THE HEALTH DEMOCRACY DEFICIT AND COVID-19

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Summary: The COVID-19 crisis has laid bare the need for robust governance in health. Advice to political leaders on COVID-19 strategies was largely provided by specialist experts or those with an established relationship with government bodies, reflecting a default governance mode which is still not inclusive. Populations, communities, and civil society were largely left out; yet, inclusive dialogue initiatives are crucial to building trust and policy adherence. Social participation, although not novel in theory, is innovative in practice as decision-makers still struggle with the 'how' of fostering health democracy and bringing people's voice into emergency responses and health policies.

Keywords: Health system governance, Social participation, People-centredness, COVID-19 response, Universal health coverage

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The Covid-19 response: the need to cast the expertise net more widely

When the scale of the COVID-19 crisis became apparent in early 2020, countries had to make swift decisions about which public health and social measures would be most effective to slow down transmission and reduce mortality associated with COVID-19. Policymakers took these decisions under immense political pressure and a sense of overwhelming urgency (see the article by Röhrling et al. in this issue); in some countries, these decisions were only taken when Coronavirus infections and hospitalisation rates skyrocketed. Such measures encompassed movement restrictions; closures of schools, cultural sites and businesses; geographical area quarantines and international travel restrictions.

These decisions were generally made by governments following advice from task forces that were newly formed or reactivated to advise the government response. Despite the far-reaching consequences for society beyond health and medicine, the task forces in most countries were dominated by virologists and epidemiologist-modelers. Besides the narrow specialist focus, COVID-19 governance lacked overall inclusiveness with regards to gender, geography, sexual orientation, race, socio-economic status or disciplines beyond health, excluding the very perspectives, expertise and lived realities which were needed to tackle virus transmission at its weakest spots.[1]

COVID-19 outbreak response decisions are still taken based on a predominantly medico-technical paradigm. In other words, the pandemic is perceived first and foremost as mainly a viral, medical and public health challenge by those sitting on decision-making bodies. Even within the health space, specialists from other medical fields, such as mental health,

child health, chronic diseases, preventive medicine, and gerontology, are not or are insufficiently represented – the same holds for the non-health specialists such as social workers, child development specialists, and human rights advocates. If at all, many of these experts are often only consulted as an afterthought or in secondary discussions; during the first wave in Spring 2020, the major collateral consequences of confinement measures such as disruptions in the essential health services as well as increased domestic violence, child abuse, food insecurity, etc. were thus not adequately anticipated with targeted alleviation measures.[2]

Civil society and community groups were largely left out of COVID-19 decision-making

Not only was the specialist expertise net cast narrowly, but also other types of experiential expertise failed to be heard by policymakers. Civil society and community groups were poorly or not at all represented on COVID-19 advisory task forces, echoing growing criticism by health experts and researchers that the COVID-19 response "largely involved governments telling communities what to do, seemingly with minimal community input".[3] Yet civil society and community groups are closely embedded within the community and societal fabric, possess insight into the day-to-day challenges faced by vulnerable groups (e.g. older people, disabled, single mothers, migrants etc.) disproportionally affected by COVID-19 measures, and can conduct risk communication in a language which is understood by their peers.

Anecdotal evidence provided by civil society groups demonstrates that the consequence of leaving out civil society voice in COVID-19 decision-making can be dire: a poignant example comes from a French dialysis patients' association's experience of rapid viral transmission in their constituency at the start of the pandemic due to a dearth of protective equipment for staff and patients.[4] This led to overly strict measures imposed by authorities with little consultation with affected parties. A mask mandate combined with a ban on eating and drinking during dialysis sessions was

one such measure – one which is hardly feasible when dialysis sessions last up to 7 – 8 hours including travel time from home to dialysis centre. It also raises key questions about quality of life, human rights, and dignity – information which merits reflection, at the very least, as part of the decision-making process.[4]

Civil society's insights also stem from their own, very active COVID-19 response efforts, which, unfortunately, was mostly wholly disconnected to the government one. A rapid UHC2030 Civil Society Engagement Mechanism (CSEM) survey conducted in the middle of the first pandemic wave in April 2020, with over 200 civil society responses from 58 countries, confirmed that, in the majority of cases, civil society's response efforts were independent from the government response.[5] Some civil society members lamented that when they did manage to get government's attention for urgent matters, it was a cumbersome process as no formal, well-functioning communication channel existed between governments and civil society.

Enriching research-based evidence with experiential knowledge for improved health decision-making

The lack of diverse expertise and voices in advisory and decision-making bodies reflects what is generally valued as 'evidence' by policymakers. Evidence is clearly "largely understood to mean research-based evidence, and not necessarily experiential, implementation-based evidence from the field".[6] Despite its significant relevance for policy, real-time experiential knowledge is underestimated, while it is the information coming precisely from the lived experiences and everyday challenges faced by people – such as the dialysis patients in the above example – which allows for adapted and feasible virus mitigation measures which a population is willing and able to adhere to.

The current understanding of 'evidence' and 'science' are, again, rooted in the traditional biomedical view of health and not necessarily the holistic practicality of health as it plays out in people's daily lives. Thus, epidemiological facts and figures are

scrutinised at great length by government and advisory bodies; qualitative research or quick surveys examining the plethora of factors impacting vulnerable groups and marginalised parts of societies are still relegated to lower priority and not given adequate policy consideration.

More transparency and trust is needed

The COVID-19 pandemic has caused a sizable trust deficit between governments and populations in some parts of the world.[7] Trust and transparency go hand in hand; governments in general have not been transparent about the considerable trade-offs involved in deciding which measures to take, when, and why. For example, two recent studies castigate the lack of public disclosure of information on who is consulted by advisory and decision-making bodies, which members had which viewpoints, which weight was given to which reflections, and even the composition of the governance bodies themselves.[1] [6]

Especially trade-offs need to be made more explicit to justify far-reaching measures depriving populations of basic freedoms, with the aim of giving people good reason to adhere to them. In an environment which easily fosters fake news and protest marches against COVID-19 restrictions, a high level of transparency can form the basis of a communication strategy which addresses what those trade-offs means for people's daily lives.

The remedy? Institutionalisation of social participation mechanisms

HIV/AIDS patients' activism of the 1980s led to the motto of 'nothing about us, without us'. This movement is remarkable for the inroads it made in including the HIV/AIDS community – not only patients themselves but family members and the wider LGBTQ+ population – in HIV policy formulation. The result has been people-centred, adapted, and responsive health services for affected patients, contributing to declines in HIV prevalence and increasing numbers of patients adhering to long-term treatment regimens.[8]

The HIV/AIDS example demonstrates the win-win that can be achieved by greater collaboration between government and civil society to address population health problems. Countries where that collaboration is regular, formalised, and/or institutionalised in normal times seem to be able to better leverage established channels of communication and coordination in service of a health emergency response. A case in point is the National Health Assembly mechanism in Thailand which convenes civil society, academia, and government once yearly to debate, and more importantly, find solutions for public health issues.[9] The Assembly resolutions serve as recommendations for policy, and is prepared for 12 months with citizen hearings, forums for interaction between government, civil society, and lay-people, and many other events. Those established channels of dialogue were easily re-activated during the COVID-19 crisis to understand and adapt COVID-19 communication and response measures to the living conditions and needs of different population groups.[4] This was mainly possible because the relationship of trust and familiarity of context existed before the crisis arose, and formed a solid foundation which allowed for a joint approach to tackling COVID-19 transmission.

“ learn to engage more broadly with populations, communities, and civil society

An example from Europe is the nascent National Health Council (NHC) in Portugal, a government advisory body whose membership consists of civil society, professional associations, and government representatives. Founded in 2017, its principal aim is to ensure an inclusive debate on priority health matters which feed into official recommendations

for policy.[10] Although the NHC was not formally included in COVID-19 decision-making, the NHC took advantage of its mandate and convened working groups to reflect more broadly on society's needs during the pandemic. Government debates picked up on the results of those NHC discussions as it provided valuable information directly from communities. This quick and trusted access to civil society offered by an institutionalised mechanism for social participation was thus recognised as a national public good to develop and refine further in the future.

Conclusion: the need to change the 'default' mode of governance

As the pandemic rages on, governments are losing out on trust and policy adherence if they do not learn to engage more broadly with populations, communities, and civil society. Besides its dire necessity in the current emergency mode, social participation mechanisms need to form the backbone of how a health system is steered. Emerging reports of countries where closer government-civil society collaboration facilitated the pandemic response indicate that institutionalised social participation structures embedded in the health sector landscape played a significant role. Yet the 'default' mode of governance as is currently on display in the vast majority of countries tackling the COVID-19 crisis does not do justice to a pandemic which is not only a health problem but a societal one,[1][3][6] where trust in institutions and adherence to virus mitigation measures can make or break the success of the pandemic response.[3][7]

While many caveats exist for formal mechanisms of social participation, their clear added value is the regularity of interaction as well its mandatory nature.[11] Despite a certain level of discomfort it may bring, key health topics of broad societal interest must be discussed by, with, and for people from all walks of society, with differing and opposing views. It means that the messy task of dealing with potent interest groups and conflicts of interest needs to be confronted head-on for the sake of finding a solution to pressing health problems. Doing so can lend legitimacy to whatever decision is

taken, however difficult or controversial, and facilitate communication and implementation of subsequent policy measures.

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