



# BARCELONA DECLARATION ON PATIENT ASSOCIATIONS

2003

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## **I. INTRODUCTION.**

On May 20 - 21, 2003, a meeting was held in Barcelona with the participation of health professionals and representatives from patient organizations and associations and users from all over Spain. The objective of the meeting was to obtain information on vision and experiences from patients or those representing them on six subjects of interest for which preparation work had been done. The organization and presentation of the information obtained forms the so-called **Barcelona Declaration on Patient Associations**, which is summarized as the **Ten Commandments for Patients**.

## **II. METHOD.**

The two days of the meeting were organized by the Fundació Biblioteca Josep Laporte with the independent sponsorship of Laboratorios MSD España and the support of Academia de Ciències Mèdiques de Catalunya i de Balears, Asociación Española Contra el Cáncer, Federación de Diabéticos Españoles, Liga Reumatológica Española, Sociedad Española de Atención al Usuario de la Sanidad and Universitat Autònoma de Barcelona. Berbés Asociados, together with Fundació Universitat Autònoma de Barcelona, was in charge of managing the logistical aspects. The meetings were held at the modernist building of Casa de Convalescència and were organized in three sections. The first section, apart from introducing the event, consisted of an opening conference by the Honorable Counsellor of the Department of Health and Social Security of Catalunya, Mr. Xavier Pomés, which was accompanied by three conferences that served as a basis for later discussion:

1.- His Most Excellent Mr. D. Lluís Bohigas, Director General of Health Planning, Information Systems and Benefits of the Ministry of Health and Consumption, introduced the elements that determine the participation of patients in the new Cohesion and Quality Law.

2.- Dr. Xavier Badia gave us the results of a study that indicated the perspective of users on information regarding medications in the EU and Spain.

3.- D. Giovanni Moro introduced us to the participating movements of citizens in the defence of patients' rights giving the example of Italy's experience.

After these three presentations, the second section of the meetings started, consisting of the two-day presentation of a series of seminars that were organized around a report that served as a basis for the discussion groups, later giving rise to the Barcelona Declaration. Each of the reports and associated discussion groups were presented and led by professionals who were specialists in the matter.

The first day contemplated the following Seminars:

- A) The patients' information needs.**
- B) Participation of patients in clinical decision-making.**
- C) Doctor-patient communication and relationship.**

The second day contemplated the following Seminars, reports and discussion groups:

- D) The patient's accessibility to health care.**
- E) Participation of patients in health policies.**
- F) Patients' rights.**

The discussion groups followed a semi-structured script that was to promote a diverse and singular participation of the groups of patients on the specific subject of the Seminar. Each representative had the opportunity to participate in two groups during the meetings. Finally, during the third section of the program, the patient organizations tackled the issue of the suitability of establishing an organizational framework in Spain that would transversally represent the joint interests of such organizations.

The 6 areas chosen for the Seminars came from the results of the international project, the Patient of the Future, presented in November, 2002 in Brussels whose results were presented, in book form, this June, 2003, in Brussels.

### **III. MAIN CONCLUSIONS.**

#### **Seminar A:**

#### **Information needs.**

**Leader: Albert J. Jovell – Reporter: Enric Pineda**

Those participating in this Seminar came to the following conclusions:

#### **1) There is an information need that meets these characteristics:**

- a. Provided by professionals, mainly doctors.
- b. That is comprehensible for patients (avoiding technical terms that misinform).
- c. Adapted to the patient's needs and his/her ability to take on the consequences thereof.
- d. Within a sequential provision model (to provide information according to the prognosis and level of understanding of the patient).
- e. To prevent the information from causing more harm than good.
- f. That gives a suitably informed prognosis and allows patients to be aware of the risks associated with the disease.
- g. That is of good quality and supported by scientific evidence and the best clinical judgment.
- h. That includes available knowledge on the advantages and risks of new diagnostic tests and treatments.

#### **2) The following risks must be anticipated:**

- a. The risk of patients not requesting information due to the fear of branding associated with the disease, which in some cases may lead to denial of the disease itself and his/her surroundings by the patient, or negative and discriminatory labelling.
- b. The risks associated with following inappropriate itineraries of information, which may lead to unsuitable treatment, like for example agreeing to non-scientifically supported therapies under duress.

c. The risk of excluding the following groups from access to health information of contrasting quality:

- Inhabitants from rural areas.
- Relatives and/or carers of the sick that act as health agents for the patient.
- Immigrants.
- Those affected by rare or not very prevalent diseases.

**3) Information must be vindicated as a normal fact in everyday society.**

**4) The diverse roles of the informer associated with health professionals and respect for the plurality of different information sources or agents are defined:**

- a. The specialist is the centre of information and coordinator thereof.
- b. The primary care doctor must coordinate information regarding the comprehensive care of patients.
- c. Patient associations and relatives are a key element in the information, support and help chain.
- d. Nursing should be specialized in developing informational skills towards patients and their relatives.
- e. Pharmacists must provide information, whenever appropriate, on the possible potential problems related to using the drugs, especially the risks associated with pharmacological interactions, inappropriate compliance and side effects.
- f. Public administrations have to provide all information that may allow comprehensive care for patients, including aspects related to socio-health care, integration into the labour market and psychological support.
- g. The media is responsible for contrasting the truthfulness and quality of the information they publish or broadcast, preventing the creation of false expectations or generating situations of social alarm. Likewise, they should become more professional by specializing information and communications on health issues.
- h. Information provided on the Internet should be accredited according to quality criteria based on ethical codes.
- i. Information produced by the pharmaceutical industries is contemplated in a different way, with there being points in favour of and against its free publication.

**5) Quality health information has to comply with these basic criteria:**

- 1) Truthfulness.
- 2) Based on scientific evidence.
- 3) Transparent information source (explicit identification of who produces it and how it is produced).
- 4) Clarity.
- 5) Fast, easy and universal access.
- 6) Adapted to the patient's understanding capacity and the evolution of the disease.
- 7) External accreditation.

**Seminar B:**

**Participation of patients in clinical decision-making.**

**Leader: Ricard Meneu – Reporter: Eulalia Hernández**

Those participating in this Seminar came to the following conclusions:

- 1) The criterion that must prevail in a health-related decision is the doctor based on:**
  - a.- Scientific knowledge.
  - b.- The patient's quality of life.
  - c.- Respect for the patient's autonomy (freedom to make decisions).
  
- 2) The patients' autonomy or self-determination capacity goes from the priority choice or rejection of the indicated therapy to the expression of preferences and values with regards to the probable evolution of the disease that helps guide the professional's decision.**
  
- 3) The participation of patients in decision-making is more justified if:**
  - a.- There are different duly informed treatment alternatives or options from which to choose.
  - b.- They can understand the nature of the disease and therefore express their values and preferences once they have been adequately informed on which clinical management option to choose.

c.- The foreseeable results of the different available therapies are anticipated.

**4) The participation of patients in clinical decision-making faces concrete obstacles:**

a.- Limited communication time between professionals and patients.

b.- Limited understanding training for patients.

c.- Little communication training for doctors at both an undergraduate and continued medical training level.

d.- Short duration of the doctor's visit.

e.- Limited accessibility to quality information sources on health issues.

f.- Patients affected by diseases that imply cognitive deterioration that makes it more difficult for them to understand and make decisions.

**5) Measures are proposed to enable greater patient participation, including:**

a.- Greater collaboration between professionals.

b.- Improved dialog capacity with doctors in aspects related to communication and information.

c.- Improved coordination between patient associations and scientific societies in the preparation of information materials and instruments that help and support the promotion of shared decision-making.

d.- To avoid tendentious information or information that generates social alarm.

e.- To develop specific strategies to attend to cases where the disease is associated with an important psychological impact, as in the case of cancer, when there is a high level of cognitive deterioration or when the patients have a limited understanding capacity.

**Seminar C:**

**Doctor-patient communication and relationship.**

**Leader: Maria D. Navarro – Reporter: Laura Fernández**

Those participating in this Seminar came to the following conclusions:

- 1) A better alternative to the term PATIENT should be found that reflects the establishment of a more symmetrical relationship model between doctors and patients.**
  
- 2) The doctor-patient relationship is very important and should be based on the following criteria:**
  - a.- Trust must be mutual.
  - b.- The doctor must have more time to attend to the patient.
  - c.- The doctor must listen to patients more actively.
  - d.- It must be oriented to meet the patients' needs.
  
- 3) The aspects that should be improved in the doctor-patient relationship are:**
  - a.- For the doctor to listen to the patient more actively.
  - b.- A personal relationship based on mutual trust and respect.
  - c.- Human values must be contemplated and incorporated into this relationship.
  - d.- The quality of the relationship should be measured and contemplated in the continuous improvement processes of the quality of care.
  - f.- To improve professional training in terms of the aptitude and attitude of professionals, which guarantees good care in personal and human aspects.
  - g.- To increase the time dedicated to the patient.
  - h.- To improve accessibility and punctuality.
  - i.- To reduce patient waiting times.
  
- 4) With regards to the patient's relationship with the doctor in primary/specialized care, the following are valued:**
  - a.- There may be a differentiation in content and context but not in the treatment received by the patients.
  - b.- A better coordination between the different care levels would be necessary.
  
- 5) Specific preparation and training is required by the doctor in the case of an informed and autonomous patient who shall wish to participate more actively in the decision-making processes that affect his/her health.**

**6) Improvement of the doctor-patient relationship and communication may be promoted if society were to follow these strategies:**

- a.- Development of an ethical code to be posted in primary care centres and hospitals.
- b.- To encourage community participation to the maximum through patient associations and/or voluntary service.
- c.- To promote mechanisms that involve citizens in the definition of health policies.
- d.- To include improved doctor-patient communication strategies in the health plans of each CCAA in a compulsory manner.
- e.- To promote organizational structures that encourage the development of greater trust between doctors and patients.

**Seminar D:**

**The patient's accessibility to health care.**

**Leader: Francisco Cárceles – Reporter: Enric Pineda**

Those participating in this Seminar came to the following conclusions:

**1) Limited access to health services is identified as shown in the following list:**

- a.- Existence of waiting lists.
- b.- Lack of or restricted access to certain benefits, including high technology and new drugs.
- c.- Limited portfolio of services in rural and/or outlying areas.
- d.- Access of immigrant populations.
- e.- Access to knowledge and relevant information.
- f.- Insufficient economic coverage in certain pathologies, especially for the hidden costs associated with the disease and the fact of being sick.

**2) The following are seen as future limitations in access to health services:**

- a.- Economic allotment to reduced health care with a lower ratio of the available budget compared to the needs to be met.

- b.- The aging of the population leads to new needs.
- 3) **Public Administrations should determine, on a joint basis with citizens, which priorities are to be financed, through active participation mechanisms.**
- 4) **The benefits from increasing patient participation in political health decisions are:**
- a.- Better intrinsic knowledge of the pathology.
  - b.- An improved quality and degree of service obtained.
  - c.- Reduction in unnecessary costs.
  - d.- Implementation of needs expressed by the patients in public policies.
- 5) **The drawbacks from increasing patient participation in political health decisions are:**
- a.- A risk of personalized health policies.
  - b.- Lobby or pressure group effect of certain patient associations compared to other less organized associations.
- 6) **With regards to the co-payment of health care by patients, it is considered that this may be paid when adjusted to the patient's income level and does not limit certain people's access to health benefits that are considered essential.**

## **Seminar E:**

### **Participation of patients in health policies.**

**Leader: Ricard Tresserras – Reporter: Eulalia Hernández**

Those participating in this Seminar came to the following conclusions:

- 1) **The circumstances that limit patient participation in the definition of public policies must be thought about. For this, the following are suggested:**

- a.- To stop seeing administration as an enemy.
- b.- For administration to stop seeing the associations as enemies.
- c.- To consider the associations as social agents whose collaboration is necessary.

**2) The following proposals are made to improve the participation of citizens in public policies:**

- a.- To promote the formation of patient associations and create federations between them.
- b. – To create an association participation forum.
- c.- For the Social Health Council to incorporate representatives of the federations and for these to be rotational.
- d.- To take the points of view of the patient association forum into account in the application of the Cohesion and Quality Law and the Patient's Autonomy Law.
- e.- For the Law to explicitly specify the number of representatives from the associations and their role in the development of the Law.
- f.- To increase training (of both doctors and patients) to encourage their awareness and participation in the definition of public policies.
- g.- To find mechanisms that favour the participation of patients who do not form part of specific associations.

**3) With regards to the recently approved Cohesion and Quality Law, the following details are expressed:**

- a.- Patient associations have not been taken into account in drawing up the Law.
- b.- Aspects on how to guarantee participation in the health system are mentioned but mechanisms to be able to participate are not developed.
- c.- There is an unbalanced representation in the Social Health Council.
- d.- The Law should include psychosocial aspects related to individual and social well-being in its content.

**Seminar F:**

**Patients' rights.**

**Leader: Margarita Retuerto – Reporter: Laura Fernández**

Those participating in this Seminar came to the following conclusions:

- 1) Most patients do not know their basic rights as patients.**
- 2) A portfolio of basic rights for patients should include the following rights:**
  - a.- Fast care to resolve health problems.
  - b.- Access to the necessary tests.
  - c.- A guarantee to receive the best available treatment.
  - d.- Free choice of primary care doctor and to change specialist.
  - e.- Access to all written reports that form part of the patient's medical records.
  - f.- Information on diagnosis, risks, prevention and available treatments.
  - g.- Free medical treatment for chronic diseases.
  - h.- A right to information on the organization and functioning of the health system.
  - i.- Informed consent in a clear and comprehensible language.
  - j.- To be treated appropriately and in a human manner.
  - k.- Access to surgical treatment within a reasonable time.
  - l.- Access to a second medical opinion.
  - m.- Existence of documents showing anticipated desires.
  - n.- Confidentiality / privacy of the medical act.
  - o.- Right to not be informed if requested.
- 2) Aspects that should be improved with regards to patients' rights are:**
  - a.- Development of a specific bill of basic rights.
  - b.- Educational programs.
  - c.- Identification of the health staff.
  - d.- To make doctors and professionals aware of the knowledge and compliance with rights issues.
  - e.- To include the degree of compliance with all rights as part of the care quality evaluation.
  - f.- To improve the information given to the patient and guarantee use of a more understandable language on the medical report.
  - g.- Publication and propagation of the bills of rights and duties to both professionals and patients.

- h.- Welcome guides and services to orient and inform patients, as a comprehensive part of specific services, and of a multidisciplinary type.
- i.- To enable accessibility to information on patients' rights upon being admitted to the centre.
- j.- Continuous suitable information and psychological support to patients over the course of their disease.
- k.- To clarify terminology to patients regarding care devices and health technology: care centre / health centre.
- l.- To provide specialized care for diseases multi-systemic, creating care models that serve as reference and enabling coordination between care devices-services.

**3) To correctly include a patients' rights policy in the National Health System, the following actions are proposed:**

A) Short-term:

- a.- Campaign to circulate patients' rights and the guaranteed evaluation of their compliance.
- b.- Improved complaint instruments.
- c.- Creation of the patient's defence figures in the CCAA.
- d.- To use the complaints as a measure for evaluating and accrediting the centre's quality of care.

B) Medium-term:

- a.- To evaluate the quality of care in terms of the level of attention given to patients' rights.
- b.- Urgent development of the Observatory (included in the Cohesion and Quality Law).

C) Long-term:

- a.- Integration of patients' rights in European networks.
- b.- Development and adoption of the European model based on the bill of fundamental rights for patients (Bill of Rights of Nice).

**4) Information on patients' rights to patients is the responsibility of:**

- a.- The Health Administration: at a central, autonomous and local level.
- b.- The doctor responsible for coordinating the patient's medical care.
- c.- Patient organizations and associations.
- d.- Specialized patient or user care units or services.
- e.- Well-structured and informed media (based on quality criteria and with respect for the subjects at hand).

**5) The guaranteed implementation of patients' rights must be backed by:**

A) Internal Level.

- The health professionals themselves.
- Specific patient care units (claims and complaints) that act efficiently in the health centres.
- Inspection or accreditation services.

B) External Level.

- Patient associations.
- Patient's defence counsel.
- Judges.

## **PARTICIPATING PATIENT ASSOCIATIONS**

- ACCIO PSORIASIS.
- AGRUPACIÓN JOVEN ESPAÑOLA REUMÁTICA.
- ALCER BARCELONA.
- ALIANZA PARA LA DEPRESIÓN.
- ASOCIACIÓN ANDALUZA PARA LA REHABILITACIÓN E INTEGRACIÓN DEL DAÑO CEREBRAL ADQUIRIDO.
- ASOCIACIÓN ASMATOLOGICA CATALANA.
- ASOCIACIÓN DE ASMÁTICOS MADRILEÑOS.
- ASOCIACIÓN ESPAÑOLA CONTRA LA OSTEOPOROSIS.
- ASOCIACIÓN DE DIABÉTICOS.
- ASOCIACIÓN DE ENFERMOS DEL CORAZON – HOSPITAL 12 DE OCTUBRE.
- ASOCIACIÓN PARA LA LUCHA CONTRA LAS ENFERMEDADES DEL RIÑON.
- ASOCIACIÓN DE ESCLEROSIS TUBEROSA.
- ASOCIACIÓN DE FAMILIAS Y MUJERES DEL MEDIO RURAL.
- ASOCIACIÓN DE PACIENTES CORONARIOS.
- ASOCIACIÓN ESPAÑOLA CONTRA EL CÁNCER.
- ASOCIACIÓN ESPAÑOLA CONTRA LAS ENFERMEDADES NEUROMUSCULARES.
- ASOCIACIÓN ESPAÑOLA DE ESCLEROSIS LATERAL AMIOTRÓFICA.
- ASOCIACIÓN AFECTADOS DE UN ICTUS DE ARAGON
- ASOCIACIÓN MADRILEÑA DE PACIENTES CON ARTRIRIS REUMATOIDE.
- ASOCIACIÓN PARA LA LUCHA CONTRA LAS ENFERMEDADES DEL RIÑÓN.
- ASSOCIACIÓ BENESTAR I DESARROLLO.
- ASSOCIACIÓ CATALANA DE FIBROSIS QUÍSTICA.
- ASSOCIACIÓ CATALANA PER AL PARKINSON.
- ASSOCIACIÓ DE AFECTADOS CRÓNICOS DE VÍAS RESPIRATORIAS “A TOT PULMÓ”.
- ASSOCIACIÓ DE DIABETICS DE CATALUNYA.
- ASSOCIACIÓ DE MALTAS DE CROHN I COLITIS ULCEROSA DE CATALUNYA.
- COALICIÓN ESPAÑOLA DE ENFERMOS CRÓNICOS.

- CONFEDERACIÓN ESPAÑOLA DE AGRUPACIONES FAMILIARES Y ENFERMOS MENTALES.
- CONFEDERACIÓN ESPAÑOLA DE FAMILIARES DE ENFERMOS DE ALZHEIMER.
- FEDERACIÓN CATALANA DE ALZHEIMER.
- FEDERACIÓN DE ASOCIACIONES DE CELIACOS DE ESPAÑA.
- FEDERACIÓN ESPAÑOLA DE ENFERMEDADES RARAS.
- FEDERACION ESPAÑOLA DE PARKINSON.
- FEDERACIÓ ESPAÑOLA DE LUCHA CONTRA LA ESCLEROSIS MÚLTIPLE.
- FUNDACIÓN ALZHEIMER ESPAÑA.
- FUNDACIÓN ANTI-SIDA ESPAÑA.
- FUNDACIÓN DE HIPERCOLESTEROLEMIA FAMILIAR.
- FUNDACIÓN ESPAÑOLA DE FIBROSIS QUISTICA.
- LIGA REUMATOLÓGICA ANDALUZA.
- LLIGA REUMATOLÓGICA CATALANA.
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