HIFA – SUPPORT-SYSTEMS thematic discussion

Report

Abstract

Between May 9 – June 6 2022, Healthcare Information for All (HIFA) organised an online thematic discussion focused on how decision-making processes for health systems strengthening and universal health coverage can be made more inclusive, responsive and accountable. Specifically, the discussion revolved around questions about why civil society participation in health policy processes is important, HIFA members' experiences with participating in health policy processes, the type of evidence and knowledge that civil society can provide, the main drivers and barriers to uptake of such evidence, and promising practices for creating greater space for civil society participation in health policy processes. We conducted a thematic analysis to analyse the discussion list contributions. This analysis is informing the SUPPORT-SYSTEMS research project.

Background

SUPPORT-SYSTEMS is a three-year project funded by the Research Council of Norway. It is exploring the question 'How can decision-making processes for health systems strengthening and universal health coverage be made more inclusive, responsive and accountable?' The project focuses on the extent to which actively involving civil society voices and other stakeholders can promote equity and humanise decision-making processes for universal health coverage and promote equity. The project is situated within the discourses around complex policymaking processes for health systems, informing these processes with evidence, and fostering civil society's agency and participation within these processes.

Methods

In March 2022, HIFA established a working group drawn from existing HIFA members and members of the SUPPORT-SYSTEMS project team. The project group discussed and agreed upon five questions to help structure the HIFA discussion. These questions were:

1. What does civil society participation in health policy mean and why is it important to have civil society participation in health policy processes?
2. Have you ever participated, either through a civil society organization or as an individual, in health policy processes at a national or sub-national level? What was your experience?
3. Can you share examples of the role of civil society organizations in policymaking at national or sub-national levels?
4. What do you think are the different types of evidence that civil society can provide, that otherwise would not be considered? What are the main drivers and barriers to uptake and use of such evidence?
5. From your perspective, what are promising practices for creating greater space for civil society participation in health policy processes and for using evidence from civil society more effectively to improve health policymaking for UHC at national and global level?

Four members of the SUPPORT-SYSTEMS HIFA working group shared responsibility for monitoring and keeping track of the discussion. They produced (1) a full compilation of the contributions; (2) a long edit (relevant content organised under headings) and; (3) a thematic analysis of the contributions. The thematic analysis broadly involved reading and getting familiar with the contributions, and assigning the contributions with labels (e.g., 'codes' and 'themes') representing a central concept or message. Several contributions could fall under the same theme. The five questions were used as overarching categories under which specific themes were organized. Preliminary themes were shared with other working group members before further refining and finalising the themes.

Results

HIFA members made a total of 80 contributions to the discussion list. The participants were from 11 countries: Canada, Croatia, DR Congo, India, Iraq, Nigeria (3), Norway, South Africa, Tanzania, UK (2),

Venezuela. Appendix 1 lists all the references to reports and peer-reviewed articles made by the contributions to the discussion. In the summary below, some of these references have been included when participants used them to support their contributions.

What does civil society participation in health policy mean and why is it important to have civil society participation in health policy processes?

Civil society plays a multi-dimensional role in health policy processes

When discussing why it is important to have civil society participation in health policy processes, contributors emphasized a wide range of dimensions that contribute to improvements in people's lives. Some of these were overlapping in nature. They described how civil society representatives can take on:

- An **advocacy** role, by promoting the voice of patients and calling for access and strengthened quality of health services
- A **service delivery** role, by improving access for for poor and hard-to-reach populations (for example people in rural areas) to high-quality preventive and curative services, including affordable drugs. A **governance** role, by increasing the demand for well-managed, high quality primary health care services and holding governments accountable for their 'stewardship'[1] role in the health system
- An **empowerment** role, by enhancing the capacity and agency of people to prevent and manage their health conditions, including empowering people with access to evidence and information needed to participate in their health care and make health care decisions
- An **evidence-to-policy** role, by representing an important mechanism for generating local evidence - such as experiential knowledge on how health system works or evidence on the needs, values and preferences of healthcare users and other community members – into decision making processes
- A **implementation** role, by contributing to knowledge about what works and what doesn't work
- A **cross-sectoral role**, since CSOs can have greater flexibility to engage across sectors to address cross-cutting health issues, such as those shaped by social determinants like poverty

For example, on service delivery, one contributor shared an example from Nigeria on how a civil society organization contributed to bring health promotion activities to scale during the first HIV day in a specific region:

"*One experiential example that comes to mind immediately is that the first HIV Day Event in Cross River State, Nigeria on 1st December 2004 was successfully planned and executed within 4-weeks, involving almost all the 3.1 million citizens, because we engaged a civil society organization called WAAM (Women Arise And Move). The CSO had one or more representatives in every town, village, hamlet in the state that enabled it to take our plans and messages to every state citizen.*" (Health systems practitioner, Nigeria)

What is meant by "civil society" needs critical evaluation and interpretation must be sensitive to context

Contributors presented several definitions of civil society, moving from broader to more specific definitions. The broadest, which is also the standard definition found in the literature, defines civil society as representing "a social sphere separate from both the state, the market and the family" (Greer et al., 2017). This definition does not tie civil society representation to organizations; thus participation of individual members of the public also constitute 'civil society participation'. Moreover, contributors emphasized that this standard definition ignores the relationship different kinds of civil society actors may have to powerful interests, both in government and industry. Accordingly, specific definitions offered by contributors stressed the need to pay attention to specific variables when defining civil society: .

---

[1]"the tasks of defining the vision and direction of health policy, exerting influence through regulation and advocacy, and collecting and using information". WHO (2000) World Health Report 2000: Health Systems - Improving Performance. Geneva: World Health Organisation

- The different **types** of actors (e.g., patient-based, professional, faith-based, social justice focused)
- The **level** at which they operate
- The **power** they hold

For example, the SUPPORT-SYSTEMS project had initially expressed an interest in studying the experiences of:

"not just NGOs and faith-based organisations, but also community groups, patient associations, and professional associations (and more). We are especially interested in civil society at the national, subnational and local levels, although we recognise that international civil society organisations can also play a major role in national policymaking." (researcher, Norway)

Several contributors emphasized the need to critically examine the actors included in the definition of "civil society", providing arguments and empirical examples indicating that *what* civil society represent is heavily influenced by a setting's historical, social and political factors. Therefore, there is a need to maintain a "fluid" view of what civil society means instead of relying too heavily on rigid definitions. One contributor expressed this as follows:

"CSOs are [....] not a homogeneous group of organisations just like the communities or the population groups they serve." (paediatrician and public health practitioner, India)

Contributors further expressed that civil society organizations could differ in their:

- **administrative and professional power,** such as health professional associations that issue clinic registrations, individual license and membership fees
- p**olitical power,** through links to political parties and access to decision-making processes
- focus on **equity**, such as the extent to which these involved marginalized populations in their operations

Given these and other factors, examining civil society participation in decision-making about UHC should be context-specific. Frequently used terms like "citizen engagement", "community involvement", "community participation" and "empowerment" need critical evaluation in terms of the extent to which these truly represent the interests and values of marginalized populations. At the same time, contributors highlighted the need to pay attention to 'systemic similarities' between countries across income levels since health systems might share the same approaches to health issues. Contributors questioned whether actors that fulfilled the formal definition of civil society but primarily represented powerful interests through their administrative, professional and political power could truly be seen as 'civil society' in the way this concept is conventionally treated. One contributor highlighted that organizations falling under the umbrella "civil society" may play several roles, ranging from activist groups, charities, NGOs, non-profit organizations, private voluntary organizations, social enterprises, social movement organisations, and/or voluntary associations.

Finally, contributors proposed theoretical frameworks such as "networks theory" that have proven useful for examining relationships and interactions between heterogenous organizations.

One contributor cited an Argentinean case study that examined community participation in mental health promotion through a network of institutions (Bang & Stolkiner, 2013). In this case, community participation was understood between organizations that actively participated in joint activities (stakeholders and CSOs).   This network was focused on holding events defined and displayed by the community linking to the needs of the neighbourhood and the collective process of health-disease care; therefore, the community's logic and participation were fully portrayed and understood. The dynamic exchange between the members enabled the creation of novel alternatives for problem-solving. The main reported challenges were faced inequities in involvement, which implied low performance of tasks and responsibilities from the population that did not respond to the established patterns of organization, and feeble generation of participatory channels for proactive decision-making process due to knowledge and power asymmetries.

Conflicting views about civil society's optimal role in health policy making

One contributor stressed that the involvement of civil society in health policy processes may not necessarily lead to "optimal health policymaking", understood here as "the best available research evidence is used to inform decision-making, characterized by systematic and transparent access to and appraisal of evidence as an input into the policy-making process." There's a risk that civil society promotes evidence that is aligned with their agenda and objectives and thereby risk contributing with a cherry-picked and biased assessment of the evidence base. Moreover, policy makers may be "overwhelmed by a cacophony of demands from 100s of civil society organizations" (clinician and researcher, United Kingdom), thereby motivating the question of what "processes are most effective to enable decision makers while giving voice to civil society organizations?". One contributor questioned the feasibility of citizen participation in health policy given the knowledge and understanding needed of complicated scientific questions.

Have you ever participated, either through a civil society organization or as an individual, in health policy processes at a national or sub-national level? What was your experience? Can you share examples of the role of CSOs in policymaking at national or sub-national levels?

Institutional structures can create a consistent pathway for broad civil society involvement, collective action and legitimacy of health policy processes

The examples shared by contributors underscored the importance of strong institutional structures for facilitating civil society involvement in health policy decisions.

One contributor described the role of community groups, patient associations and health professional associations participated in strengthening policy and legislation for mental health through a regional Mental Health Leadership and Advocacy Programme (mhLAP) organized over a 10-year period in five countries: The Gambia, Ghana, Liberia, Nigeria and Sierra Leone. For the annual mhLAP training courses, participation ranged from psychiatrists, psychologists, social workers to service users and CSO and media practitioners especially concerned with human rights as well as government officials and legislators.

After the 10-year period of the mhLAP, a National Stakeholder Council for mental health policy leadership was created (Abdulmalik et al., 2014). These had broad representation from mental health professionals, representatives of service user and caregiver organisations, officials of relevant government departments and agencies, leaders of non-governmental organizations with interest in mental health or human rights issues, and media practitioners. Establishing such a structure created consistent pathways for civil society actors to shape policy and legislation on mental health, and underscored the importance of permanent structures that facilitate civil society participation in health policy formulation:

"The Stakeholder Councils that were activated in each country became effective and credible voices in all of the participating countries, as they were actively engaged in efforts to develop policy and legislation and championing community outreach programmes. For example, mhLAP was noted to have made notable contributions to the processes leading on to the adoption of the Mental Health Policy in Nigeria and the Mental Health Act in Ghana, where the project provided leadership to civil societies and other stakeholders involved. (health sector consultant, Nigeria)

One contributor cited an article examining the contributions of hybrid coalition of international and domestic organisations in scaling up nutrition in Nigeria (Resnick et al., 2022). The contributor described how civil society coalitions "allow civil society organisations to work together in a united front with policymakers" and that "this is a lot easier than policymakers having to deal with dozens or hundreds of approaches from individual CSOs." Aligned with this view, another contributor highlighted the case of the Health Reform Foundation of Nigeria (HERFON), an indigenous non-governmental organisation (NGO) that over a ten-year period led a broad coalition of stakeholders to get a national health bill signed into law as an Act in 2014, which provides a comprehensive legal framework for the coordination, administration, financing, and governance of health care in Nigeria (Asoka, 2013; Roques, 2011; Tulloch, 2017). The contributor described how HERFON managed to break through the impasse of the Nigerian National Health Bill. It was first proposed in the National

Assembly in 2004 but between 2005 and 2010 underwent six revisions before being passed by the legislature, only to fail receiving the Presidential assent due to unresolved contentious issues.

"Given this impasse and with the passage of the Health Bill becoming a 'wicked problem' where the answers are incomplete, contradictory, and set against changing requirements (O'Brien et al., 2008), it necessitated a change of tactics whereby rather than individual organisations acting on their own, a specific coalition of civil society organisations targeted at getting the Bill passed was formed to help navigate the politically volatile environment and manage the diversity of interests. With HERFON as Secretariat, the Health Sector Reform Coalition (HSRC) as it was named became the platform through which concerted efforts were expected to be directed towards sustained advocacy to get the Bill passed and signed into law. It encompassed a diverse and multi-disciplinary range of stakeholders including indigenous health delivery civil society organisations, professional bodies (legal, health sector), International non-governmental organisations (INGOs) and the media. While organising a coalition of this nature to achieve a common goal was a daunting task with individual members still having their respective agendas, the HSRC managed to hold the collective by 'force of purpose' to deliver its outcome." (Health sector consultant, Nigeria)

Similarly, in West African countries working with mental health policies, the establishment of national stakeholder councils with broad representation helped foster legitimacy of the policy-making process.

"The Country Facilitators, as well as these graduates, are guided by priorities set by a wide coalition of stakeholders in the country, creating a unified message, with the legitimacy that comes from such a broad-based constituency. Indeed, the expectation from the leadership course participants is that they become informed advocates for mental health service development in their respective countries." (Health sector consultant, Nigeria)

Civil society can play a crucial role in promoting equitable policy options

Contributors shared empirical examples highlighting the critical role civil society can play in promoting equity impact of policy options, particularly with regards to specific disadvantaged groups. Such examples included

- How persons with mental health issues along with their caregivers in West Africa have become powerful advocates for reducing stigma and discrimination
- The role of the Treatment Action Campaign (TAC) in advocacy, evidence generation and empowering the public with evidence to promote equitable access to HIV/AIDS therapeutics (Heywood, 2009; Hoen et al., 2011). One contributor highlighted how TAC's experience showed different ways civil society use evidence in health policy processes:

"The use of 'evidence' includes making a legal case for policy change based on existing legislation, and of raising awareness among the general public about healthcare and their right to medicines and services. Doubtless the campaign also used the evidence of personal testimony." (Clinician and researcher, United Kingdom)

- Public Health Protection Network of Kurdistan's use of evidence to call out abuse of sexual and reproductive health rights of people with disability

International organizations can play a catalytical role

One contributor shared how an international organization played a catalytical role in facilitating contributions from local civil society organizations working on mental health, public health and human rights when the Kurdistan region passed a mental health act:

"One of the main facilitators for the successful introduction of the act was the active engagement of an international organisation (HAI). The latter provided financial support for bringing stakeholders together (workshops, meetings, printing materials, etc). But more importantly, it acted as a catalyst for bringing various (sometimes contradictory opinions) together." (Medical doctor, Iraq/United Kingdom)

What do you think are the different types of evidence that civil society can provide, that otherwise would not be considered? What are the main drivers and barriers to uptake and use of such evidence?

A wide range of information sources shape 'evidence' use by civil society

The empirical examples shared by contributors demonstrated that 'evidence' from a civil society perspective can include treatment literacy (understanding the major issues related to an illness or disease – such as the science, treatment, side-effects, and guidelines – so that the patient can be more responsible for their own care and will demand their rights when proper care is not available to them) (Smart, 2010), data gathered locally or nationally through for example surveys and interviews, interpretation of routine health data, interpretation of existing research, and legislative and policy knowledge. The value placed on these different sources may not necessarily follow the typical evidence hierarchies, and alternative ways of thinking about evidence suitable for informing health policy decisions could be helpful (Petticrew & Roberts, 2003).

A contributor cited an article examining the experience of the Treatment Action Campaign, whose "'starting point was to insist that the excessive pricing of essential medicines by multi-national pharmaceutical companies violated human rights" (Heywood, 2009). While such statements do not feature in conventional evidence frameworks, it was presented as an example of "a profoundly compelling piece of evidence" and "basic, and potentially much more powerful" (clinician and researcher, United Kingdom).

Civil society are uniquely positioned to give voice to populations and inform policy with tacit and local evidence and contributing to prioritization of research needs

Civil society organisations were seen to 'provide' evidence in at least two senses: they can create new knowledge (for example through surveys), and they can highlight information that has been produced by others (for example, they can use the results of a systematic review to make their case)

Civil society was seen as well positioned to undertake surveys, hold public meetings and through other strategies seek the voice of the population or specific groups within a population. At the same time, contributors highlighted the need for critical examination of civil society's representative role (see the theme "**What is meant by "civil society" need critical evaluation and interpretation must be sensitive to local context, dynamics and power asymmetries**").

Using WHO's recent publication on evidence, policy and impact as a starting point, one contributor highlighted that policy makers needs are usually met by four types of evidence: (1) scientific and codified evidence; (2) tacit evidence; (3) global evidence assembled for example through a systematic review and; (4) local evidence. Civil society could play an especially important role in filling gaps in tacit and local evidence. One contributor defined tacit knowledge in the following way:

"the lived experience of people who have something to share with others, and for all of us to learn collectively. There is the possibility of true insights from such interaction, which may be personal ("I could apply this approach to my setting") or, more rarely, a new collective insight." (clinician and researcher, United Kingdom)

For example. HIFA was seen by one contributors as a forum that could share tacit as well as explicit knowledge, where the latter could take the form of publications and reports. Civil society could also inform policy with 'co-produced' knowledge. Another contributor shared Thailand's experience with enforcing a total ban on chrysotile asbestos. Works by Tangcharoensathien et. al. and Kanchanachitra et. al. examined the processes by which co-production of knowledge informed health policy making on

this issue in Thailand (Kanchanachitra et al., 2018; Tangcharoensathien et al., 2021). They distinguish between three key groups of stakeholders and highlight how these bring different expertise and experiences to evidence generation and policy development: (1) the government sector (e.g., policy makers, politicians, local administrative organisations, and government services); (2) people's sector (civil society, communities, and citizens (people's sector) and; (3) knowledge sector (academia, think tanks, and research institutions). Focusing on a cabinet decision to enforce a total ban on chrysotile asbestos, they highlight the role of consumer protection groups in synthesizing evidence and raising awareness of the problem.

Finally, one contributor highlighted how civil society have a role in prioritizing what research needs to be done and how—a point highlighted by an article on implementation research in Latin America and the Caribbean focused on approaches bringing health system decision-makers together with researchers to collaboratively design, produce and apply research evidence (Varallyay et al., 2022).

Civil society face capacity constraints in generating and using evidence to inform policy

While conducting research was a way civil society can generate evidence, contributors highlighted that small civil society organizations typically do not have the capacity nor remit to conduct academic research using rigorous methods. To overcome this shortcoming in capacity, contributors suggested that CSOs could collaborate with research institutions.

Political economy factors have significant impact on uptake and influence of evidence from civil society

A sound understanding of the political economy factors[2] affecting policy-making can help explain why civil society is able to successfully inform and influence health policy in some areas while not in others (Ho et al., 2022). While 'evidence' may indicate one course of action, policy makers may opt for a different decision guided by values and interests. For example, one contributor shared experience with attempts by civil society to reverse a government policy in the Kurdistan Region to generate revenue by charging private market fees for public services after 1PM. Civil society attempted to inform this decision with a wide range of evidence sources:

"A number of civil society organisations came together to advocate against this policy. We had meetings with policy makers including the ministry of health and the health committee of the Parliament. We provided evidence regarding the negative impact of such policy on people's financial wellbeing. We offered real life examples of people who had to sell properties, lands, borrow money… etc to pay for healthcare. We cited World Bank research that suggested that out of pocket healthcare expenditure was one of the main causes of impoverishment in Iraq. We presented evidence about the impact this policy will have on the failure to achieve SDGs and UHC in the country. We also offered suggestions on how to raise revenues, pool them and spend them in a more efficient manner." (medical doctor, Iraq/United Kingdom)

Despite the broad evidence base that civil society could rely on to motivate the reversal of the policy, the government stuck to their decision. The contributor cited political economy factors such as the power of doctors and nurses who supported the government policy and the influence of strong interest groups that opposed alternate revenue sources like taxes on tobacco, alcohol and sugar. At

---

[2] «Political economy» is a term that has different definitions and interpretations, but generally revolves around the influence of politics, power and resources on policy making. One of the leading scholars in the field of political economy analysis of health reforms, Michael Reich, defines political economy in the following way: "Political economy can be broadly defined as the study of both politics and economics, specifically the interactions between them and their consequences for specific outcomes of interest" Reich, M. R. (2019). Political economy analysis for health. *Bulletin of the World Health Organization*, *97*(8), 514.

the same time, the presence and advocacy of civil society likely mitigated further inequity impacts, indicating the value of fostering civil society participation.

From your perspective, what are promising practices for creating greater space for civil society participation in health policy processes and for using evidence from civil society more effectively to improve health policymaking for UHC at national and global level?

Publications described experiences with different mechanisms used to promote the voice of people who are typically under-represented in health policy-making

- One addressed the use of elected representatives and open public meetings in building accountability among leaders to the populations they serve (Vian et al., 2020), with a contributor highlighting that "even if there is willingness to be accountable, there may be limited ability to deliver accountability"
- One addressed the strength of India's village health sanitation and nutrition committees in promoting evidence-informed decision-making, highlighting the need for training, infrastructure and financial resources in filling key gaps in performance (Sharma et al., 2021)
- One contributor highlighted a series of papers published in the journal International Journal of Health Governance that described positive and negative experiences with civil society participation in health policy processes on the national and sub-national level (Ashraf & Ong, 2021; Khodayari-Zarnaq et al., 2019; Rendalls et al., 2019; Sharma et al., 2021)

The need for support to and skills among policy makers was highlighted.

Conclusion

The HIFA thematic discussion on inclusive, responsive and accountable decision-making processes for health systems strengthening and universal health coverage inspired a rich discussion highlighting the need to critically examine how civil society is involved in health policy processes, the mechanisms for achieving this goal and the value this involvement brings. Contributors shared empirical examples and literature covering a wide range of perspectives on these questions. The insights from this discussion will be made publicly available and will inform the development of a qualitative evidence synthesis on the use of evidence by civil society in health policy processes.

References

Abdulmalik, J., Fadahunsi, W., Kola, L., Nwefoh, E., Minas, H., Eaton, J., & Gureje, O. (2014). The Mental Health Leadership and Advocacy Program (mhLAP): a pioneering response to the neglect of mental health in Anglophone West Africa. *International Journal of Mental Health Systems*, *8*(1), 1-9.

Ashraf, A., & Ong, S. C. (2021). Drug price control in Malaysia: a stakeholder analysis. *International Journal of Health Governance*.

Asoka, T. (2013). Much Ado about a National Health Bill: why the President may not sign the bill again. 2-5. https://www.dropbox.com/s/8vae9j2frhdcnnt/AH-Nigeria%20Nov%20%202013.pdf

Bang, C., & Stolkiner, A. (2013). Aportes para pensar la participación comunitaria en salud/salud mental desde la perspectiva de redes. *Ciencia, docencia y tecnología*(46), 123-143.

Greer, S. L., Wismar, M., & Kosinska, M. (2017). What is civil society and what can it do for health? *Civil society and health*, 1.

Heywood, M. (2009). South Africa's treatment action campaign: combining law and social mobilization to realize the right to health. *Journal of Human Rights Practice*, *1*(1), 14-36.

Ho, C. J., Khalid, H., Skead, K., & Wong, J. (2022). The politics of universal health coverage. *The Lancet*.

Hoen, E. t., Berger, J., Calmy, A., & Moon, S. (2011). Driving a decade of change: HIV/AIDS, patents and access to medicines for all. *Journal of the International AIDS Society*, *14*(1), 1-12.

Kanchanachitra, C., Tangcharoensathien, V., Patcharanarumol, W., & Posayananda, T. (2018). Multisectoral governance for health: challenges in implementing a total ban on chrysotile asbestos in Thailand. *BMJ Global Health*, *3*(Suppl 4), e000383.

Khodayari-Zarnaq, R., Kakemam, E., Arab-Zozani, M., Rasouli, J., & Sokhanvar, M. (2019). Participation of Iranian non-governmental organizations in health policy-making; barriers and strategies for development. *International Journal of Health Governance*.

O'Brien, G., O'Keefe, P., Meena, H., Rose, J., & Wilson, L. (2008). Climate adaptation from a poverty perspective. *Climate Policy*, *8*(2), 194-201.

Petticrew, M., & Roberts, H. (2003). Evidence, hierarchies, and typologies: horses for courses. *Journal of Epidemiology & Community Health*, *57*(7), 527-529.

Reich, M. R. (2019). Political economy analysis for health. *Bulletin of the World Health Organization*, *97*(8), 514.

Rendalls, S., Spigelman, A. D., Goodwin, C., & Daniel, N. (2019). Health service engagement with consumers and community in Australia for issue: Engagement and accountability with your community. *International Journal of Health Governance*.

Resnick, D., Anigo, K., & Anjorin, O. M. (2022). Advocacy organizations and nutrition policy in Nigeria: identifying metrics for enhanced efficacy. *Health Policy and Planning*.

Roques, A. A., T. . (2011). *Assignment Report: Health Reform Foundation of Nigeria (HERFON) Annual Review 2011*. https://assets.publishing.service.gov.uk/media/57a08ae3ed915d3cfd0009ce/Annual_Reviewof__the_Health_Reform_Foundation_of_Nigeria_HERFON_Report.pdf

Sharma, S., Rawat, S., Akhtar, F., Singh, R. K., & Mehra, S. (2021). Assessing community health governance for evidence-informed decision-making: a cross-sectional study across nine districts of India. *International Journal of Health Governance*.

Smart, T. (2010). *TB/HIV treatment literacy*. NAM. https://www.aidsmap.com/news/feb-2010/tbhiv-treatment-literacy

Tangcharoensathien, V., Sirilak, S., Sritara, P., Patcharanarumol, W., Lekagul, A., Isaranuwatchai, W., Wittayapipopsakul, W., & Chandrasiri, O. (2021). Co-production of evidence for policies in Thailand: from concept to action. *BMJ*, *372*.

Tulloch, O. C., S.; Ogunbayo, D.; Oreh, C. . (2017). *A Case Study of the Implementation of the 2014 Nigeria Health Act - what can we learn for public policy reform?* . http://www.perlnigeria.net/storage/casestudies/June2018/ajcSQsA69fLeSgvzRdFK.pdf

Varallyay, N. I., Kennedy, C., Bennett, S. C., & Peters, D. H. (2022). Strategies to promote evidence use for health programme improvement: learning from the experiences of embedded implementation research teams in Latin America and the Caribbean. *Health Research Policy and Systems*, *20*(1), 1-14.

Vian, T., Fong, R. M., Kaiser, J. L., Sakanga, V., Mwansa, M., Chastain, P. S., Ngoma, T., & Scott, N. (2020). Using open public meetings and elections to promote inward transparency and accountability: lessons from Zambia.

Mark Heywood, South Africa's Treatment Action Campaign: Combining Law and Social Mobilization to Realize the Right to Health, Journal of Human Rights Practice, Volume 1, Issue 1, March 2009, Pages 14–36, https://doi.org/10.1093/jhuman/hun006

Appendix 1: Peer-reviewed articles and grey literature shared by contributors

1. Examples of articles in inclusiveness

a. Engagem Soc Change. January-March 2015; 2(1): 43�64. doi: 10.4018/IJCESC.20150101004
b. Bang, C, Stolkiner, A. Aportes para pensar la participación comunitaria en salud/ salud mental desde una perspectiva de redes. Revista Ciencia, Docencia y Tecnología, 24 (46):2013; 123-143.
c. Lutz-Ley AN, Scott CA, Wilder M. Dialogic science-policy networks for water security governance in the arid Americas. Environmental Development. 2020. doi: 10.1016/j.envdev.2020.100568
d. Torres I, López-Cevallos D. In the name of COVID-19: legitimizing the exclusion of community participation in Ecuador's health policy: Special call: Health Promotion Perspectives on the COVID-19 Pandemic. Health Promot Int. 2021 Jan 20:daaa139. doi: 10.1093/heapro/daaa139

2. Examples of articles on the role of informal groups

a. Ouriques Martins SC, Lavados P, Leite Secchi, et al. Fighting Against Stroke in Latin America: A Joint Effort of Medical Professional Societies and Governments. Front Neurol. 2021; 12: 743732. Published online 2021 Oct 1. doi: 10.3389/fneur.2021.743732
b. Hassell TA, Hutton MT, Barnett DB. Civil society promoting government accountability for health equity in the Caribbean: The Healthy Caribbean Coalition. Rev Panam Salud Publica. 2020;44:e79. https://doi.org/10.26633/RPSP.2020.79
c. Corluka A, Hyder AA, Winch PJ, Segura E. Exploring health researchers' perceptions of policy-making in Argentina: a qualitative study. Health Policy Plan. 2014 Sep; 29(Suppl 2): ii40-ii49. Published onlinne 2014 Sep 11. doi: 10.1093/heapol/czu071
d. Martinez MG, Kohler JC. Civil society participation in the health system: the case of Brazil's Health Councils. Global Health. 2016; 12: 64. Published online 2016 Oct 26. doi: 10.1186/s12992-016-0197-1
e. Barredo D, Molina P, Medranda N, Rodríguez V. Health Transparency and Communication on the Government Websites of Ibero-American Countries: The Cases of Chile, Colombia, Ecuador, and Spain. Int J Environ Res Public Health. 2021 Jun; 18(12): 6222. doi: 10.3390/ijerph18126222
f. León M, Jiménez M, Vidal N, Bermúdez K, De Vos P. The Role of Social Movements in Strengthening Health Systems: The Experience of the National Health Forum in El Salvador (2009–2018). Int J Health Serv. 2020 Apr; 50(2): 218-233. doi: ;10.1177/0020731420905262
g. López-Bolaños L, Campos-Rivera M, Villanueva-Borbolla MA. Commitment and community participation towards health: knowledge creation from the systematization of social experiences. Salud Publica Mex 2018;60:192-201.doi:10.2114918460
h. Huicho L, Huayanay-Espinoza CA, Herrera-Perez E, et al. Examining national and district-level trends in neonatal health in Peru through an equity lens: a success story driven by political will and societal advocacy. BMC Public Health. 2016; 16(Suppl 2): 796. doi: 10.1186/s12889-016-3405-2
i. Salazar X, Nuñez-Curto A, Castillo R, et al. How Peru introduced a plan for comprehensive HIV prevention and care for transwomen. J Int AIDS Soc. 2016; 19 (3Suppl 2): 20790. doi: 10.7448/IAS.19.3.2079010
j. Eid M, Nahon-Serfaty I. Risk, Activism, and Empowerment: Women's Breast Cancer in Venezuela. Int J Civ

3. Examples of articles on evidence-informed health policy making

a. Diez Roux AV, Slesinki SC, Alazraqui M, et al.A Novel International Partnership for Actionable Evidence on Urban Health in Latin America: LAC-Urban Health and SALURBAL. Glob Chall. 2019 Apr; 3(4): 1800013. doi: 10.1002/gch2.201800013
b. García-Cerde R, Becerril-Montekio V, Langlois E, et al. Embedded implementation research in Latin American health systems. Rev Saude Publica. 2021; 55: 16. doi: 10.11606/s1518-8787.2021055003027

c. Becerril-Montekio V, Torres-Pereda P, García-Bello LA, Alcalde-Rabanal J. Embedding research into health services in Latin America and the Caribbean: experiences and challenges of the Technical Support Center. Rev Panam Salud Publica. 2021; 45: e41. doi: 10.26633/RPSP.2021.41

d. González AC, Jaramillo IC. Legal Knowledge as a Tool for Social Change: La Mesa por la Vida y la Salud de las Mujeres as an Expert on Colombian Abortion Law Health Hum Rights. 2017 Jun; 19(1): 109-118.

e. Zicker F, Cuervo LG, Salicrup LA. Promoting high-quality research into priority health needs in Latin America and the Caribbean. BMJ. 2018; 362: k2492. doi: 10.1136/bmj.k2492

f. Romero LI, Quental C. Research for better health: the Panamanian priority-setting experience and the need for a new process. Health Res Policy Syst. 2014; 12: 38. doi: 10.1186/1478-4505-12-38

g. Paz X, Espinosa-Marty C, Castillo-Laborde C, Gonzalez C. From instinct to evidence: the role of data in country decision-making in Chile. Glob Health Action. 2017; 10(Suppl 1): 1266176. doi: 10.3402/gha.v9.32611

h. Rodríguez L, Cofré C, Pizarro T, et al. Using evidence-informed policies to tackle overweight and obesity in Chile. Rev Panam Salud Publica. 2017; 41: e156. doi: 10.26633/RPSP.2017.156

i. Vélez M, Wilson MG, Abelson J, Lavis J, Paraje G.Understanding the Role of Values in Health Policy Decision-Making From the Perspective of Policy-Makers and Stakeholders: A Multiple-Case Embedded Study in Chile and Colombia. Int J Health Policy Manag. 2020 May; 9(5): 185-197. doi: 10.15171/ijhpm.2019.94

j. Evens E, Lanham M, Santi K, et al. Experiences of gender-based violence among female sex workers, men who have sex with men, and transgender women in Latin America and the Caribbean: a qualitative study to inform HIV programming. BMC Int Health Hum Rights. 2019; 19: 9. doi: 10.1186/s12914-019-0187-5

4. Corporation accountability

a. Crosbie E, Sosa P, Glantz SA. Defending strong tobacco packaging and labeling regulations in Uruguay: transnational tobacco control network versus Philip Morris International. Tob Control. 2018 Mar; 27(2): 185–194. doi: 10.1136/tobaccocontrol-2017-053690

5. CSO Accountability / CSOs and access to anti-retrovirals movement

a. Ardila S, Agrest M, Fernández MA, et al. The mental health users' movement in Argentina from the perspective of Latin American. Collective Health Glob Public Health. 2019; 14(6-7): 1008-1019. doi: 10.1080/17441692.2018.1514063

b. Mark Heywood, South Africa's Treatment Action Campaign: Combining Law and Social Mobilization to Realize the Right to Health, Journal of Human Rights Practice, Volume 1, Issue 1, March 2009, Pages 14–36, https://doi.org/10.1093/jhuman/hun006

c. Hoen E', Berger J, Calmy A, Moon S. Driving a decade of change: HIV/AIDS, patents and access to medicines for all. J Int AIDS Soc. 2011;14:15. Published 2011 Mar 27. doi:10.1186/1758-2652-14-15 [Full text: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3078828/]

6. Tacit knowledge

1. Kothari, A., D. Rudman, M. Dobbins, M. Rouse, S. Sibbald and N. Edwards (2012). "The use of tacit and explicit knowledge in public health: a qualitative study." Implementation Science 7(1): 1-12.

2. Kothari, A. R., J. J. Bickford, N. Edwards, M. J. Dobbins and M. Meyer (2011). "Uncovering tacit knowledge: a pilot study to broaden the concept of knowledge in knowledge translation." BMC health services research 11(1): 1-10.

3. Becerril-Montekio, Victor, et al. "Using systematized tacit knowledge to prioritize implementation challenges in existing maternal health programs: implications for the post MDG era." Health policy and planning 31.8 (2016): 1031-1038.