

Community participation is crucial in a pandemic

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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.

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—e.g., 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.^{11,12} 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,^{13,14} 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—e.g., 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.

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 (e.g., 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

References

- 1 Butler P. A million volunteer to help NHS and others during COVID-19 outbreak. *The Guardian*, April 13, 2020.
- 2 Villadiego L. Spaniards find beauty in helping each other amid COVID-19 crisis. *Al Jazeera*, March 23, 2020. <https://www.aljazeera.com/indepth/features/spaniards-find-beauty-helping-covid-19-crisis-200319105933362.html> (accessed April 30, 2020).
- 3 WHO. The global strategy for women's, children's and adolescents' health (2016–2030). Geneva: World Health Organization, 2015.
- 4 UNAIDS. Rights in the time of COVID-19. Lessons from HIV for an effective, community-led response. Geneva: UNAIDS, 2020.
- 5 Marston C, Hinton R, Kean S, et al. Community participation for transformative action on women's, children's and adolescents' health. *Bull World Health Organ* 2016; **94**: 376–82.
- 6 European Parliamentary Forum for Sexual and Reproductive Rights, International Planned Parenthood Federation European Network. Sexual and reproductive health and rights during the COVID-19 pandemic: a joint report by EPF & IPPF EN. April 22, 2020. <https://www.ippfen.org/sites/ippfen/files/2020-04/Sexual%20and%20Reproductive%20Health%20during%20the%20COVID-19%20pandemic.pdf> (accessed April 30, 2020).
- 7 Gregson S, Nyamukapa CA, Sherr L, Mugurungi O, Campbell C. Grassroots community organizations' contribution to the scale-up of HIV testing and counselling services in Zimbabwe. *AIDS* 2013; **27**: 1657–66.
- 8 Nguyen V-K, Ako CY, Niamba P, Sylla A, Tiendrebeogo I. Adherence as therapeutic citizenship: impact of the history of access to antiretroviral drugs on adherence to treatment. *AIDS* 2007; **21** (suppl 5): S31–35.
- 9 Nguyen V-K. Antiretroviral globalism, biopolitics, and therapeutic citizenship In: Ong A, Collier SJ, eds. *Global assemblages: technology, politics, and ethics as anthropological problems*. Oxford: Blackwell Publishing, 2005: 124–44.
- 10 Gillespie AM, Obregon R, El Asawi R, et al. Social mobilization and community engagement central to the Ebola response in west Africa: lessons for future public health emergencies. *Glob Health Sci Pract* 2016; **4**: 626–46.
- 11 Miles S, Renedo A, Marston C. "Slow co-production" for deeper patient involvement in health care. *J Health Des* 2018; **3**: 57–62.
- 12 Dasgupta J. Ten years of negotiating rights around maternal health in Uttar Pradesh, India. *BMC Int Health Hum Rights* 2011; **11** (suppl 3): S4.
- 13 Renedo A, Marston C. Spaces for citizen involvement in healthcare: an ethnographic study. *Sociology* 2015; **49**: 488–504.
- 14 Guareschi PA, Jovchelovitch S. Participation, health and the development of community resources in Southern Brazil. *J Health Psychol* 2004; **9**: 311–22.
- 15 UK Government HM Revenue and Customs. Guidance: claim a grant through the coronavirus (COVID-19) Self-employment Income Support Scheme. April 21, 2020. <https://www.gov.uk/guidance/claim-a-grant-through-the-coronavirus-covid-19-self-employment-income-support-scheme> (accessed April 30, 2020).
- 16 Laker L. Milan announces ambitious scheme to reduce car use after lockdown. *The Guardian*, April 23, 2020.
- 17 UK Government Department of Health and Social Care. Rt Hon Matt Hancock MP. Decision: temporary approval of home use for both stages of early medical abortion. 2020. <https://www.gov.uk/government/publications/temporary-approval-of-home-use-for-both-stages-of-early-medical-abortion--2> (accessed April 30, 2020).
- 18 Campbell C, Cornish F. Towards a "fourth generation" of approaches to HIV/AIDS management: creating contexts for effective community mobilisation. *Aids Care* 2010; **22**: 1569–79.