

Participation

The concept of participation

There are varying definitions of the meaning of participation which complicate the task of limiting the concept to just one of them. However, they all coincide on certain points, and in considering the question of public participation in the context of health systems, it can be affirmed that participation is a fundamental right covered by current legislation in which citizens and patients can decide the objectives of the health service in a free and democratic society.

If we go into more detail, we can say that participation involves voluntary and active shared responsibility between individuals as an integral part of a process of development or organization of public health. It means commitment and cooperation among all the parties that intervene in the health system.

The health system, in turn, can be described as a space which offers quality care and covers all aspects of health –not just medical attention– for the entire population without discrimination. However, as individuals that exercise their rights in the use of the health services, participation can be understood from differing points of view, depending on whether the individual takes the role of citizen, consumer (of products related with the health industry), patient or user, or, as often occurs, each person plays more than one role at a time.

Participation in the current health system: towards a new type of relation

Recent years have seen important changes in the relations between the different parties involved in the health system. Despite the development of a legal framework which reflects the first attempts to handle participation as a vital element of society, it was not until recently that the relation between the health system, the professionals and the users and patients were questioned, resulting from the development of surveys examining patient satisfaction with the treatment received, among other factors.

The traditional model was based on a hierarchical paternalistic relationship, with the health professional taking the decisions on the patient's behalf, who delegated all his/her responsibility to the doctor. It was assumed

that qualified personnel would always take the best decision, because of their superior technical and scientific knowledge necessary for treating illnesses, and therefore the patient was not involved, merely accepting the treatment proposed. This model is increasingly.

The public bodies have structures that are more and more complex with ever greater amounts of red-tape, and the decisions taken are more and more remote from direct contact with the public. Expectations have also changed, and patients now have a more developed awareness of their rights and responsibilities, and not only demand to be heard, but also claim more participation in the healthcare process – more directly, permanently and above all, adapted to current situations.

Better access to information, knowledge and services, combined with a substantial improvement in the quality of healthcare allow patients to adopt an ever more active role in the decisions that concern them.

These are the aspects that are redefining the relationship between health professionals and patients in a new model where, as explained above, the person of the patient/user claims greater protagonism in the managing of resources and public health services. As a result, both patients and personnel in this sector strive to engage actively in the running of health institutions. This change of perspective in the managing of health policies sees the patient as a subject who requests that his/her views be heard in the taking of decisions in matters of healthcare, rather than a simple consumer of services.

We can affirm that there are two types of patient: there is the patient that is aware of his/her right to decide and takes responsibility for his/her health, and the other patient that chooses to delegate all responsibility in the health system, seeing it as an agent in which to trust.

Problems in measuring participation

One of the problems we find is that of measuring a concept as abstract and complex as participation. How can the degree of public participation in the health system be measured? At what level? How far can the public be involved?

Many studies of processes of participation are based on the following theories, which can be used as instruments for guidance when measuring the situation of public participation in the autonomous communities. The Arnstein scale is considered interesting with its ladder of participation⁶⁴,

64 Arnstein, Sherry. A Ladder of Citizen Participation. AIP Journal, July 1969; 216-224. Study of forms of participation classified in 8 levels, from the absence of participation, symbolic representation, and full participation of the citizens for self-management.

as is the *continuum* of participation of Brager and Specht⁶⁵, and the *spectrum* of participation proposed by the International Association for Public Participation (IAP2), the scale of which begins at the basic level of information, followed by consultation, participation, collaboration and finally with the attribution of power, or *empowerment* at which point the power of decision making is assumed by the public.

In all of these theories, regardless of the details that separate them, information and consultation are grouped at the lowest end of the scale of participation, indicating an absence of real power for the citizen/consumer/patient. The ideal form of participation, in contrast, would be to put the power in the hands of the public for the management and planning of the health system.

The level of participation in the taking of policy decisions, according to the categories of information, consultation and active participation used by the OECD are outlined below. The first level is the simply the evaluation and opinion expressed by the public on the policies being carried out. At the next level, consultation, participation is limited to feedback from the citizens prior to the final decision. Finally the OECD defines active participation as the highest level, where the public is involved in every stage of a policy.

Although health and than health system are concepts that are always open to improvement, an ideal model of a health system would consider patients and professionals as the principal agents. Rodrigo Gutiérrez Fernández referred to it as *the government of the citizens*⁶⁶, based on mechanisms for real participation on the part of the public and professionals in the running of health facilities and organizations, mutual trust and *empowerment*⁶⁷ of health professionals and patients. Not only would this permit the sharing of responsibilities, but also the active defence of rights in a context of deliberative democracy, where public spaces for discussion would be developed for the active participation in decisions.

65 Adaptation of the Arnstein ladder to a *continuum* which starts with reception of information (low participation) and finishes with joint planning (right to exercise control and decide).

66 Round table: “New Demands in Society”, XIV National Hospital Congress, Zaragoza, 17-20 of May 2005.

67 It is defined as “a system of joint incorporation of professionals and patients in the processes of decision making in health”. *Empowerment* “does not mean delegate and transfer authority and new responsibilities to people and then withdraw. *Empowerment* means removing the barriers that separate us”, John P. Kotter.

Processes of participation in the autonomous communities

In order to check the evolution of the progress made in the different autonomous communities in 2007 in terms of participation –both collective and individual– the *Rec Recommendations (2005)*⁶⁸ have been used. These were adopted by the Committee of Ministers of the Council of Europe on “the development of structures for citizen and patient participation in the decision-making process affecting health care” in member states.

States are recommended to take measures to ensure that the directives on democratic participation, information, support and tools for participation are reflected in legislation, especially with regard to the health system.

The different autonomous communities within the Spanish state have created, developed and applied a number of laws which set out the organisms at regional level charged with public participation in the health system and its functions, including the rights and obligations of individuals as users or patients, through Law 41/2000 of the 14th of November *regulating patient autonomy and the rights and obligations regarding information and clinical documentation*⁶⁹.

The principal regulations developed with reference to the promotion of patient participation are the following: free choice of doctor, as a mechanism through which the citizens can have a direct influence on their health services; access to a second opinion; access to medical records; informed consent; the existence of procedures for establishing advanced directives/last wishes; a guide or charter of services; information on the NHS and guarantees for patients with special needs for information associated with disability. Table 61 contains the legislation developed by the autonomous communities with reference to individual participation.

However, neither rights nor the development of legislation have made equal progress, resulting in a mixed situation among the regions. In some cases, legislation has been extended to include the second opinion and access to medical records in 2007.

68 Rec Recommendation (2000) 5/24 of February 2000 of the Committee of Ministers of the Council of Europe (independent international organ whose object is the defence of human rights and parliamentary democracy, and boosting the image of Europe among the citizens of Europe.).

69 BOE number. 274, 15/11/2002, p. 40.126-40.132.

TABLE 61. Participation. Response to legislation developed by the autonomous communities, 2007

	Yes	No	No answer	Total
Free choice of doctor	12	3	3	18
Second opinion	14	1	3	18
Access to medical records	14	0	4	18
Informed consent	12	3	3	18
Advanced directives/last wishes	13	2	3	18
Guide or menu of services	10	3	5	18
Information in the National Health System (administrative information related with services and available care units and the requirements to gain access to them: freedom of choice in doctor and centre, awareness of waiting lists, etc.)	10	1	7	18
Guarantees for disabled patients with special needs for receiving information	6	1	11	18
Figure or institution defending the rights of patients	11	3	4	18

Created based on data received from the autonomous communities.

However, the fact that participation has been the subject of legislative development does not imply that specific actions are being undertaken to consolidate real and effective participation on the part of the public. A more detailed analysis will be required which takes into account all the measures carried out by each autonomous community and the results obtained in relation with citizen participation in public health.

In general terms, the issues addressed have been in the sphere of information, consultation and, in some cases, of advice. The aim is to promote health through the elaboration of service guides for users, access to clinical documents, informed consent, access to information in the NHS or through the guarantees for patients with special needs for information associated with a disability. They do not represent a level of active participation, according to the theories mentioned above. The citizen/user/patient receives information about the actions. The institution informs about the plan that it has drawn up as a measure to ensure that it goes ahead as planned, as Brager and Specht described in their *continuum*. In no sense does this type of participation appear to have any effect on the determination of health policies.

Although the communication at this level is in one direction only, and there is minimal participation of society in decision-making, the process of informing in health promotion and the obtaining of information (through awareness campaigns and health education) are indispensable if further

levels of participation are to be reached. In the words of Rodrigo Gutiérrez Fernández, presented in the round table “New demands in society”⁷⁰, it has been shown that “quality information reduces the patient’s anxiety, improves the capacity for self-help (the responsibility of the patient in the cure) and the involvement of the family, [...] and favours a better use of the resources and services by the public”.

The technological development that some autonomous communities have undertaken in their bid to provide information for users and make it available immediately is also worthy of note. The use of a virtual mailbox and fax in Castile and Leon, the enhancement of new technologies in attending to patients in the Basque Country through the web page of the health portal Euskadi-Osanet, the use of electronic signatures and an electronic health card for public use (ONA) are also notable. This autonomous community is also carrying out the development of a shared computer platform in the area of public service to improve access to services. In 2007, Andalusia extended the coverage of its Health Responds service, along with the system of appointments via internet, the virtual office InterS@S, the Information service and the 24 hour Health Advice Service. It also added an SMS channel as a new route for making an appointment with the general practitioner. March 2007 saw the introduction of the project *information means health*, a service which consists of a multichannel system which distributes health-related content for the public through screens located in waiting rooms in health centres, internet and third-generation mobile phones, where the content is adapted to the broadcast channel.

At the same time, the autonomous communities must ensure the application of community participation at all levels and in all areas of the health service to meet the recommendations of the Council of Europe. To promote this participation, the administrations must make duly regulated channels for participation available to ensure that wide sections of the population can be included in the processes without having to be organized.

One of the principal mechanisms continues to be the regional health councils of the health systems of the autonomous communities.

They are structured in terms of their territory, through the creation and extension of area and zoning committees (mentioned in the communities of the Canary Islands, Castile and Leon, Catalonia, Extremadura and La Rioja⁷¹) and by sector (for example, through advisory boards on transplants, bioethics, immigration, etc. or the professional advisory boards on medicine and nursing of Catalonia).

70 XIV National Hospital Congress, Zaragoza, 17-20 of May 2005.

71 From the information received for 2007, other autonomous communities probably have them although they do not mention them.

They include representation from administrative units, social, union and the health service. Despite the variation in representatives, they all provide consultation and advice. Which is to say that the communication in two directions allows the participants to listen, evaluate and give opinions, but does not guarantee that their ideas, criticisms or proposals will be taken into account. According to Brager and Specht, consultation, even at a low level, involves the organization seeking support to legitimise and justify its objectives.

The number of patient/user representative associations increased considerably in 2007, compared with those reported in 2006. It was assured that they all have the opportunity to give their opinions and defend their rights in healthcare. The subsidies for patient associations, however, have not grown in parallel with them. Table 62 shows the financial contribution which the autonomous communities have given to patient associations in 2007.

TABLE 62. Financial contribution of the autonomous communities, 2007

	Yes	No answer	Number of associations in 2007	Number of associations in 2006	Total quantity (euros) in 2007	Total quantity (euros) in 2006	Difference 2007-2006 (euros)
Andalusia	X		176	157	600,000.00	522,172.34	77,827.66
Aragon	X		42	46	525,750.00	504,895.00	20,855.00
Asturies	X		80	60	100,000.00	70,000.00	30,000.00
Balearic Islands	X		5	6	94,000.00	50,000.00	44,000.00
Canary Islands	X		17		284,729.44		284,729.44
Cantabria	X		13		186,692.24		186,692.24
Castile and Leon		X					0.00
Castile-La Mancha	X		147	141	1,500,000.00	1,591,700.00	-91,700.00
Catalonia	X		71	65	1,786,063.34	1,731,967.65	54,095.69
Valencian Community		X		138		870,307.79	-870,307.79
Extremadura		X					0.00
Galicia	X		122	95	12,858,323.31	10,372,462.00	2,485,861.31
Madrid	X		161		385,780.00		385,780.00
Murcia	X		45	19	225,000.00	129,526.91	95,473.09
Navarre	X		39		621,342.00		621,342.00
The Basque Country	X		77	78	498,480.00	587,000.00	-88,520.00
La Rioja	X		12	12	667,626.76	710,659.21	-43,032.45
Ceuta and Melilla		X					0,00
Total			1.007	817	20,333,787.09	17,140,690.90	3,193,096.20

An increase in the subsidy does not necessarily mean greater (active) participation by the associations. They normally contribute to improving the health services in their handling of illnesses, in prevention programmes and health promotion, meaning that they are used for informative and educational activities. Once again, the patient is informed, but has little input in this information.

There has also been an increase in the channels available for participation through the creation of bodies such as the Participation and Administration Board of Castile-La Mancha. In more general terms, the Patient Forum, created in 2004, still appeals for greater implication of the patient –and implicitly of their families and users of services– in the health system’s decision-making process.

As table 62 shows, nearly all of the autonomous communities have an ombudsman who defends the rights of patients. Despite being a positive element, another study will have to analyse whether the role played actively encourages real participation by the affected community.

The effort to ensure participation can be seen in the staging of debates where users and patients and their associations can advise, determine priorities and discuss the problems that affect them, although there is no guarantee that they will be taken into consideration.

Aragon has seen the organization of discussion forums involving professionals, managers, unions, users and associations to analyse questions that affect users in order to improve participation in the new Directorate General of Patient Services. The Participation Forum and the Virtual Forum of the Autonomous Community of Castile-La Mancha have also been created.

These new measures are still no more than consultation bodies, and no more information has been obtained on their operation, so it cannot be seen whether the results of these forums modified the original plans.

The formal procedures of systems for complaints, criticisms and suggestions are another mechanism for participation which most of the communities strive to improve. The collection and analysis of the data obtained should serve to gather information on the quality of the health service, but also as an indicator of the areas and aspects requiring improvement.

Other community participation measures in 2007 –individual and collective– to overcome the traditional model of consultation and advice, and to obtain greater access to the making of decisions were: The first Participation Conference in Aragon, where focus groups got the principal representatives of the participation units together (implying indirect participation) to guide the strategies and the work of the new Directorate General of Patient Service mentioned previously. Also important are the actions carried out in Castile-La Mancha to reach co-participation of the

public in the creation of new organs and in the annual budget of the health department (through the creation and intervention of working groups made up of the representatives of citizens' and patients' groups).

The advances that most of the autonomous communities have made by including and regulating mechanisms such as the free choice of doctor, the right to a second opinion, advanced directives and last wishes should be noted, as they allow the citizen to be responsible for his/her health beyond the stage of simply receiving information.

To sum up, participation is a legitimate right, but also a “vital necessity for the system itself⁷²” the improvement of which is bound up with the optimisation of the available resources.

Over the years, it has been observed that the greater implication of the patient in the participation process has contributed to improving the quality of healthcare⁷³.

It is therefore important to bear in mind the patient's perspective (and by extension, the user's) in the taking of decisions and the creation of measures to improve service.

In today's health system, the patient is no longer a mere receiver of information who delegates his trust in the qualified personnel, but an active subject aware of his/her actions. This proactive attitude has modified the traditional relationship between doctor and patient towards a more equal footing where the latter takes responsibility for his/her health.

The current model of regulated participation is still broadly informative, offering consultation and advice, although several communities are taking steps to reach a higher level of involvement for users, patients and organizations that represent them in the planning, operation and evaluation of services.

Given that the quality of information and education is closely linked to the real active participation of the population in all areas of the health sector, the joint responsibility generated is shared among professionals, users and patient for the efficiency of healthcare – the result of combining scientific and technical know-how on one side, with experiences and values

72 See the article by Sánchez Legrán, F., president of the Federation of Consumer Associations of Andalusia (FACUA), *La mejora de la atención primaria y la participación de los usuarios* (The improvement of primary care and user participation). *Medicina de Familia (And)*, vol 1, n.º1, June 2000.

73 See Astrid Lindström. *Implicación y coparticipación del ciudadano en las políticas sectoriales: el caso de la salud y los servicios sanitarios* (Involvement and co-participation of the citizen in the decisions of sectorial policies: the case of health and health services). Fundación Salud, Innovación y Sociedad, 2007. Working document number 31. Available at: www.fundsis.org/docs_act/109_Documento-de-trabajo-31.pdf

on the other⁷⁴. The need to evaluate the subjective experience, that is, the expectations, priorities and degree of satisfaction with the healthcare received, is assuming greater importance.

74 It is the sum of *effectiveness and affectivity*, which Astrid Lindström refers to in *Implicación y coparticipación del ciudadano en las decisiones de políticas sectoriales: el caso de la salud y los servicios sanitarios* (Involvement and co-participation of the citizen in the decisions of sectorial policies: the case of health and health services). Working document number 31, Fundación Salud, Innovación y Sociedad, 2007.