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Community participation is crucial in a pandemic

Published Online May 4, 2020 https://doi.org/10.1016/ S0140-6736(20)31054-0 Community participation is essential in the collective response to coronavirus disease 2019 (COVID-19), from compliance with lockdown, to the steps that need to be taken as countries ease restrictions, to community support through volunteering. Communities clearly want to help: in the UK, about 1 million

people volunteered to help the pandemic response¹ and highly localised mutual aid groups have sprung up all over the world with citizens helping one another with simple tasks such as checking on wellbeing during lockdowns.²

Global health guidelines already emphasise the importance of community participation.^{3,4} Incorporating insights and ideas from diverse communities is central for the coproduction of health, whereby health professionals work together with communities to plan, research, deliver, and evaluate the best possible health promotion and health-care services.⁵

Pandemic responses, by contrast, have largely involved governments telling communities what to do, seemingly with minimal community input. Yet communities, including vulnerable and marginalised groups, can identify solutions: they know what knowledge and rumours are circulating; they can provide insight into stigma and structural barriers; and they are well placed to work with others from their communities to devise collective responses. Such community participation matters because unpopular measures risk low compliance. With communities on side, we are far more likely—together—to come up with innovative, tailored solutions that meet the full range of needs of our diverse populations.

Panel: Steps to community participation in the COVID-19 response

Invest in coproduction

- Fund dedicated staff and spaces to bring the public and policy makers together
- Create spaces where people can take part on their own terms (eg, avoid bureaucratic formalities or technical jargon)
- Move beyond simply gathering views and instead build dialogue and reflection to genuinely codesign responses
- · Invest not only for this emergency but also for long-term preparedness

Work with community groups

- · Build on their expertise and networks
- Use their capacity to mobilise their wider communities

Commit to diversity

- Capture a broad range of knowledge and experiences
- Avoid one-size-fits-all approaches to involvement
- Consciously include the most marginalised

Be responsive and transparent

- Show people that their concerns and ideas are heard and acted upon
- Collaborate to review outcomes on diverse groups and make improvements

In unstable times when societies are undergoing rapid and far-reaching changes, the broadest possible range of knowledge and insights is needed. It is crucial to understand, for instance, the additional needs of particular groups, and the lived experiences of difficulties caused by government restrictions. We know lockdowns increase domestic violence;⁶ that rights and access to contraception, abortion, and safe childbirth care risk being undermined;⁶ and that some public discourse creates the unpalatable impression that the value of each individual's life is being ranked. Identifying and mitigating such harms requires all members of society to work together.

Past experience should be our guide. Grassroots movements were central in responding to the HIV/AIDS epidemic by improving uptake of HIV testing and counselling, negotiating access to treatment, helping lower drug prices, and reducing stigma.⁷⁻⁹ Community engagement was also crucial in the response to Ebola virus disease in west Africa—eg, in tracking and addressing rumours.¹⁰ Coproduction under the pressures of the COVID-19 pandemic is challenging and risks being seen as an added extra rather than as fundamental to a successful, sustainable response.

Good mechanisms for community participation are hard to establish rapidly. High-quality coproduction of health takes time. Meaningful relationships between communities and providers should be nurtured to ensure sustainable and inclusive participation. Managing participatory spaces takes sensitivity and care to recognise and harness the different types of knowledge and experiences brought by diverse communities and individuals, and to avoid replicating social structures that could create harms such as stigma.

So how can we create constructive coproduction in the context of emergency responses to the COVID-19 pandemic where time is short? We summarise the key steps in the panel.

First, governments should immediately set up and fund specific community engagement taskforces to ensure that community voice is incorporated into the pandemic response. This requires dedicated staff who can help governments engage in dialogue with citizens, work to integrate the response across health and social care, and coordinate links with other sectors such as policing and education. This engagement will require additional resources to complement existing health services and public health policy. Dedicated virtual and physical spaces

must be established to co-create the COVID-19 response, with different spaces tailored to the needs of different participants—eg, different formats for discussion, timings, locations, and levels of formality.

Second, those of us working to address COVID-19 in the health and social care sectors and beyond should look to existing community groups and networks to build coproduction. Engagement with such groups is needed to include their voices in local, regional, or national responses to the pandemic. How can we ensure that the most marginalised are represented? How can we ensure front-line providers have a chance to feed into service improvements when they are already working long hours with little respite?

Third, policy makers working on the COVID-19 response should ensure citizens understand that their voices are being heard. Showing how policy responses or local actions address specific concerns will help communities believe that their wellbeing is valued and their needs addressed, which in turn will help increase compliance with restrictions and encourage sharing of creative solutions. Examples of responses to citizens' concerns have included introducing income guarantees for the self-employed;¹⁵ implementing road closures and widening to allow safer cycling and walking;¹⁶ and policy changes on home use of abortion medication to reduce risk of infection from attending clinics.¹⁷

Institutional cultures that support coproduction must be created in political and health systems. ¹⁸ We would argue that mechanisms to ensure citizen participation are essential for high-quality, inclusive disaster response and preparedness, and these can be called upon again in future emergencies. All societies have community groups that can co-create better pandemic response and health services and politicians must be supported to incorporate these voices. Such public participation will reveal policy gaps and the potential negative consequences of any response—and identify ways to address these together. Community participation holds the promise of reducing immediate damage from the COVID-19 pandemic and, crucially, of building future resilience.

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Prevention and control of non-communicable diseases in the COVID-19 response

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Moving towards universal health coverage, promoting health and wellbeing, and protecting against health emergencies are the WHO global priorities1 that are shared by the proposed WHO European Programme of Work 2020-25.2 The coronavirus disease 2019 (COVID-19) pandemic has underlined the importance of interconnecting these strategic priorities. Of the six WHO regions, the European region is the most affected by non-communicable disease (NCD)-related morbidity and mortality³ and the growth of the NCDs is concerning. Cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes are among the leading causes of death and disability in the region,3 and an increasing proportion of children and adults are living with overweight or obesity,4 one of the major risk factors for NCDs. Prevention and control of NCDs are important during this pandemic because NCDs are major risk factors for patients with COVID-19.5 Additionally, some of the restrictive measures such as lockdowns, social distancing, and travel restrictions to reduce the spread of infection in many countries impact specifically on people living with NCDs by limiting their activity, ability to secure healthy foods, and access to preventive or health promotion services.⁶

The COVID-19 pandemic has had widespread health impacts, revealing the particular vulnerability of those with underlying conditions. In Italy, a recent report revealed that the majority (96.2%) of patients who have died inhospital from COVID-19 had comorbidities, primarily NCDs; the most prevalent NCDs among these patients were hypertension (69.2%), type 2 diabetes (31.8%), ischaemic heart disease (28.2%), chronic obstructive pulmonary disease (16.9%), and cancer (16.3%).7 An association between COVID-19 severity and NCDs has also been reported in Spain,8 China,9 and the USA.10 However, many COVID-19 deaths also occur in older people who often have existing comorbidities.¹¹ Body-mass index (BMI) might also be associated with the severity of COVID-19; in China, patients with severe COVID-19 and non-survivors typically had a high BMI (>25 kg/m²).¹²

The impact of COVID-19 response measures on NCDs is multifaceted. Physical distancing or quarantine can lead to poor management of NCD behavioural risk factors, including unhealthy diet, physical inactivity, tobacco