

Participation

Public participation often has its roots in the legitimate desire to promote and defend the rights and the individual autonomy of members of the public, both healthy and ill, although they are two different concepts. The Act 41/2002 regulating patient autonomy and the rights and obligations regarding information and clinical documentation establishes some of these rights.

The participation issue always raises the additional issues of authority and legitimacy. For this reason, the need for the greatest possible transparency on the part of the administration and the associations and groups, in declaring their interests and in dealing with any conflict of interest, and in the legitimacy of the mechanisms for resolving them, is an absolutely indispensable requirement.

As regards the participation and information sent by the autonomous communities for this report, the analysis looks into the following areas: progress in the *Development of Act 41/2002 regulating patient autonomy and the rights and obligations regarding information and clinical documentation*, the existence or not of a figure or institution to defend the rights of patients, recognition of these rights (freedom of choice, second opinions, information, etc.), patients' associations and subsidies before going on to study the health councils and the committees for public participation.

To make a comparative analysis, Arnstein's model of the ladder of citizen participation is used (fig. 15).

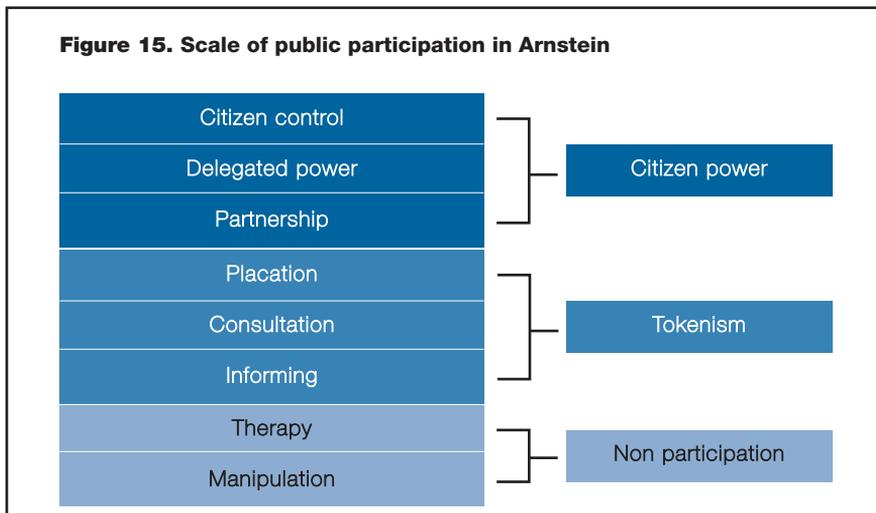


Table XVI: Participation. Number of Autonomous Communities with legislation covering each subject, 2006

	Yes	No	In process	No answer	Total
Free choice of doctor	12	2	1	1	16
Second opinion	11	2	2	1	16
Access to clinical history	12	1	1	2	16
Informed consent	14	1	1		16
Prior instructions/last wishes	13		2	1	16
Guide or service menu	13			3	16
Information on the National Health System	9			7	16
Guarantees for disabled patients with special needs for receiving information	6	1		9	16

Created by the Observatory of the National Health System.

Created on the data from the 16 Autonomous Communities that responded.

In this section, each community has specified whether it has adopted the legislation which regulates the following areas (table XVI): free choice of doctor, access to a second opinion, access to clinical history, informed consent, existence of procedure to establish advanced directives/last wishes, a guide or service charter, information about the National Health System and guarantees for patients with special needs for information associated with a handicap.

If the existence or absence of a figure or institution to defend the rights of patients is analysed, it will be seen that 12 communities have indicated that a body or institutional figure exists.

As in the previous section, the results in this area are satisfactory, although there is a margin for error.

The existence of a figure to defend patients rights also represents a step higher on the ladder of citizen participation in the sense that it authorises the voice of the patient to be heard, affirming the right to participate legally as a patient/client of the health system. This recognition should be seen as an important step forwards in terms of the patient's capacity for negotiating and represents an advance that confers a significant degree of power on the citizen.

The remaining issues refer to the recognition of rights (freedom of choice, second opinion, information, etc.) If the analogy of Arnstein's ladder is applied, this range of issues can be associated with levels of symbolic participation on the ladders of *informing*, *consultation* and *placation* they do not affect the participation in policy creation, but the guarantee of application of those that already exist.

Table XVII: Participation. Autonomous Communities and subsidies for patients' associations, 2006

Autonomous community	Yes	No	No answer	Number of associations	Total quantity (€)
Andalusia	x			157	522,172.34
Aragon	x			46	504,895.00
Asturias	x			60	70,000.00
Balearic Islands	x			6	50,000.00
Canary Islands			x		
Cantabria			x		
Castile and León		x			
Castile-La Mancha	x			141	1,591,700.00
Catalonia	x			167	4,122,432.68
Valencian Community	x			138	870,307.79
Extremadura			x		
Galicia*	x			95	10,372,462.00
Madrid			x		
Murcia	x			19	129,526.91
Navarre			x		
Basque Country	x			78	587,000.00
Rioja	x			12	710,659.21
Ingesa (Ceuta y Melilla)		x			
TOTAL	11	2	5	919	19,531,155.93

Created by the Observatory of the National Health System from data provided by the Autonomous Communities.

*Galicia is the only autonomous community which has sent the data divided according to the distribution of resources among different types of subsidised associations.

Patients' associations are among the most commonly used ways of increasing public participation. Table XVII has a summary of the results of the analysis of subsidies awarded by the Autonomous Communities to these organizations.

However, these subsidies are not necessarily used to support programmes which increase the possibilities available to patients' associations for taking part in the planning process or the taking of decisions regarding the health services which affect them. In most of these cases, they are for extensions of health services for treating illnesses, or programmes to combat possible public health risks. They therefore form part of Arnstein's ladders of *information and therapy*. The impact of subsidies on the promotion of participation is greater when they are directed towards activities that create more opportunities for specific organizations to have more say in the creation of policy and the planning of services which affect them, and which allow their delegates to attend the relevant board of health meetings and other activities. In other words, in cases where the subsidies expand the capacity of *association*,

delegation of power and control by the citizen of these associations, corresponding to the last three of Arnstein's ladders.

The Autonomous Communities that have mentioned their advances in the area of public participation are employing an interesting array of mechanisms and instruments that cover a broad spectrum, ranging from systems for complaints and suggestions using new technologies to the participation in the boards of health and even in the committees for public participation.

The most widely used mechanism of institutional participation is the board of health. It has been used in most of the communities, and seems to operate also at the area and local level¹¹⁴.

The Autonomous Communities are at different stages in the constitution of their respective boards of health. In some cases, the board is only mentioned as existing at the regional level, while others have set up as many as 105 local boards.

When it comes to describing the activities of the boards of health, many communities echo descriptions such as these: "the presentation of the report..., the explanation and discussion of the budget guidelines..., subjects of interest in health policy were brought up and debated..., the Board of Health has the responsibility of advising on the creation of health policy..., an advisory body..., etc." These descriptions clearly indicate the type of activity performed and classify them, in accordance with current legislation, on the ladders of *consultation* and *appeasement*, on Arnstein's ladder.

Besides the regional boards of health, some communities also have committees which are more specialised in certain areas, and which are consulted on a variety of topics: immunization, heart disease, tobacco addiction, mental health care, dementia and Alzheimer's disease, the public health system, diabetes and the patients' ombudsman, etc.

Besides these bodies, the Autonomous Communities have set up a number of instruments and mechanisms which are unique and worth examining. Castile-La Mancha has introduced several measures to enable "citizens to have increased access to information and play a more active role in decision-making": These measures include qualitative studies with key health agents, a working document which analyses the structure and functions of the organizations of public participation, a number of forums where the extension of these organizations is debated and reviewed, and the elaboration of a green paper for the extension of these organizations of participation in one of their fields of health care. It is emphasised that all these activities share "the goal of going beyond the traditional model of

114 Note that not all the Autonomous Communities use the same terms in areas ranking below regional level.

advice and consultation, making a greater degree of participation in health management possible”.

Other initiatives which deserve attention in this respect include the committees of public participation and the training programme being undertaken in Galicia, the text of which says that “A two-phase learning process is needed to make participation more effective: the administration must relinquish power, and the citizens must accept responsibility”.

The introduction in Rioja of the figure of a coordinator of public participation and patient services has a similar aim and seeks to increase the participation of the public.

