

There is much to learn when you listen: citizen engagement in high and low income countries

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Abstract

The need for engaging citizens in health care policy making is critical, and different approaches are gaining traction internationally. However, citizen engagement seems more difficult to implement in low and middle income countries because of political, practical and cultural reasons. Despite this, countries such as India, Malawi, Tanzania, Ethiopia, Rwanda, Mozambique, Egypt have initiated community engagement initiatives, which are contextually unique, and can be used as examples to learn from for the future. Overall, community voices need to play a bigger role in forming policy; they hold the key to improve health and forward growth. Evidence needs to move out of communities and districts through broader communication and knowledge translation avenues to influence and shape national and global level policies and strategies.

Introduction

The World Health Organization (WHO) launched its Health For All initiative in 1977, deciding that worldwide health services should be attainable to all people by the year 2000. While significant progress was made, this goal was not achieved (WHO, 2013). This is, in part, because “as health systems become more complex and costly, and as the application of new and existing technologies becomes more refined, making the right decisions about the allocation of often scarce resources has become more difficult.” Additionally, the Millennium Development Goals (MDGs) put forth by the United Nations (UN) in an effort to address extreme poverty and its impacts, resulted in uneven progress with much work left to be done. The MDGs were replaced with Sustainable Development Goals (SDGs) in 2016 in an effort to further the attainment of the goals originally set forth in 2000. One criticism of the MDGs is the lack of emphasis on local participation, local challenges and self-empowerment of the targeted populations (Deneulin & Shahani, 2009; Fehling, 2013). Future attempts to meet global goals, then, should focus on the inclusion of citizens and the public as equal stakeholders in the process of health policy development.

Citizen engagement, put simply, is facilitating the meaningful involvement of citizens at any point in the policy development cycle by allowing them to actively play a role in identifying and interpreting the issues, weighing options and solutions, and prioritizing actions (Canadian Institute for Health Research, 2012). Citizen engagement has also begun to take hold in low and middle income countries (LMICs), although the approach proves elusive to appropriately engage individuals because of political, practical and cultural reasons (Alderman, 2013). Even if the terms might be used without regard to their distinction, ‘patients’ and ‘the public’ or ‘citizens’ are different groups of people, often with different points of view. Citizens are individuals with no vested interest in and familiarity with an issue, while consumers or patients have relevant personal experience (Degeling, 2015). Fredriksson (2016) argues that it is inappropriate to use patients in the same way as citizens when making a decision; patients utilize their experiential knowledge and tend to gather around the cause which affects them most. The public, on the other hand, generates diverse perspectives collectively and has an external legitimacy claim based on input and output of result effectiveness and quality. Degeling (2015) additionally found that in deliberation groups, citizens were directed to consider community

interests while consumers (or patients) were directed to focus on personal preferences. It may be most effective to utilize only patients when focusing on one specific issue or disease and citizens or members of the larger public when focusing on prevention and health promotion, while also including a subset of patients in the larger group for representativeness

Members of the public are the most important stakeholders in the health care system. They will likely be impacted by a health policy, and they are the largest stakeholder group in number (Bruni, 2008). Additionally, engaging the public in health care priority setting is consistent with the ideals of a democracy, transparency and public accountability (Oxman, 2009), and members of the public can provide a unique and essential take on the community's values. The trend to include patients and the public in deliberation on health and social issues has increased (Wortley, 2016b; Biovin, 2014), and lets the public provide input to the broader context of the policymaking process from identifying priorities for research to using results to shape policy (Seigel, 2013). It has been concluded that participants feel that engagement processes related to health are effective and report improved knowledge and satisfaction. Lastly, these engagement processes can promote active citizenship, empowerment and improved relationships between the public and the government (Molster, 2013; Abelson, 2010). Carman (2015) found that all health-related engagement approaches used in a randomized control trial were effective in changing at least some knowledge and attitude measures.

However, it is wise to acknowledge the impediments faced when engaging citizens. Firstly, compared to policymakers or practitioners, the public is more likely to perceive personal choice or clinical judgement as trumping evidence when considering health services (Carman, 2016). They may also be more likely to suggest that care should be offered irrespective of tests which may indicate little benefit (Bombard, 2013). Various reviews show that there are not many outcome evaluations (Mitton, 2009; Conklin, 2015) and it is difficult to prove a link between community participation and improved health or system outcomes as well as to identify which components of the process lead to success or failure (Marston 2013; Rifkin 2014; Mitton, 2009; Conklin, 2015). This is partly because there are so many forms of community participation and that the terms itself is not clearly defined (Iwarsson et al., 2015). These forms range from collaborative interventions, where communities participate in decision making and/or health care

delivery and “outsiders” direct the intervention, to more community-directed development and implementation of health programmes.

Often, it is not clear which types of individuals or groups participate. George 2015 et al. state that participation without delegation of resources or democratization of power might marginalize communities or members of communities that can least afford to participate. However, meaningful and inclusive community participation could lead to more evenly distributed power across socioeconomic levels, within and between communities, healthcare professionals, and the state. Martston et al. (2013) state that this “community development or empowerment approach sees participation as a longer-term process in which communities are actively involved in deciding on and implementing strategies to alter the socio-political, economic, and psychological conditions that shape their health.”

Background

A universal approach to public engagement may not be effective, as there are many factors involved, which vary by context (Wortley, 2016b; Abelson, 2016; Abelson, 2010). These factors include the perceived complexity and decision impact of the issue, opportunities for involving the public, and resource constraints (Wortley, 2016b). Blacksher et al.(2012) propose this basic definition of public deliberation: “(1) the provision of balanced, factual information that improves participants’ knowledge of the issue; (2) the inclusion of diverse perspectives to counter the well-documented tendency of better educated and wealthier citizens to participate disproportionately in deliberative opportunities and to identify points of view and conflicting interests that might otherwise go untapped; and (3) the opportunity to reflect on and discuss freely a wide spectrum of viewpoints and to challenge and test competing moral claims.” Abelson (2013) noted that in an overwhelming majority of cases, efforts were made to meet these requirements; however the interpretation and implementation of the aforementioned elements was fairly heterogeneous.

Biovin (2014) lists several key components to achieve public involvement and states that legitimacy, credibility and power account for variations in influence from members of the public. A policy coalition which is supportive of public involvement must be built initially, giving the public legitimacy, credibility and power to be involved in deliberation. Regarding

the intervention stage, legitimate groups and perspectives must be recruited and prepared. When group members participate, they must create rational arguments and legitimate strategies, and have legitimacy to speak on behalf of a wider constituency. The public and professionals then interact and moderate, levelling for power differences and legitimizing marginalized voices. The ideal outcome should be mutual influence and agreement regarding healthcare improvement.

Abelson (2016) structured a relevant framework around four elements. The first is identifying the guiding principles and goals for public involvement which will strengthen and support initiatives, be evidence based and evaluated, and will emphasize the incorporation of social values and ethics. Secondly, a common terminology will need to be established in order to reconcile conflicting views and establish clarity. Thirdly, a flexible menu of options which indicate specific goals should be mapped out for each stage of the process. Lastly, it is vital to evaluate efforts over time to make appropriate adjustments, such as creating more robust evaluation metrics. A study on public engagement regarding intervention procedures guidelines showed that, indeed, there was substantial engagement and consultation of the public which resulted in draft changes, and concluded that other areas of healthcare should increase incorporation of this approach in order to be responsive to stakeholders. Campbell (2016) and Molster (2013) have found similar effects.

Several similar approaches to citizen engagement have been developed somewhat in parallel to each other in various high income countries. To create an initial exploration of the approaches, we ran a literature search which focused on identifying reviews (i.e. systematic, scoping etc.) which discussed various citizen engagement approaches, after which we also ran a search for primary studies on the subject. The purpose of the literature search was to identify different citizen engagement approaches, but not to systematically assess the literature. The approaches are described in Table 1 in greater detail.

The underlying idea is constructed of similar features: a selected citizen group which is broadly representative of the public; members who are given time and resources, such as citizen briefs or other plain language documents mobilizing relevant evidence to understand the issue up for deliberation; the space to formulate an opinion. The concept, however it is implemented, is to shift power to those whom the research concerns, and to carry out interventions with feedback

and reflection from citizens (Iwarsson et al., 2015). Between the specific initiatives, there are variations, however, such as amount of information available about the process, group size or participant selection method. As the field is relatively young, we do not yet have a full understanding of the impact and successes of these approaches. Quite a lot has been published, however, thus far the results have been mostly anecdotal (Iwarsson et al., 2015), and the outcomes reported inconsistently (Brett et al., 2014). Nonetheless, we believe that if properly utilized and adapted to context, the engagement processes from higher income countries can offer insight and options for LMICs.

Table 1: Citizen engagement approaches

Approach	Description	Who?	How?	Examples of these approaches in health
Citizen jury (Crosby, 1995; Street, 2014)	A citizen jury is created of a representative sample of citizens through various means. They are briefed in detail on the background and current thinking relating to a particular issue or project and presented with possible alternatives. They present their decision as they would in legal juries, often in the form of a report. The report may include recommendations for future actions or directions.	Broadly representative group of approximately 12-25 people.	<ul style="list-style-type: none"> -Random selection of jury. Jurors are usually paid. - Provide written information and expert witnesses to brief the jury, be cross-examined by the jury, and spend time discussing the issue with the jury -Engage in deliberation with independent moderators - Create jury report and recommendations. <p>If the recommendations are not accepted, provide a detailed rationale.</p>	<p>Responsibility for Maintaining Health</p> <p>A citizens' jury was convened to address the role of government and healthcare providers in maintaining the health of citizens. The jury concluded that more information should be provided on health in general and prophylactic medicine in particular, as well as feeling that the public should be more closely involved in health decision making (Elwood & Longley, 2010).</p>
Citizen panel(Crosby, 1986; McMaster Health Forum, 2017)	Can be organized at the local, regional, provincial or national level. Built on a deliberative dialogue approach to uncover citizens' unique understanding, values, preferences and insights to policy issues.	A group of 10 to 16 citizens includ[ing]: 1) healthcare professionals or employees of healthcare organizations; 2) elected officials; 3) individuals working for market research, advertising, public media or public relations firms; and 4) individuals who have	<ul style="list-style-type: none"> -A steering committee or advisory group, consisting of key stakeholders i.e. policymakers, experts, practitioners, patients and caregivers, guide the work. -Provide citizen brief -Conduct a deliberation/ panel discussion about an issue -Summarize the findings of 	<p>Preventing Interpersonal and Self-directed Violence and Injuries in the Caribbean</p> <p>A citizen panel of participants from several Caribbean countries was convened on examining the issue of preventing interpersonal and self-directed violence and injuries in the Caribbean and addressing solutions. Most participants saw violence as major health problem, with women and</p>

		taken part in two or more previous citizen panels.	the panel and distribute the findings -Evaluate key features	youth being particularly susceptible to victimization and young males engaging in violent acts. Practical priorities for action were then identified by participants. (Ciurea et al, 2015)
Citizen Dialogues (CPRN, 2005; EKOS Research Associates, 2005)	This is designed to create a channel between citizens and political decision makers to inform the policies of the latter.	Randomly selected sample of approximately 20 citizens.	-Citizens randomly selected. -Citizens given a workbook about a policy issue - Meet for one or two structured and moderated sessions of a total of 8 to 12 hours in length in small groups and plenary sessions to discuss the policy issue. -At the beginning and end of a citizen dialogue each participant completes a survey measuring the participant's attitudes about aspects of the policy issue discussed in the workbook. (Boyko, 2012)	Citizens' Dialogue on the Future of Health Care in Canada A citizens' dialogue was initiated in 5 sessions to discuss prioritizing public health goals for Canada. Participants overwhelmingly felt that decision makers should act immediately, and hoped that their input would be considered in future goal development. (EKOS Research Associates, 2005)
Deliberative polling (Fishkin, 1991; Fishkin, 2005)	Combines techniques of public opinion research and public deliberation to construct hypothetical representations of what public opinion on a particular issue might look like if citizens were given a chance to become more informed.	Usually between 130 to 450 participants (although there is no ceiling), paid. Citizens are randomly selected by either random digit dialing or by sending out 'warm-up' letters to a random sample of phone listings followed up with phone calls.	-A random, representative sample answers a questionnaire evaluating the knowledge, perceptions, and preferences on a specific question. -Another random representative is asked to participate in a 'deliberative event' and receives balanced briefing materials.	Deliberative Polling on Health Care Issues in America Citizens were polled regarding their opinions on education and health care as connected issues. Participants felt that the volume of uninsured Americans was the largest health system issue and supported policies which would require some sacrifice on their part in order to cover those individuals.

			<ul style="list-style-type: none">- At the deliberative event participants are randomly assigned to small groups with trained moderators.-Participants fill out a second questionnaire capturing opinions on the topic at hand.- First and final poll results are compared and any changes are measured and analyzed.-Findings of the final survey are disseminated through media coverage. <p>(Fishkin, 2005)</p>	(MacNeil / Lehrer Productions, 2005)
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Citizen engagement in low and middle income countries

While citizen engagement practices are becoming more established in higher income countries, and some ideas may be successfully adapted to LMICs, there are more barriers in place when bringing these ideas to lower income countries and settings. This is because resources are constrained and there are other factors to contend with, such as poverty, issues travelling, costs to the research team, social exclusion of certain groups and the lower status of women (Alderman 2013; Iwarsson, 2015). At the same time, the contextual reality of communities in LMICs might be more different to those of the decision makers in lower than in higher income settings. Hearing the voices and contributions of communities could significantly influence how services are planned and delivered. The focus on citizen engagement, or community participation, is not new: since the Alma Ata Declaration in 1978, there has been a call for enhanced participation and empowerment of communities regarding decisions about health programmes in LMICs. Decentralization reforms further reinforced this emphasis on community participation in many countries (Rifkin, 2014). As one of the most important considerations for citizen and public engagement is context, which includes a country's income level, in order to develop and apply relevant engagement strategies, it is crucial to look at LMICs in particular to get a better picture of which initiatives have been successful and why, to use this learning in similar settings.

Some evidence is available on how community participation or citizen engagement has begun to take shape in LMICs. For example, one recent review by Gullo et al (2016) addressed the effectiveness of community score cards. In this type of intervention, service users, service providers and local government identify service access, utilization and provision challenges, to generate solutions and to work in partnership to implement and track the effectiveness of those solutions in an ongoing process of improvement. The review concluded that the use of community score cards led to improvements in citizen empowerment, service provider and power-holder effectiveness, accountability and responsiveness, and expanded, effective and inclusive spaces for negotiation in Malawi, Tanzania, Ethiopia, Rwanda and Egypt.

Another vehicle to enhance community participation or citizen engagement, facilitate community agency, raise community voices and trigger social change in many LMICs is the integration of community health workers (CHWs) into health systems. Community support for CHWs is vital to the success of these activities, as the community participation is the cornerstone of this type of engagement and development. CHWs work together with facility or village health committees, which can be seen as structures for social accountability (McCoy, 2012). Recently, some scholars stated that the function of CHWs as agents of social change has been pushed from the forefront by technical tasks focusing on attaining disease specific targets (Kalofonos, 2014; Mishra, 2014). For example, in India, an ethnographic study found that relationship building with the community was valued as very important by CHWs and that the narrow indicators used to measure health system performance, including a hierarchical structure and the value of statistical evidence above field-based experiences, could disturb the potential role of CHWs as agents of social change, cultural mediators and health promoters through effective community participation (Mishra, 2014). When CHWs are required to act as agents of social change, they need to feel empowered and must be trained in soft skills such as communication, problem-solving and facilitating discussions and priority setting at community level (Redick et al., 2014). Altogether, the role of the CHW has had to remain flexible within public engagement.

In Kenya, CHWs are joined by volunteers chosen by the community to form a community health committee (CHC) which contributes to the Community Health Strategy (CHS). The committee plays a role in monitoring and feedback with regard to community health services, however, they are not functional in some areas in Kenya, as a result of lack of training and dependence of donor support (Kok, 2016). Besides the CHCs, community health dialogue days are intended to provide opportunities for duty bearers at the primary care level to share data that is collected and analysed in the community based health information system with community members. This data are to be used for decision making and collective action to make improvements. However, since the launch of CHS in 2006, no clear community health dialogue guidelines have been developed, although the communities engaged reported satisfaction with the CHWs.

Another approach which builds on a pre-existing CHC or similar health-focused group is utilized in several east and southern African countries. Lunsford et al (2015) describe a Community

Health System Strengthening model (CHSS) in which a community improvement group is formed from a CHC and one to two community members who are involved in other existing community groups and structures, including women’s groups, village savings and loan groups, local government, schools and churches (Fig. 1). As a team, they discuss local health issues based on data from the health facility. Applying quality improvement methods, they focus on key areas where improvement is needed and develop and test strategies to address these issues at the community level. Through this model, the community team becomes a locus for change while receiving supportive supervision and mentorship from local health care workers and district level health management. The model has been used to increase community engagement to address various health challenges, and was developed under the US Agency for International Development (USAID) Health Care Improvement Project (HCI) and the USAID Applying Science to Strengthen and Improve Systems Project (ASSIST) (Lunsford et al., 2015).

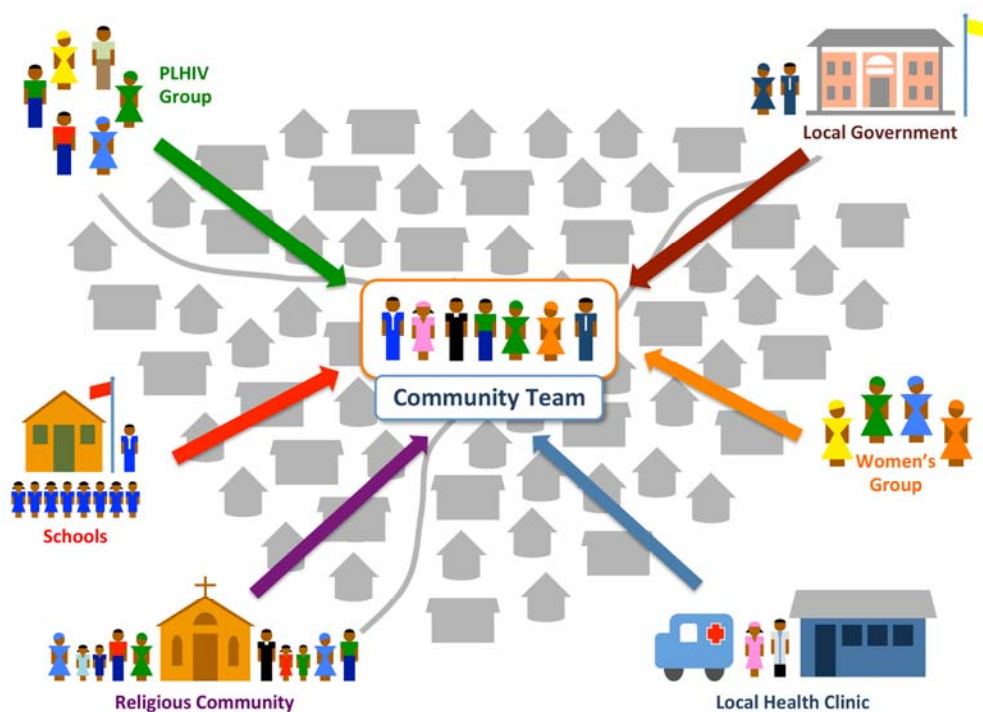


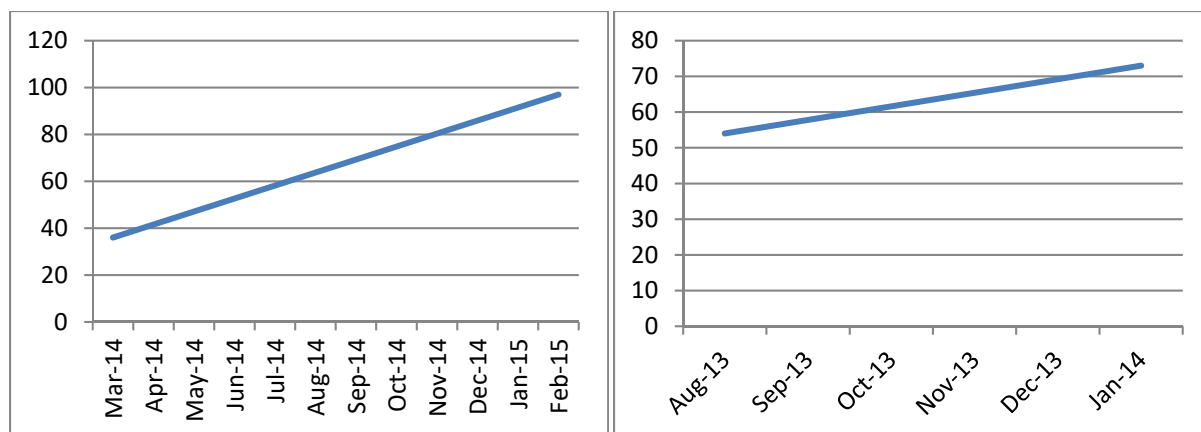
Fig 1: The Community Health System Strengthening model brings together people from existing community groups to form a community team to discuss and strategize solutions to health issues in the community

Tanzania and Mozambique have formed community improvement teams, which have effectively increased the rates of antenatal care for women in Mozambique and HIV testing in Tanzania. In both cases, community members who were involved in the community teams expressed pride in their work, saying that they now felt they had an important role to play in their community and that they were positively affecting the lives of their neighbours. In Tanzania, the community improvement teams in five communities were able to increase HIV testing by increasing communication and coordination with the health facilities and bringing HIV testing to the communities themselves. These teams also reduced the number of HIV patients who were lost to follow-up, from 44 in March 2014 to 5 in September 2014, through coordination of follow-up between the Home-Based Care volunteer (an unpaid community health volunteer system established by the Government of Tanzania) and People Living with HIV (PLHIV) groups (Lunsford et al., 2015).

Stover et al (2015) describe how the CHSS model was used in Mozambique. The community improvement team was formed in 15 villages (bairros) that make up the catchment area of Licilo Health Facility, and focused on improving antenatal care (ANC) rates, by community identification of pregnant women and encouragement to attend ANC early in their pregnancy. This intervention identified 896 pregnant women and increased the percentage of those who received ANC in the same month from 36% to 97% between March 2014 and February 2015. Additionally, the rate of pregnant women came for first ANC between 10-20 weeks' gestation, increased from 54% in August 2013 to 73% by August 2014 (See Figures 1 and 2).

Figure 1: Percent ANC between March 2014 and February 2015

Figure 2: Percent ANC between August 2013 and August 2014



The aforementioned is just a sampling of approaches and initiatives developed for use in LMICs. While these are mainly health service related, the infrastructure which already exists in the countries driving these efforts can be utilized to push for community engagement in health priority setting and policy development at the district level. Having local participants on the ground, such as community health workers, as go-betweens, is also essential in identifying and applying the engagement approaches which will be the most beneficial in the specific contexts of each country.

Conclusion

As previously stated, modern community engagement and its evaluation is still relatively new, thus, the aforementioned experiences of both higher and lower income countries can point to a number of lessons about community engagement. While the scope of these initiatives is broad, there are a number of basic principles that can be gleaned, while noting the unique features of each approach and the contexts in which they operate, including the country's level of socioeconomic development. For example, while higher income countries tend to have experience with more structured approaches to engagement which LMICs may be able to learn from, the opposite also applies; those conducting research in higher income settings should seek to reconstruct the aspect of bottom-up community building and volunteerism which lies at the heart of citizen engagement approaches in the LMIC context. It is valuable to evaluate the engagement initiatives presented extensively in order to discern which core elements lead to enhanced engagement and impact and under what contexts. Since community engagement strategies are in their infancy and rapidly evolving, both high and lower income countries have much to learn not only from their own citizens, but from one another.

There are some broader, universal lessons to learn as well. Community engagement benefits from support at higher levels, such as district structures. District structures can aid community engagement by convening, focusing the engagement on specific issues, and serving as a feedback loop. While citizen engagement in national policy dialogue is needed, community engagement at the local level should be recognized and fostered, particularly in the context of increasing decentralization of health care decision making in health systems. Lessons learned at the local level should also be used to inform both district and national policies as well as program development.

Unfortunately, we still do not have clear insight as to how and how much citizen input is incorporated into policy (Iwarsson et al., 2015), however it is clear that community voices need to play a bigger role in forming policy and hold the key to improve health and forward growth. They must be heard in the halls of local and national governance and, ultimately, articulated in the global dialogue. The community needs to exercise greater influence on national policies and global advocacy, and bring evidence to bear in decision making at all levels. Evidence needs to move out of communities and districts through broader communication and knowledge translation avenues to influence and shape national and global level policies and strategies. It is evident from the current literature that citizen engagement is needed to support a robust healthcare system. However, while there is consensus on the importance of citizen engagement, extensive work is needed to examine the different approaches within different contexts, barriers and facilitators to obtaining and disseminating the community's perspectives, and the most effective ways to ensure the outcomes of these approaches are presented to and incorporated by decision makers. It is still early days in the field and more exploratory and primary research needs to be conducted in order to learn best practices, and, of course, learn from one another.

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