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**CITIZENSHIP AND PARTICIPATION:
FROM USER-CONSUMER
TO CO-RESPONSIBLE CITIZEN**

Manuel Lopes - PhD in Nursing Sciences, University of Évora, Coordinator of the National Network of Long-term Integrated Care. Portugal

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ABSTRACT

This article intends to be a contribution to the discussion on the sustained change of the health system as an essential structure for the well-being and the development of any modern society. A critical analysis is presented regarding citizens' participation in the health system. In short, a paradigmatic development is proposed, from user-consumer to co-responsible citizen, through the combination of the concepts of co-production, local health strategies, and information and communication technologies.

INTRODUCTION

Presently, almost all the countries that structure their health systems on Bismarckian or Beveridgean models discuss their suitability to the current context of human and social development. The main reason for this discussion seems to be the ongoing financial and economic crisis. Indeed, the available indicators show that within a decade (2000-2009) a sharp average annual growth occurred in the health cost per capita, as the increase in public health investment was abruptly interrupted, especially in some of the countries most affected by the crisis, where the cuts in health spending reached very expressive values⁽¹⁾. Those cuts lead, on the one hand, to a reduction in the services or in their quality and, on the other, to the increase of the individual contribution to the health spending. At the same time, it seems, in some contexts, that we are on the verge of a real rationalization of such services.

At the height of the crisis and in the emergence of responses to external demands, we risk not seizing the chance, opting by more or less blind cuts and failing to perform the reflected change the system requires. Now, the moment requires a change that calls all stakeholders to assume their responsibilities. But for that, we need a broader view of the health system and of the barriers constraining its ability to meet the current needs of the populations. We will start from these.

HISTORICAL AND CRITICAL PERSPECTIVE

It is already a commonplace to mention the profound demographic changes in the population of the Western world, but that is not all of it. In addition to a sharp decrease in birth rates, a constant increase in the mean life expectation occurred, resulting in a material population aging which, in plain truth, is a civilizational achievement. In practice, the *baby boom* became *elder boom*. This process – as well as the improvement in life conditions and health care, among others – induce a change in the nosological frameworks, with reduction and/or reconfiguration of infectious diseases and the increase of chronic diseases.

Simultaneously, we are witnessing an intense urbanization process, fast migratory movements of all kinds, and changes in the labor market, family structure, and behavioral patterns, affecting the health and increasing the demands of public services.

That is, almost everything changed since the current health system model was created. And the model itself, how did it evolve? I would say that, in essence, it kept its characteristics. We will analyze only one of the many dimensions that could be evoked.

Therefore, the focus will be the citizen participation in any of the health system levels. That, you might say, was provided for since the Beveridge report⁽²⁾. Later, this was reinforced by the Lalonde report⁽³⁾, and especially from the conclusion of the International Conference on Primary Health Care, of Alma-Ata⁽⁴⁾, in which the final declaration stated that primary health care should be the cornerstone of the system, and these should be characterized by being “universally accessible for the community, individuals, and families, **with their full participation**, at a cost compatible for each country”. Few years later, the Ottawa Charter⁽⁵⁾ stresses the importance of actions in the community and empowerment of the individual to ensure intelligent health decisions.

Several other documents demonstrate the importance of citizen participation in health decisions, then it can be said that, conceptually, we all agree with this principle. But then we ask, what has been done, and with which results?

In the European Union, the organization *Active Citizenship Network*⁽⁶⁾ proposed in 2002 the European Charter of Patients' Rights. Whilst highlighting the own act as an example of participation in health decision-making, the document, interestingly, presents a set of 14 patient's rights as a health consumer.

A first step was given in Portugal through the creation of the User Office (Ministerial Dispatch No. 26/86 of July 24th) (PORTUGAL) in all hospital and health centers, intended to receiving suggestions and complaints of health service users. In this case, also, a user-consumer perspective prevails. Later, the Health Bases Law (Law No. 48/90 of August 24th) (PORTUGAL), addresses the issue of patients' rights, albeit vague and general, with no specific references to participation and how to achieve it. The Charter of Patients' Rights (available on the website of the General Directorate of Health) is a document that, in all aspects, coincides with the aforementioned European Charter, i.e., it has a clear emphasis on a user-consumer perspective.

In 1998, a fundamental document is presented for the first time (*Health in Portugal: A strategy for the turn of the century (1998-2002)*), in which, amongst many other aspects, the then-called Local Health Strategies – where the citizens would have an important role – are analyzed in depth. It can be said that these strategies started to be developed in the National Health Plan of 2004-2010.

Some important additional steps were given by the Primary Health Care Reform (Decree-law No. 28/2008 of February 22nd) (PORTUGAL), then presented as the cornerstone of the health system. With such reform, a notable evolution has been noted from the concept of user-consumer to that of citizen. Consequently, in the scope of Health Centers Groupings (ACES) are created the Citizen Office and the Community Council. The first aims to “promote and develop the exercise of citizens' rights and duties, encouraging their participation in the definition of the ACES priorities, strategies, and actions, as well on the organization and functioning of services”⁽⁷⁾. Community Councils, in turn, are considered administrative organs of the ACES, integrating diverse community representatives, from municipalities to patients' associations.

Despite these developments, I ask, what are the results? Is there an effective user participation? What are the gains for the health outcomes, whether individually or from a community point of view? What are the citizens' perspectives on these developments?

Gonçalves, Alves, and Ramos⁽⁸⁾ identified a set of tensions and 'gaps' in the health system, among which I would highlight the 'gap' “between the expectation of participation in health decisions and the effective participation in the making of them”. In fact, this 'gap' can be seen from two different perspectives. On the one hand, from the perspective of the system and its traditional stakeholders (i.e., health professionals in a broad sense), and in this case we wonder: do the health professionals, traditional holders of knowledge/power, make room for user participation in health decision-making in its most diverse levels? That is, does the citizen have autonomy to decide on his own health, the health of his family and

community, within the context of a health team? According to the *Europatient Empowerment Index* (2012), there is a considerable difference around patients' rights, information, and participation among the countries in southern, central, and northern Europe. In this index, which analyzes variables such as patients' rights and information, accessibility, results, prevention level, and reach of the services provided and pharmaceuticals, Portugal is in a modest 25th place.

On the other hand, we could also wonder if the users show they want such participation. According to some studies conducted in the European Union, 51% of users expressed a preference for the sharing of decision-making; 26% admitted preferring the paternalistic model, and 23% stated they prefer decision autonomy⁽⁹⁾.

Regarding Portugal, Barros and Almeida Simões⁽¹⁰⁾ state that despite some interesting initiatives taken to encourage the patient's involvement, aiming to encourage the population to take responsibility for their own health care and to obtain a better quality of care, participation is still confined to legislative references and intentions announced in documents.

In turn, based on an exploratory study by Lobo⁽¹¹⁾ about the process of community participation and primary health care development, we concluded that the degree of community participation in this scope is not satisfactory due to the lack of information and knowledge on the projects and activities of the Health Centers; lack of confidence in their own capabilities; perception of not having enough strength or ability to change the health services, ultimately dominated by the professional power; and inadequate organizational structure in primary health care contexts.

Various other examples could be invoked, but all that we found point to the same direction: there is a conceptual consensus on the importance of citizen participation in the most diverse levels of health decision-making, there are even some legislative mechanisms to provide for it. However, from the organizational and professional point of view, there are several barriers to such participation; and, from the citizens' point of view, the evidence is somewhat contradictory: on the one hand, they seem to be satisfied with what is offered to them, on the other hand, they are willing to participate more. In view of this, what to do?

A PROPOSAL FOR CHANGE

To begin with, it should be noted that there are no magic formulas to quickly and painlessly change the current scenario. However, if we all agree that citizen participation in decisions concerning their own health, the health of their families and communities, is a fundamental right, and that many advantages may emerge from there, which will help us to overcome some of the current constraints in the health system. Then, we have no other choice but to find a mechanism to do so. We believe that all instruments for the creation of such mechanism or platform are already available. We will explain them.

It is clear to us that the paradigmatic evolution from user-consumer to co-responsible citizen should be deepened and further developed. This means that all organizational and/or instrumental mechanisms should be used to achieve this aspiration. Among these mechanisms, we will only refer briefly to three: *the concept of co-production* added to *local health strategies* and with the *information and communication technologies* applied to health. We argue that the combination of these three mechanisms can result in benefits, with repercussions in health outcomes, system sustainability, user satisfaction, among others.

The concept of co-production, or the evolution to the paradigm of the responsible citizen

The concept of co-production was firstly introduced in the early 1970s by the Nobel Prize for Economics Elinor Ostrom and her colleagues. This economist was trying to explain why the service provision, when centralized by large institutions, was less effective than predicted. Later, Edgar Cahn turned this academic concept into a practical system changing agenda, namely through the creation of “*time dollars*” and “*time banking*”.

Currently, co-production can be defined as the provision of public services in a relation of equality and reciprocity between professionals, people who use the services, their families and neighbors. When activities are thus produced, services and neighborhoods become much more effective agents of change⁽¹²⁾. According to Bovaird⁽²⁾, the concept of co-production is revolutionary in public services, as it puts the citizen and the community in the center of the decision-making process.

Such concept is based on six fundamental principles, namely:

1. **Assets:** it transforms the perception of people, from passive receivers of system services and charges to a view in which they are equal partners in the design and provision of services.

2. **Abilities:** it changes the model of public services provision from a deficit-centered approach to another perspective, one that recognizes and develops personal abilities and actively supports them in favor of the individuals and the community.
3. **Reciprocity:** it offers people a range of incentives to get involved, allowing them to work in reciprocal relationships with the professionals and other citizens, in a situation of mutual responsibilities and expectations.
4. **Networks:** it creates networks that involve citizens and professionals, as the best way to share knowledge.
5. **Blurring of roles:** it removes the well-defined limits between professionals and patients, service providers and consumers, thus reconfiguring the ways in which services are developed and delivered.
6. **Catalysts:** it enables public services to become facilitators instead of unique and centered service providers.

McLaughlin⁽¹³⁾ defends that if this concept is at the heart of the organization of a new health system, it will be more productive and sustainable because it is based on a radical definition of partnership between health system/professionals, on one side, and citizens/consumers, on the other. He believes the current concept of co-production demonstrates a new order, which integrates a practical position that consists of a co-productive dialogic and dialectic partnership with shared interests, instead of conflicting interests between health professionals and citizens⁽¹⁴⁾.

This concept proposed a profound change in the relationship of health consumers with the system, thus moving them from an outsider to an insider perspective of the health system. This compels the entire care production process to change, implying in an alteration that goes from the organization dimension of health care services to new competences the professional will need to develop to make such model effective.

Investigation already provides some results regarding the use of co-production strategies. We will name just a few.

Self-care support groups for lay people are a good example of peer education in teaching self-care skills, which are effective in the increase of self-efficacy and energy levels among patients with diseases of extended lifespan. Moreover, they are probably cost-effective in a period exceeding six months⁽¹⁵⁾. The cost-effectiveness of the Expert Patients Program was assessed, and a significant reduction in the cost per capita was verified, showing this program is a cost-effective alternative to the traditional care for people with long-term

diseases⁽¹⁶⁾. In turn, Joosteen et al.⁽¹⁷⁾ have developed a systematic review using only RCTs, comparing the difference of impacts of shared and unshared decision-making on long-term patients. They concluded the shared decision-making can be effectively used to reach an agreement on long-term decisions in treating people with chronic diseases. Finally, the Programs Nurse-Family Partnership, in the USA, which were evaluated for more than 15 years, demonstrated a reduction of 48% for children abuse and neglect, 61% for adolescents' imprisonment, and of 90% for "incurable behavior". Parsed into scale, this translates into a profit of about five times the investment, and savings in public expenditure of about 41,000 dollars per child involved (see at <http://www.nursefamilypartnership.org/>).

To conclude the presentation of this concept, it is noteworthy that, according to Boyle and Harris⁽¹⁸⁾, co-production can create the most important revolution in public services since the Beveridge Report.

Local Health Strategies

Regarding the concept of local health strategies, we can define it as a set of health goals, (committed) social partners, activities (effective to materialize these goals), and resources (existing or obtainable) able to improve the health status of a community, in a high-complexity context⁽¹⁹⁻²²⁾. Those same authors added that such strategies are essentially a local "changing vector". According to these briefly presented elements, it is possible to realize the proximity between this and the abovementioned concept (i.e., co-production). Both assume the active participation of all stakeholders and coordinate local action.

Information and communication technologies (ICT) applied to health

ICTs can be defined as tools that facilitate the communication and the processing and transmission of information by electronic means. These tools are increasingly present in everyone's life, as the "literacy" they require are less and less an issue. The ICTs "invaded" the clinical context and now they are present in all areas, from the administrative field (clinical or not) to the day-to-day of all health professionals, through the instruments they use or actions they take. In such a way that it is already possible to recite a set of benefits arising from their use, namely:

- 1 – **They promote the dissemination** of information on public health and facilitate the public discourse and dialogue around the major threats to public health;
- 2 – **They enable remote consultation**, diagnosis, and treatment via telemedicine and tele-homecare;
- 3 – **They facilitate the collaboration and cooperation** among health professionals, including knowledge and training exchange;

4 – **They make the health research** more effective and simplify the dissemination and access to research results.

Thus, it is possible to say that ICTs have the potential to impact many aspects in the health field. The ability of communities to access health services is influenced by more information and communicational processes, which are mediated by the ICTs.

In such development, the next step is the bi-directionality of the communication between professionals/services and users, with all of them having access not only to the *outputs* but also to the *inputs*.

BY WAY OF CONCLUSION

From the ideas presented here, it becomes clear that citizen participation, despite advocated and defended whether because of principles or aiming to health outcomes, is far from being a widely widespread reality, present in the health system organization on a daily basis and at all levels of health care. However, due to the financial and economic circumstances we are going through, as well as to the multiple social and demographic changes in society, a change of paradigm is demanded. The change we propose here is the transition from user-consumer to co-responsible citizen through the integrate use of already existing instruments, namely: co-production, local health strategies, and information and communication technologies applied to health.

Basically, we advocate a system in which the citizen is co-actor in all health decisions, whether individual, familiar, or communal. Such system will be more and more successful as much as it is based on local strategies, suitable to concrete realities, and with integrated resources. This whole process can now be much facilitated if ICT-based, as they enable information flow, access to resources, and self-management of the health-disease process.

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Correspondence: mjl@uevora.pt