

TOWARDS MEANINGFUL ENGAGEMENT OF PEOPLE WITH LIVED EXPERIENCE IN POLICY DECISIONS: THE CASE OF DIABETES MELLITUS IN PERU

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Photo: WHO

How this policy brief was developed:

This policy brief is based on the research project “Towards meaningful engagement of people with lived experience in policy decisions: The case of diabetes mellitus in Peru”. The research was conducted under the guidance of the University of Geneva, Switzerland and CRONICAS Center of Excellence in Chronic Diseases from the Universidad Peruana Cayetano Heredia, Peru, and benefited from the incentive grant for young researchers provided by the World Health Organization Global NCD Platform and UNITAR’s Defeat-NCD Partnership in collaboration with the Alliance for Health Policy and Systems Research. The activities were conducted within the ACCISS study that receives funding from The Leona M. and Harry B. Helmsley Charitable Trust.



What is this policy brief about?

This policy brief summarizes the findings of a qualitative study to explore barriers and facilitators for the implementation of meaningful engagement of people living with diabetes in policy decision-making processes in the Peruvian context.

Who is this policy brief for?

This policy brief primarily targets national, regional and local health policy-makers in Peru, however other decision-makers, practitioners and researchers interested in the meaningful engagement of people with lived experience of a specific condition in the decision-making may find the content of this policy brief relevant.

This policy brief includes:

- The case of Peru in promoting the engagement of people with lived experience of diabetes in policy decisions in Peru
- Methodology and key findings of the qualitative study that informed this policy brief
- General policy recommendations to support induced participation of people with lived experience

This policy brief does not include:

- Strategies to implement the provided recommendations
- Comparison of several policy options and recommendations on the best option

PROBLEM STATEMENT

- Meaningful engagement of people with lived experience of a specific condition leads to a stronger consideration of their insights and perspectives when making both policy and medical decisions.
- Some initiatives to promote the engagement of people with lived experience with diabetes in policy decisions exist in Peru.
- These initiatives include both, induced (government-led) and organic (civil society-led) participation.
- It is capital that both types of participation co-exist to set the political agenda and produce change to improve health care.
- Assessing previous experiences on meaningful engagement of people with lived experience and learning from these experiences is important to improve future policy and implementation actions.
- In this study, we use diabetes as a “tracer” condition to explore barriers and facilitators for the implementation of meaningful engagement of people living with diabetes in policy decision-making processes in the Peruvian context.

IMPLICATIONS

- To support the induced participation of people with lived experience in the decision-making processes, it is critical to:
 - (i) raise awareness of the benefits of engaging civil society in decision-making;
 - (ii) train decision-makers on skills and procedures to engage with people with lived experience;
 - (iii) increase resources to facilitate the engagement of people with lived experience in decision-making;
 - (iv) develop a clear recruitment process to ensure representation, diversity, and redistribution of power.
- To **support the organic participation**:
 - (i) it is essential to raise awareness of the value of the organic participation of civil society;
 - (ii) civil society should work on building cohesion among its different members, long-lasting relationships with authorities and a good reputation.

1. FRAMING THE PROBLEM

BACKGROUND

Meaningful engagement of people with lived experience of a specific condition is powerfully summarized by the motto “nothing about us without us”. Defined by the World Health Organization (WHO) as a process in which the individual is “*empowered and acts as an agent of change and is respected, valued and included in a range of activities and processes, from start to finish*”, meaningful engagement of people with lived experience provides a platform for a stronger consideration of the insights and perspectives of these individuals when making both policy and medical decisions [1].

The World Health Organization has proposed including the meaningful engagement of people with lived experience as an

intervention to improve care globally. Furthermore, a WHO framework for meaningful engagement of people living with noncommunicable diseases (NCD), and mental health and neurological conditions has been published to propose an operationalization of meaningful engagement, principles and enablers [2].

Peru can serve as an interesting case study as the government already recognizes the importance of engaging different stakeholders in public decisions to improve the provision of services to the population. This has resulted in some progress towards meaningful engagement in policy decision-making at various levels of the health-care system.

Using diabetes as a “tracer” condition, the aim of this study was to explore barriers and facilitators for the implementation of meaningful engagement of people living with diabetes in policy decision-making processes in the Peruvian context.

Where can I find out more about “meaningful engagement”?

The [WHO Framework for meaningful engagement](#) of people living with noncommunicable diseases, and mental health and neurological conditions (2023) aims to advance knowledge and action on meaningful engagement and related participatory approaches from an evolving evidence base.

The framework provides practical guidance and actions for transitioning from intention to action to operationalize meaningful engagement by both, WHO offices at the global, regional and country level, and Member States.

METHODS AND DATA SOURCES

This policy brief draws on the results of a qualitative descriptive study to explore previous experiences on decision-making processes in the public health sector in Peru from different stakeholders’ perspectives to identify barriers and facilitators. Stakeholders included patient associations working on diabetes, professional societies, and decision-makers at the Ministry of Health or the Peruvian Social Security.

Altogether fifteen in-depth interviews were conducted using Zoom in two waves from 2022 to 2023. The first took place early in 2022 and included representatives from the Ministry of Health and Social Security with experience in the development of clinical practice guidelines and health technology assessment. In the second wave, which took place in late 2022 and early 2023, representatives from diabetes patient associations, professional societies related to diabetes care, and civil society representatives who work on decision-making processes in general were interviewed.

There are various examples of civil society participation in Peru, such as community committees, working committees, altruistic initiatives (volunteering), advocacy, citizen vigilance and online platforms for public consultation, which are regulated by government-promoted guidelines and directives.

The study employed the framework proposed by Mansuri et al. [2] that classifies participatory approaches as either induced, or organic. For induced participation, participation is

“promoted through policy actions of the state and implemented by bureaucracies” [2]. While organic participation is driven by “intrinsically motivated leaders in the community and usually in opposition to the government” [3].

Two examples of induced participation were investigated:

(1) “vigilancia ciudadana” or “citizen vigilance” which is a decentralization process that was first regulated in the year of 2011 that facilitates the creation of a local commission composed of members of the community to conduct audits and surveillance on the functioning of the system and provide feedback on health-care services [4];

(2) participation of civil society (people with lived experience) in health technology assessments to decide the inclusion of medicine or medical devices in standardized treatment of chronic conditions. This participation process was approved in the case of cancer by law in 2022 [5], and later that year, the regulation was published [6].

Organic participation of civil society in Peru led to the inclusion of type 1 diabetes into law for diabetes that provides different protection mechanisms [7]. This type of participation was explored in interviews with members of patient associations working on type 1 diabetes and professional associations working on diabetes in general.

Additionally, we used the COM-B model to describe barriers and facilitators in terms of capabilities, opportunities, and motivation [8].

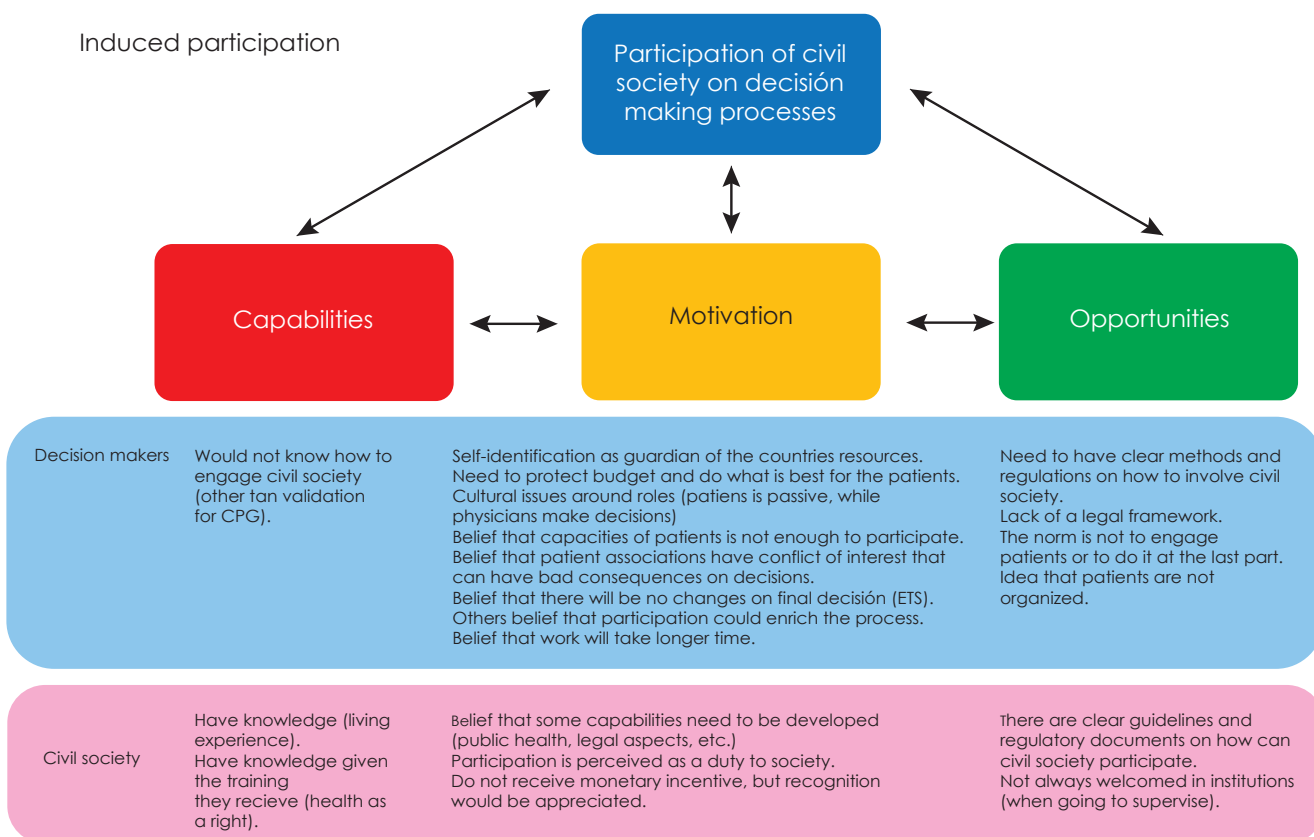
2. KEY FINDINGS

INDUCED PARTICIPATION

Assessment of the induced participation case “surveillance by civil society” illustrated that civil society had received training that allowed them to perform this task. Additionally, this form of participation was perceived as a duty to society that required some recognition. However, interviewees mentioned difficulties when doing their supervision duties in health-care establishments.

In the case of induced participation of civil society in decision-making processes for health technology assessments or clinical practice guideline development, decision-makers believed they did not have the knowledge or skills to work with civil society.

Figure 1 summarizes our findings about the induced participation of people with lived experience.



Decision-makers had mixed perceptions of the impact that participation of people with experience may have on decision-making processes. Some believed this could enrich the process, while others felt it would not change the outcome. They considered the process time-consuming, and were afraid of potential negative consequences of working with patient associations due to potential conflicts of interest. Decision-makers mentioned the need for clear methods and regulations on the matter.

The social norm in Peru is not to engage people with lived experience or to engage them only in the last part of the development of the documents in a consultation. In the case of representatives of patient associations, they considered they had the living experience and could participate in this process. However, they acknowledged the need to be trained in public health or legal aspects to be able to participate properly.

ORGANIC PARTICIPATION

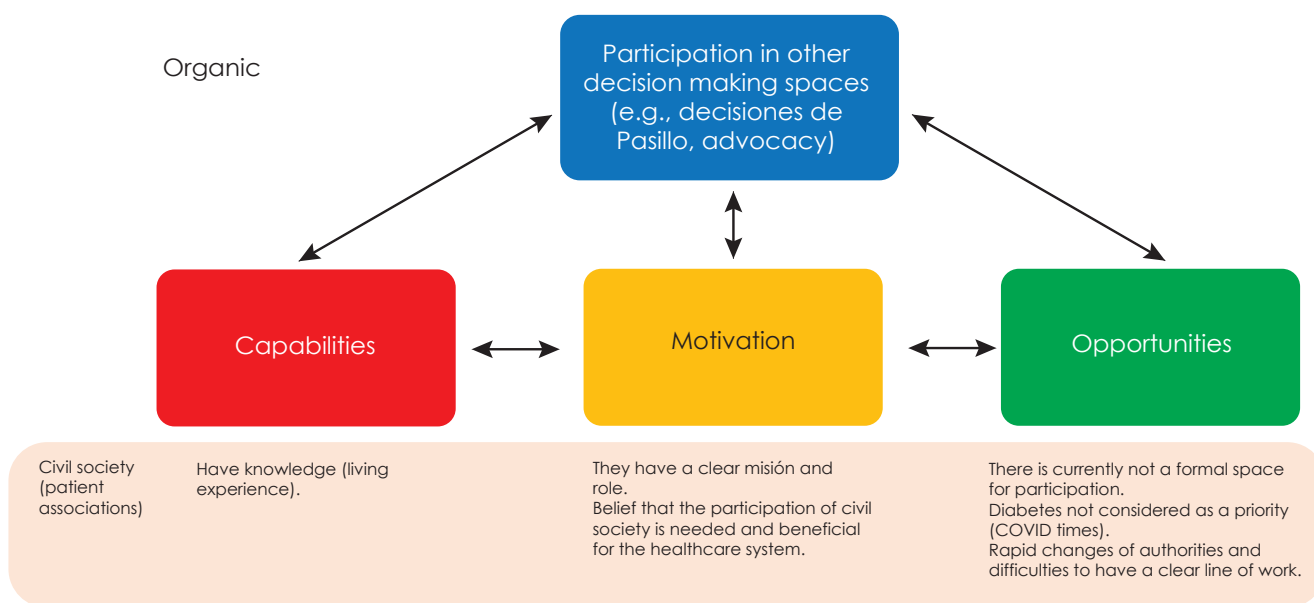
Patient associations naturally operate based on organic participation as they try to find ways to meet with authorities to make their case. These associations are characterized by having a clear mission rooted in the shared belief that their participation is necessary to improve the health-care system.

The interviewed patient associations representatives reported that the major barriers they face are (i) a lack of spaces created by the government to involve civil society in decision-making processes, and (ii) rapid changes in health authorities and priorities.

In the case of the representatives of type 1 Diabetes Mellitus organizations, their main focus was on mobilizing the promulgation of

the Diabetes law with a specific focus on type 1 Diabetes Mellitus. Activities carried out by the representatives of people living with type 1 diabetes predominantly involved face-to-face or virtual round tables with representatives of the Peruvian State. This group of interviewees emphasized that these meetings were held with congressmen who showed greater awareness of Type 1 diabetes mellitus, since this helped to include the approval of the law on the congressional agenda.

Although working groups have been set up on this issue, their operation was interrupted by the COVID-19 pandemic which the attention and efforts of decision-makers in the health and other sectors. **Figure 2** below illustrates our findings about the organic participation of people living with diabetes mellitus in decision-making processes in Peru.



FURTHER FINDINGS

The Peruvian government has enacted several regulations to guide society's participation in the health sector. Some examples include the regulation on health technology assessment, the National Essentials Medicines list, and citizen surveillance.

There is a law on cancer and health technology assessment that proposes that the views of people living with cancer should be taken into account when deciding which drugs should be covered by the insurance. Using COM-B, we found that most of the

barriers to patient involvement in health technology assessment mentioned by decision-makers were related to the motivation domain. A common belief was that people living with the condition were unable to participate in decision-making processes such as health technology assessments or the development of clinical practice guidelines because of conflict of interest they may have or low health literacy. Additionally, decision-makers had mixed opinions on the impact of involving people living with the condition in the decision-making processes and considered this undertaking as an additional burden.

There is also a requirement to include civil society participation in the development of the National Essentials Medicines list which involves completing an online form that includes a conflict of interest statement. However, there are no known mechanisms to regulate requests for advice, nor measures to be taken in the event of conflicts of interest.

Finally, the citizen vigilance mechanisms promote the exercise of rights and the fulfilment of responsibilities by the government. While the Peruvian regulations for “surveillance by civil society” clearly indicate how the civil society should be trained, on what subjects, with what frequency, and who is responsible for it, people with lived experience of diabetes are often limited by the lack of space for dialogue and the rapid changes in authorities and priorities.

3. IMPLICATIONS AND RECOMMENDATIONS

INDUCED AND ORGANIC PARTICIPATION

The **two types of participation** that co-exist in the Peruvian context, **induced** and **organic**, are important and have helped achieve meaningful engagement of people with lived experience in diabetes. Even when there are efforts to increase induced participation, there are some aspects that need to be strengthened. As an example, having a legal framework is capital, but is not the only aspect that should be developed.

To support **induced participation**, the following areas of action require a special focus:

- Providing education and raising awareness on the benefits of engaging civil society in decision-making processes.
- Training decision-makers on skills and procedures to adequately engage with people with lived experience for decision-making processes.
- Increasing resources to design and implement processes to facilitate the engagement of people with lived experience in decision-making processes.
- Developing a clear and transparent recruitment process to ensure diversity, representation, and redistribution of power.
- Raising awareness of already available induced participation platforms so people with living conditions know when and how their experiences can help.

- Providing some form of recognition (not necessarily economical) to people with lived experience who participate in decision-making processes.

As for **organic participation**, it is led and organized by different members of civil society including people with lived experience. It is essential to raise awareness of the value of organic participation of civil society. Additionally, civil society should work on building cohesion among its different members, long-lasting relationships with authorities and a good reputation.

Finally, it is important that induced engagement does not limit organic participation, but rather sees these two approaches that engagement of people with lived experience as complementary.

CONTRAST WITH THE WHO FRAMEWORK

The WHO Framework for Meaningful Engagement of People Living with Noncommunicable Diseases, and Mental Health and Neurological Conditions proposes a definition of meaningful engagement, principles and enablers. The processes in which people living with NCDs could participate are laws, policies, healthcare services and other systemic NCD decisions. Our study identified a number of gaps that require commitment and efforts from the health sector.

With regard to the principles suggested by the WHO framework, dignity and respect are based on participation as a human right. Our study showed that even when the experiences and knowledge of people living with diabetes is valued by some decision-makers, people living with diabetes do not have equal power in decision-making because they are often not involved, and when they are, they are only consulted at the end.

As for inclusivity and intersectionality, WHO suggests transparent recruitment to achieve inclusivity and to avoid overrepresentation of individuals from advantaged or privileged backgrounds. Interviewed decision-makers stressed the importance of representing different subgroups of the population. However, the methods to ensure a fair and transparent selection of participants seem to be lacking in Peru.

Institutionalization and contextualization could be understood as the formal integration of patient participation into institutional practices and culture. In the Peruvian case, the norm of involving civil society at all or only engaging

them at the last moment should be modified so that participation can be achieved from the beginning to the end of the processes.

With regard to some of the enablers, WHO suggests that individuals with lived experience should be remunerated at the same rate as technical experts. However, when conducting interviews in Peru, we found that people who actively participated had motivations other than money and we identified other ways to reinforce civil society participation, such as recognition or seeing results. However, resources to pay for meeting organizations including travel-related expenses to ensure the participation of people based in different cities are important.

Finally, capacity building is an enabler proposed by WHO that was important for the interviewees, who emphasized the need to develop capacities on both sides: (i) civil society representatives need to understand how to participate, how their experiences can help, and better understand the regulatory framework, while (ii) decision-makers need to know how to engage civil society.

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