an Emergency Response Team. They began a campaign called Mercy Mission to support the most vulnerable residents in the city. NGO staff organized food drives and mask donation campaigns. They worked closely with local providers to reduce the costs of raw materials and organize transport for food deliveries. A multi-layered media and social media campaign were part of the effort and included local community members recording messages of support for the campaign.

Mercy Mission advert

https://www.mei.edu/publications/civil-society-and-covid-19-india-unassuming-heroes

Given the strict lockdown conditions in India and the often fraught relationships between police and politicians on the one hand, and NGO staff and community members on the other, members of the Emergency Response Team had to be creative in building relationships with local police officers and city officials. This was critical to ensuring relief efforts could proceed in spite of lockdown restrictions. Emergency Response Team members also engaged with community members from middle-class communities who lived close to the areas in need. The team worked with them to support local-level distribution efforts near where they lived and could move more freely.

A well-established coalition of local NGOs with long experience in the area were able to draw on their networks and resources to mount an urgent food aid initiative among the most vulnerable in Bengaluru. To make this effort work, they had to develop strategic alliances with and support from a number of actors including the local police and city officials, local food and transport businesses and local residents in nearby middle-class communities who could act as brokers for the food delivery activities.

Siyech, M. S., and Jouhar, N. (2020). Civil Society and COVID-19 in India: Unassuming Heroes. *Middle East Institute*. https://www.mei.edu/publications/civil-society-and-COVID-19-india-unassuming-heroes

5.7 Movement for Change and Social Justice in Cape Town communities

An existing health social movement in Cape Town quickly pivoted to COVID-19 and began supporting food relief, prevention efforts, water and sanitation improvements, and ongoing access to health care using strategies borrowed from AIDS activism. For further information visit MCSJ: https://www.facebook.com/mymcsj/

While South Africa was widely praised for its early and strict lockdown measures, they have had significant costs. In a highly unequal society like South Africa, these costs fall heavily on socially and economically marginalised families who already face significant problems in employment, housing, food security and health.

The Movement for Change and Social Justice is small health social movement based in the Cape Town township of Gugulethu. It was started in 2017 as a partnership in a research activity based on men, masculinity and HIV at the University of Cape Town (UCT). Its members are all drawn from the local community and it has developed broad recognition and legitimacy over the course of the last 3 years from the several health campaigns it has undertaken. Its community engagement and activist strategy is informed by principles used by AIDS activists in South Africa in the 2000s. This included close collaboration with academic experts and local NGOs, grassroots mobilisation in affected communities, a strong emphasis on community-led agenda setting, strategic alliances with local health service personnel and a balance between advocacy and support for service delivery.

MCSJ meeting with community members,

UCT news

When COVID-19 spread in Cape Town, MCSJ focused its initial efforts on ensuring access to hand sanitisers and masks and distributing food vouchers to the most vulnerable to address short-term food insecurity. They worked with UCT, Doctors without Borders and the local Department of Health to increase their reach beyond Gugulethu. As the lockdown continued, they put pressure on local councillors to address service delivery barriers in the area, such as blocked sewers, missing taps and inconsistent water deliveries. They worked with local health providers and NGOs to ensure access to ART medication and HIV self-testing kits during lockdown. MCSJ members, as part of their Men's Forum initiative, called attention to the intersecting epidemics of COVID-19 and gender-based violence and have organized meetings and discussion to push this issue forward.

MCSJ volunteers preparing for the day

UCT news , 2020

As a health social movement rooted in the local community and with a broad lens on health and social justice, MCSJ could quickly address COVID-19. MCSJ has borrowed principles and strategies learned from AIDS activism in South Africa and used these to build effective alliances with a wide range of stakeholders, to have impact in the communities where it works.

1. Colvin, C. J., van Pinxteren, M., Majola, M.,et al., (2020). Fostering a healthy public for men and HIV: a case study of the Movement for Change and Social Justice (MCSJ). *Palgrave Communications*, *6*(1), 25. https://doi.org/10.1057/s41599-020-0402-y
2. Mbokazi, N. (2020). The Power and Importance of Community-based Organisations: Initiative and Solidarity. *DSBS Fieldnotes*. http://www.dsbsfieldnotes.uct.ac.za/news/power-and-importance-community-based-organisations-initiative-and-solidarity

5.8 People's Solidarity Brigades in Italy, France, Switzerland and Belgium

Self-organized collectives of anti-racist and anti-fascist activists in cities across Europe have set up 'People's Solidarity Brigades' to provide independent and collective care and support to the most precarious populations in their communities. For further information see People's Solidarity Brigades: https://www.brigades.info

The COVID-19 pandemic spread rapidly in many European countries and many imposed strict lockdowns and other public health measures. While effective with respect to reducing the pandemic's overall transmission rate, these lockdowns often had significant social and economic costs for populations, including unemployment, food insecurity, lack of access to basic supplies and housing, significantly reduced access to health care, increased mental health challenges, and for some, increased vulnerability to state violence, domestic violence and other forms of oppression. These costs were disproportionately borne by immigrants and other racially and economically marginalised communities within Europe.

People's Solidarity Brigade Logo, https://mtlcounterinfo.org/fascism-and-antifascism-during-a-pandemic/

In response to the need for social and economic support for and solidarity with the most vulnerable of those living in Europe, small collectives across France, Italy, and Belgium began setting up 'People's Solidarity Brigades' to offer self-organized support to oppressed communities. The brigades began in Milan, Italy and quickly spread throughout neighbouring European countries. They describe themselves as 'self-initiated mutual aid groups' working in the interest of the most precarious populations. They promote a model of 'collective care' that is distinguished from forms of private or family care or public care governed by the state. Brigades describe this kind of collective care as 'self-defence from below'. They explicitly operate independently of the state, seeking no partnership with political institutions, considering them as corrupt and in service to neoliberal policies that serve private, corporate interests. Many of them are connected to anti-racist and anti-fascist movements in the cities where they operate. Their range of work is wide, including supporting fire-fighting efforts during mountainous wildfires in northern Italy.

The People's Solidarity Brigades website collates contact information for the 56 individual brigades listed on the site, Brigades work at the level of urban neighbourhoods or small city sub-districts. The site also collates information on brigade activities. As of September 14, it reports over 104 209 masks and gloves delivered, 17 888 meals provided, 468 pedagogical hours supporting students, and 1756 bottles of their own self-produced hand sanitiser distributed. In addition to supporting access to basic needs like food, housing and health care, brigades collect collective health information from communities to better address their needs.. Most brigades maintain a Facebook page where they document their activities and announce events.

The People's Solidarity Brigades have provided support to highly marginalised populations in European cities that may have been less able to access to state or private support during the pandemic. The Brigades operate independent of the state, but many cooperate closely with other brigades and with other like-minded groups, potentially increasing their impact, visibility and legitimacy among the communities they serve.

1. McFellin, A. (2020, June 13, 2020). From Passionate Uprising to Sustained Rebellion. *New Politics*. https://newpol.org/from-passionate-uprising-to-sustained-rebellion/
2. Montréal Antifasciste. Fascism and Antifascism during a Pandemic. *Montreal Counter-Information*. https://mtlcounterinfo.org/fascism-and-antifascism-during-a-pandemic/

5.9 An 'Outbreak of generosity' campaign in Europe

Italian youth supported by the Forum of European Muslim Youth and Student Organizations (FEMYSO) launched a campaign called 'Outbreak of Generosity' that aimed to encourage and organize young people across Europe to volunteer to help vulnerable communities during COVID-19. For more information see FEMYSO and Outbreak of Generosity

Italy was severely impacted by COVID-19 early on in the pandemic, with one of the world's highest infection rates. The first case was reported February 21 and an Italian Government decree was issued that closed down all non-essential businesses on March 22.

After seeing the impact of COVID-19 in Italy, Nourhene Mahmoudi and a group of young people launched Outbreak of Generosity through FEMYSO on March 16. FEMYSO is an NGO that represents 33 member organizations in 20 European countries and focuses on empowering youth through volunteer work. It is run by Muslim youth and works with the European Parliament, the United Nations and other significant international European organizations like the European Students Union, European Roma Grassroots Organizations (ERGO) Network, and several other European, national, and local partners.

Though it was initiated by the FEMYSO, Outbreak of Generosity targets European youth from any religion and background. The Outbreak of Generosity campaign aims to support work across Europe through the use of tailored "toolkits," or volunteer guides, for 16 European countries. These toolkits are filled with guidelines and resources to help inspire and mobilize young people to help vulnerable communities, particularly elderly people, in their own settings. The toolkits emphasize the importance of consistent outreach and follow-up and include help cards to distribute throughout volunteers' local community, such as the one shown. They encourage youth to share their participation in the campaign on social media with the hashtag #outbreakofgenerosity to encourage the spread. Posts have featured youth grocery shopping for high-risk communities, delivering food and sewing masks for neighbours and leaving messages of care and support for households with sick family members. In the UK, youth participating in the campaign set up a color-coded system to alert community members of needs in the area: a green piece of paper is placed in the window of a house if those inside are fine, and a red piece of paper signals that the residents need assistance such a transportation, medication, or shopping help.

Sample 'Help Card' to leave in neighbour's mailbox, at the store, etc

http://outbreakofgenerosity.org/wp-content/uploads/2020/03/English-YOUTH-TOOLKIT.pdf

Because Outbreak of Generosity is an international campaign, tracking its impact is difficult beyond social media presence. The various international and local organizations partnering with Outbreak of Generosity help promote the campaign, and the toolkits specific to each country and translated into different languages makes participation in the campaign accessible to a wide array of youth living in Europe. The toolkits offer accessible and concrete suggestions and resources for ways individual youth and groups of youth can engage in their local context.

Wickramanayake, J. (April 3, 2020). Meet 10 young people leading the COVID-19 response in their communities. *United Nations*. https://www.un.org/africarenewal/web-features/coronavirus/meet-10-young-people-leading-COVID-19-response-their-communities

5.10 Mutual Aid Groups Connecting Citizens in Spanish-Speaking Countries

A mutual aid platform started in Spain using Kenyan software. It grew to include 16 different Latin American country sites offering a wide range of innovative citizen-led initiatives to respond to COVID-19. For more information see Frena La Curva: https:// frenalacurva.net

While later in its onset, the COVID-19 pandemic in Latin America has had a rapid rise in many countries as it became the global epicentre of the pandemic. Most Latin American countries, except Brazil, imposed some form of early lockdown.

Frena La Curva ('Slow the Curve") was originally developed in Spain, with some initial government funding, as an online platform where a small group of volunteers could collect COVID-19 resources, organize information and offer useful tools to the public. It has been described as "a citizen platform where volunteers, entrepreneurs, activists, social organizations, makers and public and open innovation labs, cooperate to channel and organize social energy and civic resilience in the face of the COVID-19 pandemic by giving a response from civil society that is complementary to that of government and essential public services."

Soon after its launch, it added a mapping feature so that users could see where community needs were, where help was being offered, and where public services were available in their local area. Frena La Curva worked with Ushahidi, a social enterprise and technology firm based in Nairobi, Kenya to develop its site. Ushahidi had developed a crowd-sourcing tool during political violence in Kenya in 2008 and has since worked to improve the 'bottom up flow of information' for partners around the world. Frena La Curva volunteers worked with Ushahidi to develop and refine its mapping functions, and to expand its platform and make it available to Spanish-speaking countries throughout Latin America. Since early April, Frena La Curva has expanded its base and offers country-based platforms for community-driven exchange and mutual aid in 16 countries in Latin America.

Screenshots: Frena La Curva impact indicators

https://frenalacurva.net

As of the time of writing Frena La Curva reported a wide range of indicators of engagement across its platforms, including more than 900 initiatives listed in the Citizen Innovation Guide and 28 000 donated masks. They have more than 9 000 map pushpins indicating help needed or services offered. They have also supported the creation of 13 'Distributed Citizen Laboratories' that work on citizen-led social innovation projects like basic solidarity income, a COVID-19 confinement diary, and efforts to support local small business through pre-paid purchases of local goods and services. One of the 'Common Challenges' projects developed an initiative called 'CoAct: Citizen Science and Mental Health' that allowed users to share, normalise and socialise challenging mental health experiences during the pandemic.

The use of a low-cost and easily scalable platform that was developed in Africa and focused on bottom up citizen engagement allowed the original Frena La Curva project in Spain to rapidly increase its reach across Latin America. Each country manages its own site and tailors its functionality and content to suit local needs and contexts.

Lungati, A. O. (March 25, 2020). Frena La Curva: Connecting spanish speakers with critical resources around them. *Ushahidi - Our Blog*. https://www.ushahidi.com/blog/2020/03/25/frena-la-curva-connecting-spanish-speakers-with-critical-resources-around-them

6. Case studies of community engagement on planning and strategic review of responses

The first four case studies in this section show how communities engaged with technology to strengthen their presence and voice in decision making, but also to include their voice in decisions on technology.

6.1 'Sunucity': a digital innovation for community voice on COVID-19 in Senegal

Sunucity is a locally developed mobile phone app in Senegal for local people to report unusual events, problems, epidemic outbreaks to authorities and for the latter to provide information to communities. For more information visit Sunucity at https://sunucity.com/

Senegal, in West Africa, reported it first case of COVID-19 on March 2nd. The government implemented preparedness and response plans to address COVID-19 even before the first reported case. A challenge identified in implementing the plan was seen to be community engagement and there were concerns around good information. Dakar as a large city also raised challenges for community tracking and reporting of suspected cases.

Engineers from the Ecole supérieure polytechnique (ESP) of the University Cheikh Anta Diop of Dakar, led by Ibrahima Kane a local engineer, developed a mobile app to support the link between communities and health authorities' in the interventions against COVID-19, called Sunucity. The target user of the app was identified to be the local population, as they can easily report any unusual events, problems, epidemic outbreaks and suspected cases of COVID-19. They thus intended the app to enable people to make reports that could facilitate a rapid response from health ministry personnel and their partners from local and international NGOs. They also thought the app would be used by authorities to publish notifications and information through it to the population, especially for people in areas where the risk or cases were high, or concerns existed on the response.

Launched in March 2020, by mid-August over 1 000 people had download the app and use was growing. The Sunucity app complements and does not replace the national COVID19 disease monitoring electronic platform but it does bring relevant information from the health authority more directly to communities and from communities more directly to health authorities in real time and on a mobile. It helps when call centres are inaccessible or congested. "From an administration console, ministry officials see in real time the information sent by individual cases about symptoms, unusual events, traffic accidents and so on, and can answer them directly or go to seek them if necessary thanks to the GPS coordinates", explains the designer. While it is used for COVID-19, the reports may also be on other health problems that need attention.

It is seen as a work in progress. The young engineers who developed the app have invited Senegalese users to download and test it and to give them feedback at sunucity.com/feedback with a view to improving it. For the lead developer, Mr Kane, the initiative is one of many that intend to better use technology for social participation in public services. Beyond the coronavirus pandemic, the health ministry and communities can continue to use the platform for prevention activities on other issues. The issues can be diverse and locally specific, as the information and announcements on Sunucity can be distributed in a geographically targeted manner.

The main challenge for widening uptake of this experience, as for other digital developments, are levels of adult literacy and digital access in Senegal. Solving these limitations would be important for the intention of such apps to be more widely integrated as tool for both disease prevention and for social voice in providing evidence and decision making in public health.

6.2 International indigenous communities hackathon challenge

Indigenous communities took part in a crowdsourcing challenge that involved them co-designing culturally appropriate COVID-19 response methods. The hackathon was run virtually and aimed at enhancing the local capacity among indigenous groups around the globe. Further information can be found at the GEO Indigenous Hackathon website.

Indigenous groups face structural challenges that cause them to be disproportionately affected by political, economic, and social harms, but also to often not be given voice in the responses. The COVID-19 pandemic raises the risk of intensifying these challenges. While some indigenous communities have been able to exercise some degree of autonomy over responses to COVID-19, this is often not the case.

In June 2020, the Group on Earth Observations proposed a "GEO Indigenous COVID-19 Hackathon 2020" that involved indigenous and underrepresented groups participating in virtual hackathons in response to COVID-19. It was organized by the Group on Earth Observations (GEO) and the GEO Indigenous Alliance. It occurred virtually in various indigenous communities around the world, many located in rural and remote areas. The virtual platform allowed community members and leaders to engage across diverse locations, with 146 representatives from Kenya, Ecuador, the US, Brazil and 29 other countries involved. The groups involved included: the Samburu Tribe of Kenya, the Rosebud Sioux Tribe in the US, the indigenous Shuar of Ecuador, a Quilombola leader from the Trombetas region of the Brazilian Amazon, the Suri people of the Brazilian Amazon, and the indigenous Kichwa from Ecuador. The hackathons aimed to develop various Earth observation-based solutions that are culturally situated and in tune with the specific needs of communities. 'Earth observation data' refers to satellite imagery, remote sensing, and other geographic information system (GIS) data.

Indigenous communities in these diverse settings were mobilized through social media and existing social networks to create new tools for communication, engagement and pandemic response using Earth observation data. The intention was to identify build capacity in indigenous scientists and communities. The 'solutions' included apps that allowed members of the Samburu community in northern Kenya to develop culturally-relevant maps to figure out how to sell livestock without having to go to local markets. Another app enabled members of the Lakota Sioux Nation to share digital stories of the experiences with COVID-19 that were connected to features of the local landscape, while the Quilombola community in Brazil created a data visualization of socioeconomic and health data that community members have been collecting on their own since 2017.

The project created culturally relevant solutions using Earth observation/ GIS data for indigenous communities to equip them to gather and analyse their own evidence and identify and implement measures they saw to be relevant to the needs and cultures. The hackathon demonstrated the potential of virtual engagement and the importance of open access datasets on which these apps were built, while the participation of more than 100 representatives from 33 countries demonstrated the growing capacity of members of indigenous communities to participate in relevant ICT initiatives from which they have historically been excluded.. The apps created suggested how technology can support, not suppress, the integration of local experience and knowledge in public health responses.

1. Barberia, L. G., and Gomez, E. J. (2020). Political and institutional perils of Brazil's COVID-19 crisis. *Lancet*, *396*(10248), 367-368. https://doi.org/10.1016/S0140-6736(20)31681-0
2. Group on Earth Observations. (2020). GEO Indigenous COVID-19 Hackathon 2020. *observations blog*. http://earthobservations.org/geo_blog_obs.php?id=432
3. Long, G. (2020). How Ecuador Descended into COVID-19 Chaos. *Center for Economic and Policy Research*. https://cepr.net/how-did-ecuador-spiral-into-its-COVID-19-nightmare/
4. Space in Africa. (2020). Teams From Africa Win At GEO Indigenous Hack4COVID Event. *Space in Africa*. https://opportunities.africanews.space/teams-from-africa-win-at-geo-indigenous-hack4COVID-event/

6.3 Preserving a digital record of COVID-19's impact on people in Utah

The 'Utah COVID-19 Digital Collection' is creating digital collections of photographs, stories, and oral histories to document the impact of the COVID-19 pandemic on local communities and community responses to the pandemic and responses by local authorities. The collection is crowdsourced and includes direct information from residents all over the state. For more information see https://lib.utah.edu/services/digital-library/COVID19_digitalcollection

Utah is located in western USA. It is a relatively affluent state with a largely urban population and a low population density. The population of Utah is mostly Mormon, and the Mormon Church significantly shapes the state's social and economic profile. There is a small percentage of racial and ethnic minorities, with Latinx people from Central and South American heritage the largest minority group. Healthcare services in Utah are largely provided by private corporations and by churches.

Utah was less affected in the first wave of the COVID-19 pandemic in the US but has recently seen increases in cases. In mid-March the Governor of Utah issued a stay home advice and social distancing measures were enforced in some public areas.

The Utah COVID-19 Digital Collection Project was implemented after March, engaging with the public through social media. Local researchers used Twitter to ask residents to send in stories, photographs and other content about their experiences during the COVID-19 pandemic. This message was also broadcast to a wider audience through local TV news outlets and word of mouth. All content collected was unchanged by the archivists and residents had full control in telling their stories of how the pandemic had affected them. Later, interviews were used to get oral histories from people and were transcribed for the archive. The project collected photographs that capture different aspects of life during the pandemic such as quarantining, online weddings, and people wearing masks. It has also collected written stories from K-12 and university students about how the pandemic has changed their lives.

After the first week of seeking input from the public, 147 submissions were received. After eight weeks, this number increased to 404. In June, the project received attention from library organizations, which helped to spread news about the initiative to a wider audience. In mid-June 15, the digital collection had obtained over 50,000 views. Project staff also regularly receive inquiries from schools, universities, public libraries and the public in general asking both how they can support the collection effort and whether and how they might begin using the content for their own initiatives.

Involvement of and support from the public has central to the success and growth of the Utah COVID-19 Digital Collection. This project has shown that collecting knowledge on significant social events like COVID-19 is best done during rather than after the event. Easily accessible platforms can provide voices to be heard and the complexities of issues to be communicated and examined more closely.

Neatrour, A. L., Myntti, J., and Wittmann, R. J. (2020). Documenting contemporary regional history: the Utah COVID-19 digital collection. *Digital Library Perspectives*, *36*. https://www.emerald.com/insight/content/doi/10.1108/DLP-04-2020-0025/full/html

6.4 Engaging on ethical concerns in a vaccine trial in South Africa

Community and civil society advocacy groups in South Africa in alliance with other networks engaged on the design of the Task BCG COVID-19 vaccine trial, especially on its lack of proper community engagement and lack of PPE being provided to healthcare workers and participants.

Cape Town is the second most populous city in South Africa and is home to a strong public health academic and activist community. The Task BCG COVID-19 vaccine trial is based at Cape Town's Tygerberg Hospital, which provides healthcare to both private and public patients and is the second largest hospital in South Africa. The trial investigates the BCG vaccine—currently being used against TB—as a protection from COVID-19.

Screenshot from TASK website vaccine section / TASK logo,

https://task.org.za

In June 2020, local and national health advocacy groups, including the Vaccine Advocacy Resource Group (VARG), Community Constituency COVID-19 Front, the South African National AIDS Council (SANAC) Labour Sector, the SANAC Civil Society Forum, the Tuberculosis TASK Team, Show Me Your Number, the Treatment Action Campaign, and the STOP TB Partnership, came together to raise concerns around the design and conduct of this trial.

The groups criticized the lack of community engagement and transparency with information, as well as a lack of personal protective equipment (PPE) being provided and worn by the trial's healthcare workers.

As a result of their concerns, several of these groups issued a joint statement calling for the suspension of the Task BCG COVID-19 vaccine trial and a new review to be completed by the organizations that originally approved the trial, that is the South African Health Products Regulatory Authority, the Pharma-Ethics Independent Research Ethics Committee and the University of Cape Town.

Ntando Yola, founding member of VARG, explained that too often, such trials highlight inadequate engagement of communities in the design. She commented that a single meeting is often taken as sufficient to say, "…we have consulted with people or at least we've consulted with committees." Despite the community concern, as of September, the trials are continuing.

Advocacy groups outside of the trial raised substantive concerns around what constitutes adequate community engagement and ethical conduct of trial research. If international standards or specific laws do not provide levels of community engagement and consultation that are perceived by communities to be adequate, the issue will remain contentious. While the eventual outcome of this particular action is not yet clear, strong civil society/activist engagement, with support from the communities they represent, can play an important oversight in COVID-19 biomedical research.

1. Abdool Karim, A. (2020). Cape Town COVID-19 vaccine trial comes under fire from activists. *Bhekisisa Centre for Heath Journalism*. https://bhekisisa.org/health-news-south-africa/2020-06-08-COVID19-bcg-trials-south-africa-task-personal-protective-gear-trained-immunity/
2. Abdool Karim, A. (2020). Unions, activists call for Cape Town COVID-19 clinical trial to be stopped. *Bhakisisa Centre for Heath Journalism*. https://bhekisisa.org/article/2020-06-13-unions-activists-call-for-cape-town-COVID-19-clinical-trial-to-be-stopped/
3. Abdool Karim, S. S. (2020). The South African Response to the Pandemics. *New England Journal of Medicine*, *382*(24), e95. https://doi.org/10.1056/NEJMc2014960

The next three case studies show in diverse ways of how communities are engaging with different levels of state authority to input to and monitor design and decisions on responses to COVID-19.

6.5 Faith-based organizations' say in COVID-19 measures in Burkina Faso

Cercle d 'Etude, de Recherche et de Formation Islamique (CERFI) a faith based organization for the Muslim community worked with the government in Burkina Faso to frame and explain public health measures for COVID-19 in a manner that would be credible to the religious community, and thus more widely implemented. For further information visit CERFI at http://cerfi.bf/cerfi/

Burkina Faso in West Africa is a secular country with a population of about 20 million. Muslim communities represent around 60% of the population and play a key role in development. Between March and July COVID-19 cases rose, but there are now few daily confirmed cases and restrictions, such as a curfew and social distancing, have been lifted. Concerns were, however, expressed of the need to prevent further outbreaks and faith-based organizations, such as Cercle d 'Etude, de Recherche et de Formation Islamique (CERFI) engaged further on this.

CERFI is a Moslem faith-based organization that has had a long presence in the country and contributes to socio-cultural, economic and health development. It engaged on measures for COVID-19 prevention to identify those that would be acceptable for the community and for public health. CERFI in collaboration with the Ministry of Health and the Burkina Faso communication council identified the need to temporarily close religious mosques, schools and festive activities throughout the country and assured that this was in line with both state law and religious verses. CERFI showed religious verses the consistency between public health measures like handwashing and social distancing in relation to disease transmission and religious norms. For example, the 'hadiths' which record the traditions or sayings of the Prophet Muhammad that are revered as a major source of religious law and moral guidance by the Muslim community were referred to by a former president of the CERFI, noting that while no hadith provides for social distancing ".....with the protection of life coming first, all Islamic laws take this into account, and in sharia, necessity overrides the law'' . The CERFI also contributed to development of a plan for safe re-opening of religious institutions.

Social distancing practicing during the Ramadan prayer in Burkina Faso

CERFI, 2020

The collaboration between CERFI as a faith-based organization and government was enabled by a prior consultation framework set up by government that existed for many years. Dialogue is organized yearly with all associations and NGOs around health and development issues. The inclusion of faith=based organizations in developing measures is not seen to undermine principles of state secularism but as a means of ensuring successful implementation of measures. CERFI played a role in communicating measures that it had played a role in developing in a manner that was understood by the community. It also used its own resources to provide PPE, implement safety measures and water and soap for washing hands for vulnerable populations. It is pertinent that no outbreak occurred at the time of writing in CERFI mosques.

1. Radio Oméga. (2020). Burkina : Coronavirus : Le CERFI décide de la suspension des activités de masse, des prières ordinaires et de vendredi dans toutes ses mosquées *19 March*
2. lefaso.net. (2020). *Coronavirus au Burkina : Le CERFI invite ses fidèles à respecter strictement les mesures prises*. https://lefaso.net/spip.php?article95439, 13 March
3. Boureima, B. (2020l). Coronavirus au Burkina : les propositions de la FAIB pour la réouverture des mosquées. *Wakat Séra*.

6.6 African American community voice in community coalition boards

A community coalition board provided a means for local, often marginalised African-American residents to raise and engage on their needs and concerns of African-American residents during the COVID-19 pandemic in health research, health literacy, and socio-economically situated mitigation strategies implemented by the local university.

Atlanta, Georgia, is an urban setting in the south-eastern United States. It has a large African-American population, most of whom are economically marginalized and all of whom are subject to various forms of structural racism that have persisted for over 400 years, with consequences also for inequalities in health and its social determinants. These disparities have also been intensified in the COVID-19 pandemic, and have contributed to disproportionate adverse health and social outcomes among African-Americans. Low-income workers who do not have jobs that allow them to work virtually are at an increased risk and those who have lost employment are now facing dramatic financial challenges. While the federal government passed the Coronavirus Aid, Relief, and Economic Security (CARES) Act to address economic burdens and states and local area governments implemented strategies to stimulate local economies, with free food, nutrition and unemployment benefits in some areas, these benefits did not always reach the most marginalised communities. In Georgia, the governor has resisted the use of masks and social distancing and has passed executive orders preventing city authorities from enforcing mask mandates.

Black Lives Matter Plaza, Washington, DC USA

Tedeytan, 2020

The Morehouse Prevention Research Centre (PRC) and local community in the area have had a community coalition board for over 20 years. It is made up of residents, particularly from more marginalised communities, and representatives from academic institutions and local social services. The residents hold sole decision-making power. The represented communities are 87% African American. Residents were initially identified through local census rolls and encouraged to join. Those with pre-existing health conditions are targeted for leadership. In the work the research centre does, the residents have significant power in developing research questions and identifying top health priorities. One example is the community health needs and assets assessments (CHNA^2) that occurs every 4 years. It is run by community members who act as citizen scientists. The methods are co-crafted and co-led by community members. Furthermore, the community coalition board has formed an internal committee to focus on the development, monitoring, and evaluation of survey designs and data analysis conducted by outside researchers.

The community coalition board has made input into planning and local responses to the pandemic. Virtual webinars and other digital technology have been used to engage the wider community, with high-blood pressure, diabetes, obesity, nutrition, and mental health raised as their top concerns in the pandemic. The community coalition board organized a virtual forum for community members, community leaders, psychologists, and researchers meeting to discuss strategic responses.

This initiative provided a means for substantive resident power in co-creating solutions for local health challenges. A long-standing mechanism and set of relationships and activities between the university and community laid the foundation for meaningful engagement during the pandemic.

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6.7 Civil society engagement in planning COVID-19 responses in Chikomba District, Zimbabwe

The Civic Forum for Human Development (CFHD), a national civil society coalition network has worked with communities and civil society using a rights framework and make links to bring their inputs to formal planning for COVID-19 in Chikomba district.

Chikomba district in Zimbabwe has both rural large and small scale farms and peri-urban areas. It has rich forests and wildlife and agriculture is the main economic activity. With 121 162 people it has 43 schools, a district hospital and eight rural health service centers. The Chikomba Rural District Council governs the area, with elected councilors and five traditional chiefs in the council.

When the pandemic became evident in March, the district put in place a COVID-19 committee to involve all key stakeholders in developing the local response. This included key government departments (health, education, labour, social welfare, transport, youth, women, enterprise), traditional and local leaders. The committee meets regularly and has visited local communities and their leadership to advance and assess progress in implementing agreed preventive strategies.

The Civic Forum for Human Development (CFHD), a national civil society coalition network, consulted its network of 12 community and civil society organizations in Chikomba and other districts to bring their experience and perceptions of actions needed to the district plans, recording the priorities within a human rights framework. At the same time CFHD engaged with the district authorities to bring community input to plans, to identify shared needs and ensure support for local community and institutional preparedness in the plans. The areas below reflect shared views on areas that need to be addressed in the planning as a result of this process.

Financial Support	Material Support	Technical, and Capacity Building Support
• Supporting budget deficits for COVID-19 District Action Team to reach out to communities with information awareness, meetings with local leaders and communities, WASH Training and Hygiene Education, Community Infrastructure development for improved water, sanitation and health practices. • Financial support to cover transport, operational and subsistence costs of District Action Team members deployed to the communities.	• Printed awareness raising materials on COVID-19, fuel for outreach visits to communities and materials on preventive measures for communities. • PPE for District Action Teams to distribute to relevant institutions in the frontline of COVID-19 awareness raising and in rural health clinics and any other materials for enhancing safety of health workers and other staff involved in COVID-19 at local level.	• Partnership with the District Action Team to ensure adequate training of DAT members in community outreach and awareness raising on COVID-19, risk mapping and assessments, community preparedness planning training and capacity building, resilience, monitoring effectiveness of COVID-19 responses at the community level, and partnerships with other agencies for improved community responses.

Having an already established network of community and civil society organizations helped to organize collective views and compile evidence in the district. Social media platforms - WhatsApp and Facebook – played an important role in communication. Co-operation and good relationships with local traditional leaders have enabled monitoring to bring evidence for dialogue with authorities.

1. Chikomba District (2020) COVID- 19 Responsive Plan 2020, Chikomba district, Zimbabwe.
2. Civic Forum on Human Development (2020) COVID-19 Monitoring Briefing Paper, Mimeo, CFHD

The last two case studies describe different approaches of human rights civil society in bringing voice to plans and decision making on COVID-19.

6.8 Social resistance to authoritarian responses to COVID-19 in Kenya

Community members have used social movements to shape information sharing in Kenya and citizen-led communication methods are enabling their voices and evidence to profile and engage on authoritarian responses to COVID-19 in Kenya.

Nairobi and Mombasa are vibrant growing cities in Kenya, but with significant socio-economic inequalities. The Kenyan Government imposed a strict curfew from dusk to dawn on March 27, 2020 in response to the rise in COVID-19. The government closed school churches, airports, and imposed strict border controls. Citizens who broke curfew were forced into government quarantine facilities.

The COVID-19 measures applied presented many challenges for poor and especially homeless communities. In Nairobi, many people were reported to have beaten and tear gassed by police for being out past curfew without regard to their socioeconomic situation.

Local social movements in Nairobi and Mombasa began to organize in response to police brutality and government neglect. Activists spread information about cases of police brutality and citizen rights. Communities used various social media to communicating incidents and their experiences and to advocate for their needs. Protests organized by local social movements and NGOs working as coalitions enabled local residents to highlight grievances that were not being heard in dominant media channels. Community members used videos, photographs and hashtag-driven social media posts to share information about incidents, protests, resources, and to discuss community experiences and needs. Social media enabled people to overcome the physical barriers of lockdown to organize around issues such as police brutality and reached a wide audience. Organizers used graffiti on walls, spoken word poetry, and music to educate and mobilise people and to express their grievances on a range of COVID-19 justice related issues.

When a young boy was killed by a stray bullet fired by police enforcing a local COVID-19 lockdown, it sparked outrage in the community. He was shot while standing on the balcony of his apartment. A vigil and protest followed to raise awareness of the linked problems of ongoing systemic oppression by the police, intensified in the more recently established curfews and police powers justified in the name of COVID-19 lockdowns.

The challenges faced by urban poor people in Kenya highlighted how social media communication has offered social movements and poor communities an opportunity to highlight longstanding injustices and new oppression from authoritarian forms of response to COVID-19. While it has enabled protest against injustice it has also built alliances and new forms of community engagement and mutual aid within and across communities..

1. Chukunzira, A. (2020). Organising under curfew: perspectives from Kenya. *Interface*, *12*. https://www.interfacejournal.net/wp-content/uploads/2020/07/Interface-12-1-Chukunzira.pdf
2. Wangmo, T. (July 31, 2020). Kenya Stops Abusive Forced Quarantine Related to COVID-19. *Human Rights Watch*. https://www.hrw.org/news/2020/07/31/kenya-stops-abusive-forced-quarantine-related-COVID-19

6.9 Human rights activist input to social protection in prisons in Ivory coast

L'Observatoire Ivoirien des Droits de l'Homme (OIDH) as local human rights organization played a role in profiling and protecting the rights and public health of a particular vulnerable group, the prison population and raised other rights violations through sustained and multiple forms of interaction with relevant authorities and public outreach.

Ivory Coast is a west African country with a cosmopolitan population of 22,6 million, many coming from other west African countries. The first cases of COVID-19 were reported in March 2020 and cases were mainly concentrated in the capital city, Abidjan. With potential human rights limitations due to the public health measures imposed to control COVID-19, local organizations such as Observatoire Ivoirien des Droits de l'Homme (OIDH) have a role to play in contributing to protecting human rights. OIDH is a human right organization created by young activists in 2014 and operating throughout the Ivory Coast. Its mission is to protect, defend and promote human rights by training, informing and raising public awareness and influencing authorities in Côte d'Ivoire.

With the current COVID outbreak, OIDH focused its attention on the main prison named 'Maison d'Arret et Corection d'Abidjan' (MACA). The prison population is estimated at 5 400, although the normal capacity is 1500, suggesting levels of overcrowding, estimated at 266% for the prison population as a whole in the country. This has raised concern on disease transmission on the prisons. OIDH have thus taken actions to engage authorities and the public to limit the spread of the virus in prisons and protect health rights of prisoners and their families. The wrote a public letter for attention of the Ivorian Ministry of Justice to seek alternatives to preventive detention and, in accordance with Article 154 of the Code of Criminal Procedure of Ivory coast, to ensure preventive measure for prisoners and visitors, including limitation of visits or safe distancing, setup access to water and soap for hand washing and information on COVID-19. In a second public letter to the same ministry they urged measures to decongest the prisons reduce overcrowding. They monitored implementation of a COVID contingency plan in prison. OIDH also wrote a letter to the Ministry of Defence and Ministry of Justice condemning acts of police violence against citizens for contravening curfews or frequenting public spaces. Their letters were also shared on social media like Facebook.

The OIDH activities sought dialogue and collaboration with the health and justice ministries and heads of penitentiary facilities on these issues. That its engagement with government on prisons started before the pandemic helped to build the relationships needed to address new issues. After the OIDH interventions and the concerns on prison transmission, the government released about 2 000 prisoners by presidential decree and implemented prevention and control measures in the prisons. By July there had been only 19 reported cases of COVID-19 in the two Ivory Coast prisons. OIDH protests regarding police actions also appeared to have limited such actions.

The initiative showed how a local human rights organization played a role in profiling and protecting the rights and public health of particular vulnerable groups and the general population, through sustained and multiple forms of interaction with relevant authorities and public outreach. Having international human rights positions to support such actions, such as that of the UN Office of the High Commissioner for Human Rights, has also been important.

1. Francis, O. I. (2020). *COVID-19/ Grâce présidentielle : l'OIDH reste préoccupée par la fluidité de la chaîne pénale et la surpopulation carcérale.* OIDH.
2. Francis, O. I. (2020). *Visite d'échanges : L'OIDH reçue en audience par le Régisseur de la MACA Hincleban KONE.* OIDH.
3. Francis, O. I. (2020). *Dabou/ Visite d'échanges : L'OIDH reçue en audience par la Régisseuse de la MAC Nathalie KOUASSI*. OIDH.
4. Francis, O. I. (2020). *Lutte contre la COVID-19 en Côte d'Ivoire : l'OIDH demande le désengorgement des prisons*. OIDH.
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6. Richard, F. (2020l). Prisons en Côte-d'Ivoire : des libérations, mais « ce n'est pas assez». Liberation.fr.

7. Key features and insights for community engagement in COVID

This section discusses the learning and insights from across the case studies.

Diverse stories of contribution, solidarity and meaningful engagement

While all the case studies present some facet of how communities are engaging in the responses to COVID-19, the first issue to note is their uniqueness. They come from diverse contexts and political economies and reflect different histories, including of socio-political struggle. In identifying common features and shared insights there is no intent to ignore that **uniqueness and diversity.**

The second key issue is to note **their contribution** to managing the health and social demands placed by the presence and consequences of COVID-19 and the responses to it. The case studies, coming as they do from countries north and south at all income levels, and located within stronger and weaker health systems, show the contribution and relevance of meaningful participation of communities in all such contexts. This is important. This contribution is often discounted or added as an afterthought when plans have been made and service issues addressed. Yet across the case studies there is evidence of a significant contribution to prevention, to medical care, to diverse forms of social and economic protection and to social solidarity, values and trust. Rather than poorly implemented approaches that treat people as objects to be managed, the people involved are subjects, full of life, with rights, ideas and rich experience.

The case studies show experiences, actions and solutions that may inspire others:

a. They report the creative development local apps and use of existing information technology (IT), including WhatsApp and other social media platforms for different community groups to: map real-time availability of face masks in shops; report problems and outbreaks to authorities; in hackathons to design technologies and responses; to communicate between volunteers and others, including in the diasporas; and to provide guidance and learning materials, including in liaison with book publishers to support home schooling. Social media and radio have been used to rapidly organize and inform people across wide geographical areas, including in areas of conflict where access may be limited. Social media platforms have enabled school children to send digital cards to hospital patients and youth in Europe to obtain toolkits and resources for an '#outbreakofgenerosity' campaign to help people in vulnerable situations. These platforms connect people across communities and countries in a range of initiatives. They are also used to crowdsource digital photos, stories and oral histories of community experiences of the pandemic.

b. They show community organization around prevention, including through leaders, community health workers, supporting symptom surveillance, encouraging uptake of testing, contact tracing and links to care, including for groups such as returning migrants. Community members have implemented their own risk mapping, identified high risk areas, such as local markets, and suggested alternative ways of organizing them to reduce risk. In some areas through local committees/ councils, community representatives have participated in discussions on the timing of lifting of lockdowns and participated in monitoring the implementation of what was agreed.

c. Community volunteers and 'citizen scientists' have organized and been trained to produce information materials, open source face masks, hand sanitizers and PPE kits (visors, masks, suits, gloves) to accredited standards for local health service personnel and for community and other frontline workers.

d. The case studies report organization around care, including self-organized medical networks and use of telemedicine to support counselling and referral to public facilities and to arrange blood donations; organization of quarantine facilities and emergency transport, preparation and provision of food packs, blankets, winter clothes, sanitary napkins and other inputs for particular groups and families in need. Understanding local sensitivities has enabled this support to be done in a way that avoids stigma, while social media apps have helped to locate services offered. CHWs have also provided support for childbirth, including virtually.

e. There are interventions that have explicitly recognised the psychosocial dimension of the pandemic, using social media and local languages to discuss mental health and other needs and challenges faced; providing short stay facilities, community counselling for those affected by domestic violence; responding to and discussing alignment of interventions to cultural and religious beliefs; and calling socially isolated and elderly people to check that their needs are being met.

f. Initiatives responding to wider needs generated by COVID-19 and lockdowns have linked small scale farmers to household deliveries for food security and have organized and provided food through communal gardens, community kitchens and 'people's' restaurants for those in need. They have supported access to emergency lodging, benefit schemes; and safe water.

g. Many of these initiatives drew on resources in civil society, from crowdfunding and from public, private and international agency contributions. In many cases the actions taken and demonstration of response was used to negotiate and lever resources from local and central governments for areas or groups that had been excluded or underfunded.

h. The civil society and social advocacy processes worked with local and sometimes central government, including to protect rights of groups like prisoners, but there were also examples of resistance to and advocacy on abuses of authority, lack of adequate engagement on vaccine trials or rights violations.

The 42 case studies show many examples of what is possible! There are certainly more such experiences not yet captured. Most importantly they show as deliberate acts, a compassionate, justice and rights driven face of society. The 'outbreak of generosity' campaign by young people in Europe expresses it well, as a deliberate intention to communicate solidarity. This kindness has often been hidden by the physical isolation and distancing in COVID-19 – ironically termed 'social distancing' - and the use of war rhetoric in authoritarian responses to COVID that has often treated people as passive objects, or worse as problems to control. The case studies show that **a compassionate society is not contradictory to and in fact enhances public health.**

They are bound by a common theme – how are communities organizing, engaging and being engaged in relation to COVID-19, not only in superficial forms of information outreach and ad hoc consultation by authorities, but in more **meaningful forms of engagement**, where those affected can assert their collective realities, experience, power, where they can collectively act on issues that matter to them; exert influence on actions that affect their wellbeing, and learn from that action.

They include a range of **participatory, multi-sectoral, solidarity- and equity- driven interventions** for public health and wellbeing. They are not without challenges and reversals and raise problems, but are also consistently **solution-focused**. They do not intend to take over what the state has a duty to provide and many **use their actions to negotiate and lever the resources and relationships that they expect from the state**.

Features of the social organization supported flexible, agile and affirmative action

While all the case studies show some evidence of this collective self-determination, the **degrees and depths of this power and collective organization differ**. Their strength, the pace at which they respond to the changing conditions and uncertainties brought by the pandemic and the impact they have on social conditions and institutional practice appear to be influenced by a number of factors, some of which relate to the social organization itself:

a. Deeper more proactive forms of community organization and engagement **build on histories, ideologies, structures, organization and relationships that began long before the pandemic**. While some case study experiences began after the pandemic, most built on prior work, sometimes decades long organizing, building relationships of trust and shared principles with the community and other stakeholders. Community and civil society organizations that have had this longer history and have built capacities to support voice and agency seem to have been 'faster out of the gate' and more likely to have a deeper impact (as for examples in Brazil, Ivory Coast and India). They also intend for relevant innovations to be sustained, such as in links between farmers and consumers that

cut out price-hiking middlemen. In the context of emergency responses to COVID-19 that have often seemed ill-prepared and inconsistent, not effectively engaging such assets would seem to be a mistake.

b. **Communities are not homogenous.** The diversity within communities is recognised in the particular attention given in some case studies to more socio-economically disadvantaged groups *within* communities, such as Dalits (Scheduled Castes), landless and displaced people in Maharashtra, or groups that may be socially marginalised, like adolescent girls in Vadodera, or elderly people in Yale New Haven. Many of the initiatives link more powerful groups within the same communities, whether professionals, producers, opinion leaders and government workers to these disadvantaged groups. While COVID has added new harms to the socio-economic inequalities faced by these groups within communities, in the case studies the **community organizing focuses not simply on the disadvantage of these groups, but also on the assets and energy they bring to collective processes.** In Cameroon, local residents are engaged with as 'citizen scientists'. In Taiwan and Brazil as 'community researchers' and in Yemen and many other sites as producers. Those involved in the process engage not just for what they benefit, but for what they contribute. In some processes social differences in communities were explicitly engaged with**,** such in the integration of religious beliefs in planning preventive actions in Burkina Faso, or in the networking across different religious groups in Maryland USA, in both cases to better connect with community cultures and concerns.

c. Existing programs that are **focused on a range of health and social problems** were often able to pivot and adapt their work to COVID-19. It appeared that the more holistic the lens of the social organizations and the more responsive they are to community priorities, the more they were able to take on the mix of issues raised by COVID-19 for different groups (as in Brazil, or the CANs and MCSJ in South Africa). At the same time the scale of the social and economic disruptions raised needs that were not all appropriate for communities to take on, and some case studies cautioned that efforts to support in a crisis not turn into taking over roles and duties that belong to the state (such as in Paraisópolis Brazil).

Viral street art, Hull

Paul Harrop, 2020

d. **Prior investment in capacities** of the collectives, including through training, leadership, literacy and review, appeared to enable the strategic and creative thinking for an uncertain and dynamic period during the pandemic. There is also evidence of the role of **leaders, facilitators, brokers and activists** in many (such as individuals who were catalysts in South Africa's CAN and FoodFlow, or in Paani Foundation's social worker catalysing farmer-to- community links in Satara India).

e. **Organizing processes that were participatory and democratic** were able to create a more inclusive space where differing needs of different sections also found a voice, such as in the deliberate inclusion in in the Kudumbashree in Kerala of marginalised people or those with special needs for membership or the inclusion in Dewas of marginalised women in the SHGs. This enabled unique needs to not be crowded out by concerns of more powerful groups and locates these groups as actors not victims, in confrontation with existing social hierarchies.

For communities, engagement implies negotiating and managing relationships with other actors, including holding the state accountable for its obligations.

Beyond the features of the social organization, the case studies show the importance for community engagement on COVID-19 of the **relationships between actors** in the response:

f. In a number of the case studies, important new relationships were built between **communities and producers**, (in mutually beneficial small farmer to community links in Satara India; Food Flow in South Africa; Kudumbashree in Kerala and SPS and the SHGs

in Dewas India) and in some cases building **communities *as* producers** (such as women PPE producers in Yemen). This showed the value of productive capacities and economic interactions that were previously ignored. Their contribution to COVID-19 was evident, but there was concern about how sustained these new economic relations would be.

g. In a similar manner, there are interesting experiences recounted in the case studies of local engineers and scientists working with communities to build their scientific capacity and to co-produce technology, recognising their role as '**citizen scientists'.** One key support for this is ensuring open source protocols to be used in research and development, (as raised by Mboalab in Cameroon). In this site, the capacity to produce PPE depended in part on access to open source technology. This is often not available, even for essential health technologies. Not all the organizing around science and technology is based on affirmative processes- some were more conflictual, such as the contrasting experience of VARG and others in South Africa contesting their exclusion from the design of vaccine trials.

h. **The relations with the state, especially local government, are vital, and point to the value of multi-sectoral approaches and more collaborative decision-making**. Some of the community actions were triggered by imposed measures that were insensitive to community realities, generating barriers in access to food, or loss of employment. However, many case studies pointed to the role of the state in setting the enabling conditions for community engagement, and collaborative space for joint work and decision-making. This was more often achieved with city and local governments, especially where state capacities were decentralized (as in Kerala) or autonomous (as in the Native American Reservations). In Kolkata, West Bengal, registration of the self-organized COVID-care network with the state enabled effective referrals to and from public services. Interactions with national governments were more limited and around policy (such as on the prison conditions in Ivory Coast). Where local state resources and capacities were more constrained, however, so too was local government responsiveness to communities. Supporting local governments thus also became a matter for engagement (as in Chikomba Zimbabwe). As noted in Brazil, Ivory Coast, South Africa, Philippines and elsewhere, self-organization in communities, often a response to deprivation or deficits, was **not intended to take over state duties.** These case studies used their actions to create pressure on the state to allocate resources to these underfunded areas and to advocate for recognition of disadvantaged groups such as prisoners or homeless people, and to engage the state for accountability on its obligations, roles and resources.

i. **Alliances between community members and health workers contributed in many ways.** Medical and doctor activists and community health workers acted as a bridge between communities and health services in many settings (from Doulas in the USA to medical activists in Kolkata, West Bengal). Health professionals could provide support to claims on other sectors (as in the work on prisons in Ivory Coast or with returning migrants in Malawi). At the same time the community organizations were able to respond to the non-medical aspects of COVID, noted earlier.

j. **Collaboration with the state did not mean being dominated by the state**. While the interaction with the state infuses positively and negatively all of the case studies to different degrees, the relationships took very different forms, linked to context, but also the way the context was read politically by the social organizations.. One strand of community engagement was explicitly independent of or even anti-state, organizing 'from below' (such as the Brigades in Europe). This lens emerged in social movements whose issues have also been amplified by the pandemic, such as racial and social justice activists. In other settings the relationships were more adversarial, such as in Kenya's social movement resistance to authoritarian COVID-19 action by police. In many other case studies the relationship with the state appeared more nuanced, with co-operation and engagement while also organizing communities around their rights to hold the state accountable (such as in Ivory Coast and Zimbabwe). The balance between collaborative and adversarial relationships is a strategic and often political decision. In Sapopemba Life Brigade experience in Brazil, collaboration generated productive actions on COVID-19, but the

organization of communities and social movement and their advocacy was observed to be what makes the state move.

k. There were also strategic links with **international organizations**, such as on migrant issues (with IOM in Mozambique), on human rights issues (such as on prisoners' rights in Ivory Coast), for support from international civil society (as in the case of the slum dwellers and HPFPI in Philippines) or with **diaspora communities** (as in the Syria case study supported by social media). These examples suggest that international alliances may be even more important where resources and political space may be more limited. What is evident is that the relationships described in the case studies appear to be more **solidarity transfers and common cause support,** significantly different from the top-down application of predetermined funding and technical support found in some international agency interaction with community levels on COVID-19.

The process and tools are also key contributors to the outcomes

Communities and their organizations use a range of **methods and tools** in their engagement around COVID-19.

a. **Information communications technology (ICT) tools enable community roles rather than simply extracting community information.** Access to such tools are critical for meaningful engagement. As shown by technologies such as g0v in Taiwan, Sunucity in Senegal, the Utah COVID-19 Digital Collection or GEO Indigenous Hackathon globally, open source technology offered as a public good, often by local developers, with intent to service community needs (masks, response to problems, indigenous understanding and evidence) provide forms of ICT that enable social power. It is thus not access to *any* ICT that supports meaningful community engagement, but rather ICT that supports problem solving, provides outlets for the expression of marginalized voices and experiences, builds public accountability that do this. **Affordable digital access is critical for this, and continues to be a challenge in many communities.**

b. **Social media, particularly WhatsApp,** appears to have played a critical connecting role in many of the case studies, such as in connecting local and diaspora populations in Syria or communities to farmers in India. The experience from Mali showed also the role of journalists and community radio stations as 'connectors' – not just in sharing information but also in linking social networks in areas affected by conflict not easily reached by others. As pointed out in Sapopemba, having **remote meetings** using online platforms was a potential asset. It enabled a far wider range and scope of people to connect, if digital access is there. It is interesting that **south-south exchange** is now growing with these media, such as between Ushahidi in Kenya and Frena La Curva in Latin America, on platforms that appear to be enabling the type of social interaction needed in these settings.

c. **Simple tools, norms and standards, and open data facilitate creative community engagement**. Several case studies highlighted the potential impact of, for example, having globally recognized norms and standards for products like PPE and hand sanitizer or for the ethical conduct of trials. These improve the legitimacy of local efforts to solve problems and engage meaningfully in COVID-19 response projects. Similarly, having access to open data, open science tools and open protocols and activist scientists that see community knowledge as an asset greatly facilitates bottom-up problem solving and the meaningful engagement of communities that have been historically marginalized from these forms of innovation.

The challenges presented by the pandemic are creating demand and space for innovation, and in many settings communities are rising to that demand.
The uncertainty of a new pandemic and how to manage it opened spaces and flexibility for new ways of thinking, organizing and acting, new relationships and new opportunities for solidarity. The uncertainty has enabled flexibility in some settings for local levels and workers to try new approaches. It has stimulated new ways of developing and using technology and different forms of interaction between consumers and producers, between state, civil society and others and between 'expert' and local knowledge.

The case studies show inspiring examples of how communities and their organizations and partners have used the space to build on experience and innovate, with positive benefit for often disadvantaged communities. **This huge mobilization of affirmative community effort and creativity needs to be recognized in the story of the 2020 pandemic.**

We hope that the case studies inspire the proactive efforts of other organizations and communities. They also carry a consistent message: The response to COVID does not need to generate fear and coercion- it can be inclusive, creative, equitable and participatory.

Coronavirus art from 6th street in Austin, Texas

L Rodgers, 2020

There is not a monopoly of wisdom and experience in any one constituency or one level, from local to global, in organizing the response to a challenge like COVID-19, that raises different experiences in different contexts, that arises due to multiple social determinants, including structural socio-political and economic determinants and that has impacts across many levels and dimensions of wellbeing. We should give space to bring in, listen to and work with a diversity of experience, knowledge, capacities and ideas, at the center of which are those from communities.

There are challenges and limitations in investing in meaningful forms of community organization for self-determined engagement on COVID-19, especially as cases escalate. However, the few case studies captured in this report affirm the opportunities and gains in doing so. We would argue that co-production and co-determination with affected communities are not an optional 'add-on' to COVID-19 responses. They are fundamental to a successful response.

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