Addressing Health Disparities through Community Participation

Subjects: Health Policy & Services

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Multilateral health institutions, public health agencies, and the scientific community agree that the involvement of communities in public health policy, practice, and research is a necessary condition for achieving their goals and reducing social inequalities in health.

co-creation participatory research equity public health

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1. Introduction

Among the ten essential public health services that should be implemented in all communities, according to the Centers for Disease Control and Prevention (U.S.), two are related to community participation: “Communicate effectively to inform and educate people about health, factors that influence it, and how to improve it”, which is a first step towards fostering community participation; and, “Strengthen, support, and mobilize communities and partnerships to improve health” [1]. Active citizen participation, empowerment, and community mobilization have been inherent features of Health Promotion since its origins and are, in fact, a requirement of good public health practice [2][3]. Public health ethical frameworks include community participation as a requirement for different actions. The Nuffield Council on Bioethics (U.K.) recommends minimising interventions that are introduced without the individual consent of those affected, or without procedural justice arrangements (such as democratic decision-making procedures) which provide adequate mandate [4]. Similarly, the principles of the ethical practice of public health of the American Public Health Association (U.S.) indicate that public health institutions should provide communities with the information they have that is needed for decisions on policies or programs, and that they should obtain the community’s consent for their implementation. Moreover, public health policies, programs, and priorities should be developed and evaluated through processes that ensure an opportunity for input from community members [5].

Consequently, the participation of citizens and communities in public health practice is not an option; it is a core part of public health action. The challenge is to identify the ideal forms, degrees, and procedures of participation to ensure that policies, programs, and interventions achieve optimal outcomes in terms of health, wellbeing, and equity. A variety of approaches have been described in public health practice and research to engage citizens and communities. Whatever approach is taken to incorporate community participation in public health activities, it must address the continuing challenge of inequalities in health and wellbeing.

Given that the social determinants of health inequalities are potentially modifiable, community engagement interventions can play a key role in the reduction of health inequalities. The evaluation of such interventions suggests they offer the ability to identify health inequalities and particular aspects that are uniquely identifiable through community participation [6]. According to the review carried out by Heimburg and Ness [7], public health and co-creation find their nexus in the importance they lend to community participation and the application of a more human-centred approach in any health action. In other words, they find their union in the fundamental aspect of the community and its wellbeing. Some of the terms and methodologies related to participation are outlined below.

2. Citizen and Community Engagement in Public Health

The National Institute for Health and Clinical Excellence (U.K.) views community engagement as “encompassing a range of approaches to maximise the involvement of local communities in local initiatives to improve their health and wellbeing and reduce health inequalities. This includes needs assessment, community development, planning, design, development, delivery, and evaluation” [8].

Community engagement is applied both to improve service delivery and to enhance the capacity and empowerment of communities to improve their health [9]. Participation of citizens in improving the delivery of health interventions can help to tailor the design of interventions to users’ needs, and to facilitate implementation and adherence. Yet, this is not the only kind of involvement of lay people that health promotion requires to achieve its goals. The participation of target populations can also contribute to improving the reach of interventions designed by professionals and to facilitate maximum coverage, removing difficulties of access and reception by the most marginalised groups [10]. Regarding public health policy, when the need for community involvement is invoked, reference is often made to the fact that it leads to more democratic and inclusive policies. Effective participation increases individual and collective control; this genuinely devolves sufficient power to the population to promote health equity by addressing the social conditions that contribute to poor health, in collaboration with professionals, health authorities, and other stakeholders [11][12].

A Science for Policy report by the Joint Research Centre (JRC) (BE), the European Commission’s science and knowledge service, indicates that “a boost in democratic legitimacy, accountability and transparent governance can be one of the main positive outcomes of community engagement” [13]. Among the recommendations, the JRC document states that, “A better use and integration of citizens’ inputs can potentially expand the evidence or expert-based paradigm towards a citizen-based policy-making. This implies that not only more types of knowledge are needed at the table, but also the recognition that community engagement is a matter of democratic rights to be differentiated from pure interests.” There is an interest in the involvement of citizens and communities in public policy in the European Union that is reflected in various actions, such as the promotion of citizen science, which, by involving citizens in the production of knowledge, has been proposed as a facilitator of more inclusive policy-making [14].

It is important to note that the term community, as used here, is understood as a set of heterogeneous individuals, institutions, and associations interacting and sharing social, economic, geographical, or sentimental characteristics.

It is defined by a sense of belonging and shared perspective [15]. In analysing health improvement from community participation in research, a report by the National Academies of Sciences, Engineering, and Medicine (U.S.) concluded that projects with community power groups must put issues of power, race, and inequality at the centre of the discussion; otherwise, it is easy for projects to move in tactical and not necessarily enriching directions [16]. In fact, the research model that has been most frequently applied to address health inequalities is Community-Based Participatory Research [17][18], which does so by addressing power imbalances through equitable community engagement [19][20].

3. Community-Based Participatory Research

Israel et al. defined Community-Based Research as focusing on social, structural, and physical environmental inequities through the active involvement of community members, organizational representatives, and researchers in all aspects of the research process [21]. Partners contribute their expertise to enhance the understanding of a given phenomenon and integrate the knowledge gained with action to benefit the community involved. Compared to other models of community engagement that have successfully addressed health disparities, Community-Based Participatory Research has three components that are considered key drivers of success: engagement of community partners at all stages of research development, including the dissemination of findings; facilitating knowledge exchange between the community and academic partners; and achieving a balance between research and action [19][20]. The possibilities, realities, and challenges of this research approach were reviewed by Wallerstein and Duran, who examined the challenges of achieving a truly balanced researcher–community relationship for issues such as power, privilege, participation, community consent, racial and/or ethnic discrimination, and the role of research in social change [22]. This last aspect is one of the ongoing challenges in public health: how this transformative research paradigm influences practice and policy to reduce disparities. The same authors also investigated the barriers and limitations in intervention and implementation sciences, and concluded that Community-Based Participatory Research has an important role in expanding the reach of translational intervention and implementation sciences to influence practices and policies for eliminating disparities [22]. In this regard, attention is given to the idea of “co-creation”, that is, developing and implementing actions or interventions in partnership with the community. Several researchers have considered its potential for improving the implementation of community-involved actions aimed at changing the social determinants of health [23][24]. The idea of co-creation, as a way of getting actions implemented through collaboration, provides an additional way to achieve a public health policy and practice that is closer to community priorities and helps to overcome the implementation challenges [24].

4. Cocreation and Public Health

The term “co-creation” finds its origin in the public sector and public management [25]. Voorberg at al. have clarified its meaning by making a difference between three types of co-creation: citizens as co-implementers, co-designers, or co-initiators. In their review, they found that co-creation/co-production is a practice to be found in numerous policy sectors, but predominantly in health care and education. In the health field, co-creation was from the outset related to the improvement of the design of consumer goods and services to adapt better to the expectations of end-users [25]. Hence, its diffusion in the design of health actions or technologies aimed at specific individuals has been relatively wide. In the field of public health, there are also examples closely related to more individual actions and service delivery (hand washing, screening, etc.). However, its application in more complex public health programs has not been as frequent, as it is not only a matter of adapting the intervention to the end-user; the end-users also take part in all stages of intervention design and implementation. They are both the target population and active stakeholders, who initiate population-level changes in health through their effective involvement. Assuming the complexity inherent within health, wellbeing, and equity within a socioecological framework of complex adaptive systems, Von Heimburg and Cluley explored existing links between co-creation and Health Promotion to outline the potential to integrate these approaches in public value-creation [23]. They stated that a shared moral ethos renders co-creation an appropriate approach for complexity-informed Health Promotion practice, and to nurture further development of Health Equity in All Policies. Yet, they noted that some conceptualizations of co-creation can lead to increasing inequity through disparity in participation. Addressing questions of power and decision-making about who participates, how they participate, and to what extent in the creation of public health policy is one of the key issues when examining the potential role of co-creation in contributing to the achievement of public health goals [23][26].

As co-creation is becoming a core principle of public sector reform, it is advisable to have an overview of experiences that, in practice, have applied co-creation to generate and implement public health actions that incorporate the principle of equity. The purpose of this research is to review these experiences to contrast what methodologies have been used, how the participation of citizens and communities has been articulated, and what effects on health and equity have been observed.

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