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Meaningful Community Engagement—The Foundations of Global Oral Health Research

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ABSTRACT

The global burden of oral diseases and shocking inequalities highlight the failure of current oral health systems and policies. One of the limitations with existing approaches is that they rely almost exclusively on professional perspectives with minimal input from communities, and in particular disadvantaged populations. As a consequence, interventions often fail to achieve sustained improvements and have limited impact in reducing inequalities. Within global health, there is growing recognition of the importance of meaningful community engagement in all aspects of policy, practice and research. The CORE global oral health research programme is being conducted in four middle-income countries (Brazil, India, Colombia and Kenya) and an innovative element is that the planned research will be informed by community engagement with disadvantaged communities. Through a process of co-design, local communities will be actively involved in designing, implementing and evaluating interventions. The planned community engagement activities include community mapping, establishment of community forums, appointment of community link workers and community outreach activities including visual and performing arts events. The aim of this commentary is to critically review the policy context and principles of community engagement, and to reflect on insights gained through the initial engagement activities undertaken as part of the CORE programme.

1 | Introduction

For too long, oral health policy and research have been dominated by a professional perspective which has largely excluded the views, experiences, perspectives and expertise of people with lived experience of oral diseases, particularly those from marginalised and disadvantaged groups in societies [1]. It is now time to reframe oral health through meaningful community engagement, share power with people with lived experience of oral diseases and their wider communities to facilitate the co-design of future oral health policies, programmes and services that effectively address community needs and priorities, to achieve sustainable and equitable improvements in oral health.

The CORE global oral health research programme funded by the UK National Institute of Health Research (NIHR) is being conducted across four lower-middle and middle-income countries (Brazil, India, Colombia and Kenya) and comprises three interconnected work packages on oral health inequalities, commercial determinants of oral health and oral health system

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reform [2]. An innovative element of the programme is that all planned research will be informed by community engagement with disadvantaged and marginalised communities in each partner country, with all three of the work packages benefiting from the planned community engagement work [2]. This commentary aims to critically review the policy context, concepts and principles of community engagement and to reflect on insights gained through the initial community engagement activities undertaken as part of the CORE programme.

2 | Policy Context

Community engagement is not a new concept. Community participation in health is enshrined as a human right in both the 1946 WHO Constitution [3] and Article 12 of the UN International Covenant on Economic, Social and Cultural Rights [4]. The 1978 Alma-Ata Declaration highlighted the importance of community participation in developing more responsive health systems through primary health care [5]. In research there are certain topic areas where community engagement has been established for a considerable period of time. In the early 1980's people living with HIV were subject to discrimination, stigmatisation and lacked access to essential health services. AIDS activists challenged the discriminatory and bigoted treatment they received and through bold advocacy, demanded that people living with HIV should be involved in designing and delivering treatment and prevention policies and services. Ultimately the high-profile advocacy activities led to various international agreements that ensured people living with HIV were included in future efforts to treat and prevent the condition [6]. Researchers in mental health and maternity care have also adopted to some extent community engagement.

More recently in recognition of the need to tackle health inequalities and the limitations of profession-centric models of health care, renewed interest has been placed on community engagement within global health policy circles. In particular, WHO has produced useful policy guidance on promoting community engagement in health promotion [7], universal health coverage [8] and in tackling non-communicable diseases [9]. These drivers for policy change have also influenced research priorities and highlighted the need to include meaningful community engagement in all aspects of research planning, implementation, and dissemination [10].

In oral health policy and research, people with lived experience of oral diseases and members of the wider community are rarely, if ever, engaged in decision making processes in the planning of oral health services, policy development or research. A very traditional biomedical and hierarchical professional approach dominates oral health with 'patients' still seen as passive recipients of care or 'subjects' of research [1]. As a consequence, oral health services, policies and research are often poorly aligned with community needs and priorities leading to ineffective and inequitable outcomes. Even when positive results are achieved, they are often not sustained in the longer term as 'top-down' approaches fail to have community support and are poorly aligned with the realities of life. An additional limitation of current approaches in oral health is the almost total exclusion of people from socially disadvantaged and marginalised communities in service, policy and research developments [11]—hence the very limited progress in tackling persistent oral health inequalities over recent decades [12].

Those dominant knowledge systems have traditionally dominated oral health research; therefore, the CORE programme incorporates alternative theoretical approaches which help to understand that oral health inequalities are rooted in historically established power dynamics and complex overlapping systems of oppression [13]. The decolonial theory, for example, has been helpful for us to comprehend the importance of the meaningful restoration of power and agency to historically marginalised groups, who remain colonised by economics, geopolitics and inequities between and within countries [14–16].

3 | Conceptual Theory Base and Principles of Community Engagement

The WHO have provided a useful definition of meaningful community engagement as 'the respectful, dignified and equitable inclusion of individuals with lived experience in a range of processes and activities within an enabling environment where power is transferred to people, valuing lived experience as a form of expertise and applying it to improve health outcomes' [17]. In essence community engagement seeks to level out power imbalances through creating an enabling and supportive environment for participation—amplifying the voice, agency and empowerment of diverse and excluded communities. Informed by the seminal work of Paulo Freire [18], individual and civic empowerment is a process of enabling communities to exert greater control over their lives through capacity building processes to develop and enhance individuals' skills, self-confidence and agency to ultimately improve their life experiences and opportunities [8] (Figure 1). Arnstein's ladder of citizen participation also provides a useful model to understand different levels of participation from passive non-participation through tokenistic informing and consultation activities, leading to partnership, delegation and ultimately, citizen control [19, 20].

The concepts of community engagement very much inform and align with people centred participatory action research (PAR) [21]. This approach to research seeks to build meaningful and sustained partnerships with communities to jointly identify priorities, gather and analyse data and co-design and implement solutions to achieve social change [22–26]. PAR challenges existing dominant power relations, colonial legacies and how these perpetuate health/oral health inequalities.

While there is wide recognition of the importance of community engagement in public health, systematic reviews identified a limitation of research and evidence on best practice of community engagement in low- and middle-income countries, with the majority of studies focused on infectious diseases [27, 28].

4 | Positionality Statement

Our collaborative international team comprises a combination of community members, early career researchers, and senior academics. We acknowledge that the programme leads, academics, and most of the young researchers are from academic, urban

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elites. While we also acknowledge the colonial and Eurocentric history of our academic institutions, we remain committed to decolonizing our viewpoints and approaches. We are also committed to learning from the diverse communities involved in the programme and the processes of collaboratively designing the community engagement activities, research studies, and intervention strategies. Ultimately, through this project, we seek to gain more informed insights to influence policy actions to improve population oral health and tackle inequalities in the four partner countries.

5 | Overview of Community Engagement in the CORE Programme

In recognition of the urgent need to engage with communities in global oral health research, from the very onset of developing the original application for NIHR funding, community engagement has been a foundational element of the CORE research programme. The team of co-investigators includes senior representation (MC) from the Self-Employed Women's Association (SEWA), a highly respected civil society community organisation with over 50 years' experience of successfully working with self-employed women across India [29]. Such high-level expert community input has helped steer the design and conduct of the research from the very beginning. To avoid tokenistic approaches, the research budget provides funding for dedicated community engagement coordinators and a range of community engagement activities in each country (see below for details).

At the onset of the programme in 2023 and informed by the global health literature and WHO, NIHR and FDI guidance [7, 8, 17, 30–32], the research team developed and agreed an overview plan to coordinate all community engagement activities. A key element of this initial plan was agreeing to a set of guiding principles for community engagement activities planned across the four countries (Table 1).

In each country in 2024, dedicated community engagement coordinators were appointed to lead and develop the community engagement plans and activities. The appointed individuals came from a diverse range of backgrounds, but all demonstrated an understanding and commitment to share power with local communities across all aspects of the planned research programme. The local teams then carefully considered which particular disadvantaged and marginalised communities they should focus upon in their community engagement plans and subsequent research activities. Community can

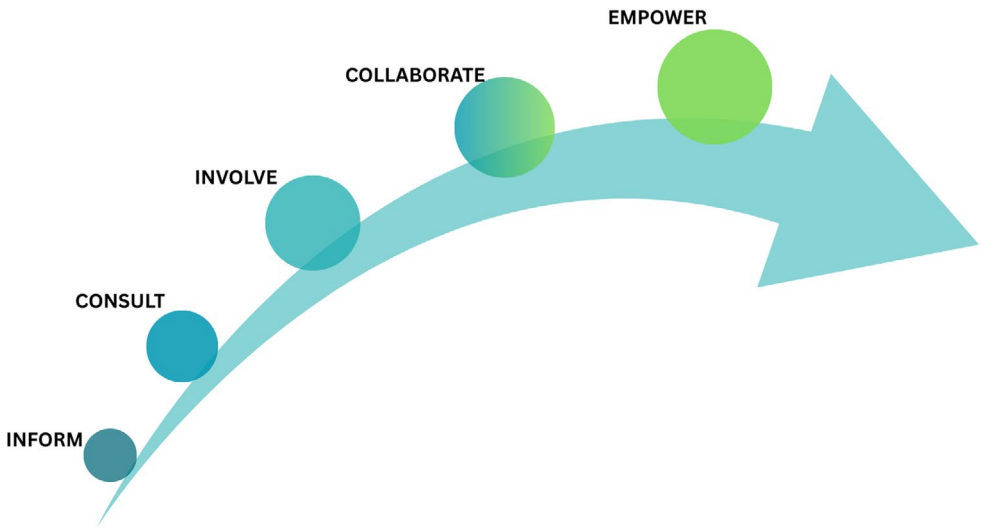


FIGURE 1 | Levels of community engagement. (Adapted from World Health Organisation 2020 [7]).

TABLE 1 | CORE guiding principles of community engagement.

- Community engagement embedded throughout the whole research process
- Importance of mutual understanding and recognition that communities are complex, heterogenous and dynamic
- Importance of building respect and trust with communities
- Central importance of equality, diversity and inclusion and the need to ensure transparent processes of representation are undertaken
- Ensure power imbalances are addressed across stakeholders, and co-design approaches are developed and implemented
- Strengthening community capacity through offering appropriate skills and empowerment training
- Use creative and innovative engagement approaches
- Monitor, evaluate and learn from community engagement approaches and share insights with relevant stakeholders

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be defined in different ways—as a geographical location or neighbourhood or groups of people with shared cultural, ethnic, religious or social identities [33]. As tackling oral health inequalities and promoting a pro-equity agenda are central to this programme, the local teams selected the priority communities based upon their local knowledge of social and ethnic inequalities.

In Kenya, two contrasting community settings were selected to capture the realities of oral health in both rural and urban communities. The urban setting was Mathare North Ward in Ruaraka Sub-County, Nairobi County, one of the largest informal settlements in Nairobi. This area is characterised by high population density, diverse ethnic composition and vibrant informal economic activity. The rural setting was in Kisau/Kiteta Ward of Mbooni East Sub-County in Makueni County. This population is more ethnically homogenous, mainly composed of the Kamba community. This rural setting provided a comparative perspective by highlighting a community primarily engaged in small-scale farming and local enterprises.

The two selected communities in Colombia were located in different geographic regions of the country. Both have historically experienced internal conflict and violence and the presence of vulnerable populations. The rural community of Aguas Claras in Ocaña, Norte de Santander, has specific socioeconomic and political dynamics as it is a strategic border area with Venezuela, and its main source of income is agriculture. In contrast, the urban community of Danubio Azul in Usme, Bogotá, is located on the outskirts of the city, is a densely populated area and has a predominance of informal employment and includes many migrants fleeing economic and political challenges in Venezuela. These two communities were chosen to capture the diverse realities of the Colombian context.

In Brazil both urban and rural communities were also selected. Two urban areas in the city of Recife, Pernambuco were chosen—Alto do Pascoal, an area with significant urban deprivation, with high levels of violence and unemployment and the Health District I, an urban area with a high concentration of homeless people. A third community setting, Santa Terezinha village, a rural community located 120 km from Recife, in Água Preta-Pernambuco, where sugar cane production dominates the local economy.

In India reflecting the complex cultural diversity of the country, two geographical regions were selected, one in Gujarat and the other in northern India in Rajasthan. In Gujarat five diverse community settings were selected to provide a range of urban, rural and tribal perspectives—Sabarkantha (rural and tribal), Vyara (rural and tribal), Surat (urban), Ahmedabad City (urban) and Ahmedabad District (rural). A range of tribal communities including Bhils, Garasias and Vasavas were selected and both the urban and rural communities comprised informal workers with little or no formal work and high levels of income insecurity and poverty—indeed these communities are some of the poorest and most vulnerable in India. In the Jaipur district in Rajasthan in northern India, three communities were selected again to represent the diversity of vulnerable population groups—Shastri Nagar, a densely populated mixed population living in an informal settlement in an urban area, Barh Baldeopura, a poor rural area and Jawahar Nagar another extremely poor informal settlement in an urban neighbourhood.

Once the communities had been selected, a community mapping exercise was then undertaken in each country to investigate in depth the nature, characteristics and dynamics of the selected communities, their resources, assets and needs. Community mapping is a process of identifying existing resources and assets, especially human resources, within a particular community that can be leveraged to develop effective solutions to promote social inclusion and participation, with the ultimate goal of improving community well-being and resilience [34]. A community mapping tool was developed to provide a comprehensive and structured template to record all the gathered information with each community (Figure 2). The mapping tool comprised several key sections including:

- Community demographic profile—population size, density, age structures, ethnic, religious and cultural profiles, social and economic indicators and needs
- Community leadership—community structures, leadership structures (both formal and informal) and communication networks
- Civic society organisations, community groups and other community assets—non-governmental organisations and local community groups operating in the communities
- Educational institutions—provision of local schools and other training organisations/groups
- Health service provision—oral health and general health service provision, resources and activities
- Public health programmes—public health programmes delivered to local communities
- Government agencies—law and order, housing support, development offices, and any other relevant services
- Neighbourhood facilities—availability of safe meeting spaces in public buildings
- Existing community-based research activities – any experience of previous or current research activities

A mixed methods approach was used to gather the required information. Some population level data was gathered from publicly available government statistical sources, while other information was collected through informal discussions with community leaders and small groups conducted during community visits. To gain access to the communities required local approval from the relevant agencies and through initial discussions with community representatives who acted as gatekeepers for their communities. Building trust, respect, and understanding with the communities took time and was facilitated through existing trusted networks. Local research ethics approval was not sought for the community engagement processes including the community mapping exercise.

The community mapping exercises with the local communities in each country provided a wide range of useful collective insights to inform the planned community engagement activities (Table 2).

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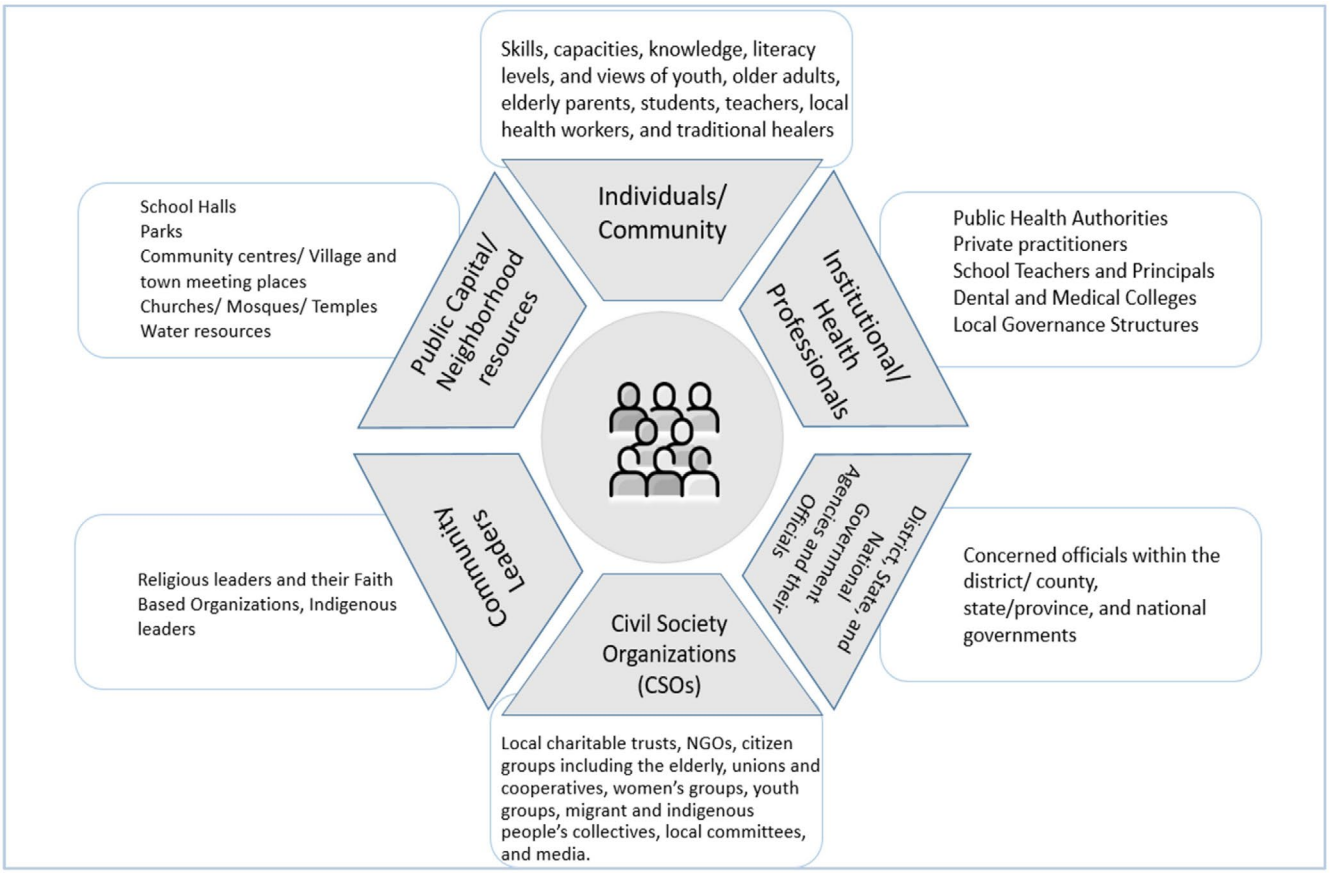


FIGURE 2 | Resources to be identified through community mapping process (Adapted from Community Asset Mapping Guide [35]).

TABLE 2 | Insights gained from community mapping.

Process of engagement: building trust and respect takes time, early involvement of communities and leaders builds legitimacy, importance of flexibility to different community contexts, bureaucratic obstacles often hinder progress of engagement.
Community characteristics and needs: stark evidence on high levels of social and economic need, diverse range of vulnerable groups identified, complex community structures, dynamic communication networks, range of community assets and support networks.
Oral health needs and services: very limited availability of oral health services especially in the rural communities, structural barriers to developing oral health services, widespread reliance on informal health practitioners, traditional practices commonly linked to cultural and social norms, limited awareness of oral health needs, limited involvement of oral health professionals in health promotion, very limited or no community engagement with oral health services.
Experience of research: very limited experience of research but strong desire and enthusiasm for involvement in this oral health research programme, ethical issues in relation to raising expectations for change.

On completion of the community mapping exercises, in each country a community engagement forum was then established to provide on-going community engagement into all aspects of the planned research programme. Each community forum comprises approximately 12 diverse community members recruited from the local communities. These forums meet on a regular quarterly basis to review and comment on all elements of the programme. To help build capacity, confidence and skills, forum members have been offered training and support to enable them to perform their roles. Evaluation will be undertaken of the training for the forum members to assess its value and impact. Forum members are fully reimbursed for their time attending meetings.

Informed by the findings of the community mapping exercises and on-going discussions with the community forums, community engagement action plans have now been developed in each country which outline the planned engagement activities with their respective communities. In 2024–26 a variety of successful community outreach events have been held. For example, in Brazil and Kenya community events were organised to celebrate World Oral Health Day. Community members were joined by national and regional government officials and professional representatives from national dental associations to discuss priorities for oral health and dental service developments including the imperative to engage local communities

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to achieve more equitable oral health policies. Interactive visual and performing arts outreach activities have also been held. For example, in Colombia a play about oral health as a human right was performed by two community groups in Aguas Claras: children and teenagers, and separately, by mothers and older adults. Through the process of preparing and then performing the plays, the community members discussed a wide range of ideas about oral health and expressed an interest in continuing these discussions through future arts activities. Materials and resources used in the community mapping process and other community engagement activities are freely available on our FigShare site.

In the context of this commentary, it is also important to highlight that all decisions regarding research studies and community-based actions result from a collaborative process between the research team and community forum members. For example, CORE teams and forum members in each country discuss the aims, principles and logistical considerations of the studies and then those are shared and agreed in our programme management group meetings. Based on those discussions, strategies that could then be used for conducting the research studies are collectively identified and implemented.

6 | Future Plans for Community Engagement Activities and Outputs

The teams in each country will continue with their on-going community outreach events and will increasingly focus their engagement activities on the remaining research studies that are planned. In particular, once local research ethics approval has been secured, a community survey will be conducted with the disadvantaged communities in each country to assess their experiences of oral health services, the barriers they face and ways to improve their access to appropriate local dental services. Finally, feasibility studies are planned to co-design and test multicomponent interventions to promote oral health equity and improve dental service access amongst the disadvantaged communities. A critically important element of these feasibility studies will be the community input in co-designing the intervention and their evaluation. Participatory action research approaches will be used in these studies. A small team of community link workers, approximately 10–15 individuals per country, will be recruited from the local communities and will be supported to act as community advocates for these research studies. The link workers will support and guide all aspects of the remaining research and in particular support the engagement of the most vulnerable and isolated members of their local communities in the planned research. The link workers will be offered training and support to enhance their skills and confidence to enable them to undertake these roles. Evaluation will be undertaken of the link worker training to assess its value and impact. A dedicated budget has been allocated to cover all the link workers' expenses and time that is devoted to the research programme.

On the completion of the planned research programme, the research team will develop a community engagement toolkit for oral health researchers that will provide practical guidance on community engagement for oral health research. Based upon the insights and experiences gained in this programme, the toolkit will guide oral health researchers on the principles of community engagement and how best to establish, facilitate, and evaluate community engagement activities in research.

7 | Reflections on Community Engagement and Involvement Processes to Date

The community engagement approach adopted by the CORE programme has facilitated the development of collaborative relationships with community members, providing a solid foundation for on-going involvement. The community mapping exercise proved particularly valuable in developing a detailed initial understanding of local contexts and informing engagement strategies with marginalised communities. The partnership with SEWA was instrumental in supporting the development of practical community engagement guidance and resources that facilitated early stages of implementation. In addition, the recruitment of local individuals into community forums and roles as community link workers strengthened community ownership. However, several challenges were encountered. Community participation was constrained initially in some communities by low levels of trust and limited perceived relevance of oral health initiatives in the context of competing health priorities (such as infectious diseases and maternal and child health). In some settings, tensions were evident between marginalised communities and local service providers responsible for facilitating transportation to activity-based events. These tensions appeared to be shaped, in part, by prevailing local stigma, which influenced both service delivery practices and community engagement. Finally, escalating instability in conflict-affected settings posed risks to community access, and the safety and wellbeing of research teams.

8 | Conclusion

There is an urgent need for meaningful community engagement in global oral health research to achieve more sustainable and equitable outcomes. The CORE research programme has incorporated a variety of community engagement approaches with a diverse range of disadvantaged communities to inform and co-design the planned interventions. Through this participatory approach, very valuable initial insights have been gained and meaningful and trusting relationships established between the local research teams and their communities.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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