



**THE FUTURE PATIENT PROJECT**

**International Project**

**FOCUS GROUP RESEARCH IN SPAIN**

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## 1. OBJECTIVES

The research objectives were:

- To determine how today's health care is perceived.
- To determine what changes are deemed good or bad for health care consumers in the future.
- The patients' role in health care.
- The role of other health care professionals.

## 2. METHODS

### Sample

The research was carried out by means of 6 focus groups with the following characteristics:

<b>Group</b>	<b>Group participants</b>	<b>City</b>	<b>Age</b>
1	Population	Madrid	18-30
2	Population	Barcelona	30-50
3	Chronic diseased	Madrid	50-65
4	Chronic diseased	Barcelona	50-65
5	Chronic diseased	Alicante	30-50
6	Population	Rural Castilla	18-30

Groups consisted of 8-9 persons, of both sexes (50%), belonging to middle, middle-low, and middle-high social classes.

In the rural group selected, persons from the following villages of the Madrid Community were included: Collado Mediano, Soto del Real, Galapagar, Brunete, El Álamo, and Villa del Prado.

Those persons enrolled were selected by screening filters.

### 3. RESULTS

The research data are summarised below, according to the objectives set.

#### 3.1 CURRENT HEALTH CARE EXPERIENCE

The way the patients in the focus groups perceived the health service depended mainly on the type of care received, and on the so called “chance factor”:

- ❖ **The type of** care included primary care, specialist and surgical care, and emergencies.
- ❖ **The “chance factor”** referred to the different attitude of the professionals’ in their treatment of the patients, interpersonal and communication skills, the degree of clinical expertise, and to the general management of health services

The latter variable included the delay in obtaining an appointment with a specialist, the waiting times in primary and emergency care and the loss of medical records.

- ❖ **Perception of public health according to the type of service given.**

#### General Practitioners

Regarding primary care physicians, or “general practitioners”, two basic problems were mentioned:

**Waiting times:** From the patients’ point of view the main issue is the heavy demand upon doctors although this seemed to be less of a problem in the rural areas.

*" I go to the general practitioner and he has 35 to 40 patients..."*

*"I have to wait 1 hour to be seen by the doctor"*

*"They do not answer calls for a medical appointment and you have to go to the health centre and wait one hour to get an appointment"*

(Madrid, Chronic diseased - 50-65 years old)

*"It discourages me a lot to request a medical appointment"*

*"If I am going to visit a doctor because I have flu by the time I get an appointment I no longer have the flu".*

(Barcelona, General population - 30-50 years old)

**Doctor-patient relationship.** This heavy demand is believed to adversely affect the relationship between doctor and patient which is thought to be impersonal and time-restricted. Patients are not given adequate information about their condition and the treatments prescribed. They are not examined, diagnostic tests are not requested, routine prescription is the rule and there is a resistance to specialist referrals.

*"If I go with a problem, doctors pay no attention to it, irrespective of the type of problem. Maybe, they see me as a young person or they feel that I am worrying about things unnecessarily.*

(Madrid, General population - 18-30 years old)

*"For me the experience is always negative. You go, they see you and check your health faster. I know there are queues, but they need a quick solution because demand is increasing"*

(Barcelona, General population - 30-50 years old)

*"When you go to visit a doctor, they always prescribe you a drug without a lab test, and any other test...."*

*"The physician-patient relationship is inappropriate.....they have half an hour to see 30 patients and, thus, they see 30 patients in half an hour"*

(Alicante, Chronic diseased - 30-50 years old)

### **To summarise:**

- Lack of attention to the person or interpersonal care.
- Routine, superficial care.
- Lack of information on the patient's situation .
- Prescriptions as substitutes for personal care.
- Non -specific prescriptions.

These perceptions changed when the GP was the regular doctor or source of care.

*"He/she knows you."*

*"He/she knows how to treat you personally".*

*"He/she counsels you".*

### **Specialists and surgical services:**

Patients' experience of specialist and surgical care was defined by long waiting times, and good professional competence.

*"I had endometrial cancer and in the public system I would have had to wait four months to be treated. I did not want to wait so long and so I went through the private system and in four days I underwent surgery"*

*"For elective surgery you can wait all your life: For me it is urgent, but I do not know if it is for the doctors...."*

(Madrid . Chronic diseased - 50-65 years old)

*"I did not have to travel long distances to get care. The health centre was near home. The interpersonal care was not bad. I have an allergy, I requested an appointment and I saw the doctor who has been caring for me all my life. I had the lab tests in the Alcorcon hospital. I did not feel I was treated impersonally"*

(Rural group, General population - 18-30 years old)

### **Long waiting times:**

In general terms, this was the most consistent complaint about specialist services, particularly when the condition involved some degree of pain.

Focus group participants realised that what constituted an emergency differed between doctors and patients.

*"...My mother went to the oculist and got the appointment for February"*

(Rural group, General population - 18-30 years old)

*"If you want to see the gynaecologist, they don't have an appointment in the next four months"*

(Barcelona, Chronic diseased - 50-65 years old"

### **Professional competence:**

Despite the fact that the health care system was regarded as inefficient, both specialists and surgeons were generally considered to be highly qualified professionals.

The occasional mention of diagnostic or similar problems did not harm the essentially positive image of these professionals.

*"I think there are good professionals in the public health care system but there is a lack of manpower and good organization. The resources go first to the public system and, after that, to the private system. Thus, the public system has the best resources and professionals"*

(Madrid, General population - 18-30 years old)

*"My experience was positive. They caught me in time. The cardiologist gave me an ECG (electric cardiogram) and a stroke was detected. Thanks to his competence"*

(Madrid, Chronic diseased - 50-65 years old)

*"In my case they had difficulties deciding on a diagnosis. There were several opinions among doctors and I was going from one appointment to another for six months. And I had terrible pains!"*

(Madrid, Chronic diseased - 50-65 years old)

### **Emergency services:**

Emergency services were considered to be

**The most efficient way into the system** It was thought that anyone with a clinical condition has a better chance of good, fast care if they are admitted to an emergency ward.

*"Specialists see you for a few minutes..... Until you go down in the middle of the street and the SAMUR (mobile emergency care) take you to an emergency room... then you get the scanner.. then they do everything for you....!"*

(Madrid, Chronic diseased - 50-65 years old)

### **Long waiting times:**

This was a common complaint in situations that were seen as real emergencies.

*"I, for example, can be in an emergency room in the public system and I can be in the waiting room for 5 hours, dying, vomiting on the floor, until I'm seen"*

(Alicante, Chronic diseased - 30-50 years old)

- **FUTURE EXPECTATIONS**

Patients expect future care to be more personalised. They consistently expressed the desire for a personal relationship with their practitioner, in which the mutual exchange of information takes place. Patients want doctors to provide regular care in each neighbourhood and believe mutual trust is more important than a prompt consultation with an unknown doctor. For serious clinical conditions, where there is no treatment available locally, focus group participants would like the possibility of consulting the best specialists elsewhere.

### **Possible scenarios.**

**Telephone**  
**Access to information on specialized care**  
**Smart cards**  
**Telemedicine**



## Telephone

Greater use of the telephone was considered useful for “minor” consultations or for less serious diseases. It was also considered adequate for guidance on administrative issues. But for the diagnostic consultation, the telephone, like the Internet, was viewed as impersonal and prone to risks or biases.

*" A telephone consultation is better than Internet. You can talk with the person"*

*"The Internet is cold. You might go in the wrong direction"*

*"I prefer to see the doctor's face and be seen by him"*

(Chronic diseased population - Barcelona - 50-65 years old)

## Access to information on health professionals and hospitals

Having information on the performance of doctors and specialist centres, and on the expertise and quality of the experience offered, means that patients could choose to travel to the centres and doctors are rated most highly in their field.

The willingness to travel depends on the type of clinical condition, the degree of severity, and the alternative treatments available. Against this idea of global care, patients tend to prefer the more familiar and easily accessible, except for extreme life-threatening conditions.

There is an underlying need to feel safe and secure in times of illness.

*"It is good because there are always centres more specialized in a specific area. If you were burnt you could always go to the centre with more experience in treating burns instead of going to your local centre..."*

*"The problem with this approach is that some centres could become overcrowded and others empty"*

*".....it's important that health care is closer to people not the contrary.."*

(Madrid, General population - 18-30 years old)

### **Continuity of care v, fast treatment.**

The possibility of consulting any available doctor in order to be seen quickly was only considered appealing for specialist care. In general, and in line with the expectation that doctors know their patients well, focus group participants preferred to see the same doctor. Being able to get an appointment quickly was seen as a different type of benefit, not comparable to that of having a your own doctor.

Each consultation with a doctor was seen as part of a process, not an isolated fact. Continuity of care was considered important. Patients were upset when they had to start again with another doctor and preferred to wait.

*"It depends whether it's specialist care or primary care. In primary care I prefer to wait and see the same doctor. It is better than jumping from one doctor to another, even if I have to wait. My doctor knows me, knows my medical record, asks me how I am, informs me about new drugs to lower blood cholesterol..... The other doctor doesn't know me and he has to ask questions... They have changed my doctors recently and I am feeling very bad about it"*

(Madrid, Chronic diseased population - 50-65 years old)

*"If you have a good doctor, nothing in the world makes you accept a change. First of all, he knows you, and how to treat you. We are talking about the doctor you see regularly, who knows your problems, who advises you. I do think what they do (changing doctors) is not good"*

(Barcelona, General population - 30-50 years old)

*"What is clear is that if you get a doctor that you like and trust, and he provides solutions to your problems, then you are not going to change him. If you have a doctor who confronts you or doesn't treat you well, you might want to change"*

(Madrid, General Population - 18-30 years old)

## Smart cards.

There was unanimous support in the focus groups for the idea of an electronic card that could hold an individual's complete medical history. The perceived advantages were:

- Patients could carry this information with them all the time.
- Quick access to personal information by the health professional who may need it.
- Information is always available, under all circumstances: accidents, unforeseen situations, etc.
- Possibility of keeping all the information permanently updated.
- Possibility of connecting to a data bank.
- Errors, bureaucracy and loss of time are avoided.

The only perceived disadvantages were the risk of losing control over personal data and an abuse of confidential data.

*"It's perfect"*

*"It would be all faster"*

*"If you are travelling or anywhere it would be essential....if you have an emergency or whatever need.."*

(Alicante, Chronic diseased population - 30-50 years old)

*"You can go travelling, they have all the information. Allergies, operations.... All the data that might be of interest for a doctor if something happens. Prescribed drugs... all this will be there"*

(Barcelona, Chronic diseased population - 50-65 years old)

*"The negative side is that if somebody steals it and knows its content. It should be code protected. Something that guarantees privacy"*

(Rural population - 18-35 years old)

## Use of telemedicine for diagnosis and treatment.

The idea of consulting a doctor via a telephone and video-link ie telemedicine was viewed in the same way as the use of the Internet or the phone. It was considered practical for some things, including minor conditions or health-related questions, but not for those consultations that require a real diagnosis.

Once again, the main reservation was the concern that it might replace the essential personal contact between doctor and patient.

*"No, the treatment would not be personal, and if he has to check your pulse, how can he do that by phone or video?"*

*"It can be prone to error"*

*"It is like sex without contact, I want physical contact. The more contact with a doctor the better we are"*

(Alicante, Chronic diseased population - 30-50 years old)

## ● THE INFORMATION REVOLUTION

### Demand for information

The general attitude towards "wanting to know" was diverse. Some hints of differences between men and women were seen immediately in the focus groups, regardless of the age and type of patient. Thus, men seemed to be more inclined to ignore health-related topics, even those that might directly affect them .

Women seemed to be more active in the search for information, except for some isolated cases where there was a family history of cancer, or a tendency to hypochondria.

On the other hand, the rural group, and the younger age groups showed no special interest in health topics.

Patients with specific conditions expressed a range of attitudes:

- Explicit wish not to know about the disease.

- Passive acceptance of the screening or continuous surveillance
- Lack of interest in information once it is available.

In general, the type of information patients wanted was that needed to make decisions on the management of a disease:

- Direct knowledge of the diagnosis.
- Information on the progress of the disease and prognosis.
- Treatment options.
- Range of therapeutic measures.
- Indications and contraindications of prescribed therapies.

Behind patients' need for information is the wish to take greater responsibility for their own health. Significantly, the demand for information was related, almost invariably, to a specific disease. It is significant that no other general health and prevention issues were mentioned.

*"I don't want to know anything, I don't want any information, I want a fast cure"*

*"I should have regular tests every year but I by-pass them"*

*"My health needs do not need any information"*

(Rural population - 18-30 years old)

*"If I need information, I go to the doctor".*

(Madrid, Chronic diseased population - 50-65 years)

### **Information sources currently used for health topics.**

The most important information source in the opinion of all groups was the family doctor.

In addition there were other sources of information depending on specific needs. The following were noted:

- **Pharmacists:** They were mentioned as information sources in which counselling was the main element. They rank second in importance, after doctors.

- **Libraries:** Require a high level of motivation. They are used in cases of a specific, intense need.
- **Internet:** Internet searches seemed to be a must due to the great amount of information they generate. They require some degree of motivation, or at least, curiosity.
- **Health care organisations:** They were regarded as good starting points for information on health-related topics and support material on specific conditions.
- **Scientific journals:** These satisfy an interest in more obscure topics.
- **Television:** The programme *In Good Hands* was mentioned as an example of information not specifically sought after, but enticing enough to keep the audience interested.

*"I do think the best source of information is to go to the doctor and tell him what's wrong. Leave the consultation knowing what you have and then you do not need to search for information."*

(Madrid, General population - 18-30 years old)

### **Satisfaction with health information received.**

The information sources available to patients raised different expectations.

Patients in the focus groups distinguished between information received from medical institutions and that provided by other sources.

### **Satisfaction with the information received from medical institutions:**

Information provided by a general practitioner was part of a two-way process, in which the patient was particularly sensitive to the personal care given by the doctor.

When information was not part of a good communication process, it caused dissatisfaction.

*"....First what you expect is eye contact, that they hear you and, once you have explained your symptoms, he gives you satisfactory answers, prescribes you a treatment and orders regular check ups"*

*"When they give you information it should be understandable, because sometimes they begin to talk, and talk, and talk.....and you think: well, he must have thought I was beside him when he was studying medicine!..."*

(Barcelona, General population - 30-50 years old)

### **Satisfaction with other information sources:**

The other information sources mentioned were valued very differently by patients. .

#### **Pharmacists**

According to the data obtained, pharmacists were the most consistently satisfactory information source. The information received was interpreted in terms of personal care, support, and needs' satisfaction.

#### **Health care organisations and associations**

Organisations, such as Social Services, the Red Cross, organ-donation or – disability groups were highly valued for the information they provide.

#### **Other sources of information**

Other sources of information were not expected to offer anything further in the future.

- Internet searches and encyclopaedias seemed to meet the objective of the consultation: complementary information, according to a specific need.
- Magazines, television, and radio should just be seen as entertainment, of occasional curiosity value.

#### **● INTERNET**

The focus group participants saw the Internet as fast, immediate access to information. They felt it would dramatically change the information exchange between health providers and patients, but trust in its effectiveness varies depending on the type of service required. Thus, access to

information on a particular disease was valued more highly than the possibility of a “virtual” consultation with a doctor or specialist. This possibility raised both doubts and concern about errors and misinterpretation.

### **Possibility of doctor – patient consultations via the Internet:**

- Concerns about the reliability and quality of the information source.
- Need for an endorsed information source by means of accreditation.
- Perception of an immediate advantage: ease and speed in the consultation.
- Concerns that the patient may provide non-reliable data.
- Acknowledgement of the need to provide doctors with valid evidence in order to get reliable information and diagnosis.
- Mistrust and feeling of insecurity about test results, even if tests through the Internet may be possible.
- Need for the physical presence of the doctor. Direct contact is what reassures the patient.

As a way to avoid risks:

- Contact with a familiar doctor
- This doctor would know the clinical record of the patient.
- The consultation would take place with audio and video support.
- The consultation would only deal with minor illnesses.

### **Other possible uses of the Internet:**

- Booking a medical appointment.
- Choosing a specialist
- Access to information on the qualifications, specialisations and performance of practitioners
- Prescription requests

For older patients, the physical presence of the doctor was seen as essential. The main complaint was the coldness of the Internet compared to the warmer doctor-patient contact in the surgery.



*"I can check the Internet for minor conditions and non-essential questions., but if it is for a major illness I need to see a doctor face-to-face and see how he uses the technology"*

(Madrid, General population - 18-30 years old)

*"I do not think the Internet is very reliable, because you don't know who you are talking to. He can introduce himself as a doctor of something else but.... I do not see too much reliability"*

*"If doctors can commit errors in a face-to-face relationship, you can imagine what can happens with the Internet!.. Well, if you have the flu, it might work, they can prescribe you Couldina (a drug for flu) and so on, but if it is for a serious clinical condition, it's a bit more difficult"*

(Madrid, General population - 18-30 years old)

*"When my father had a heart problem, I went to a library to search for information. I also searched the Internet"*

(Rural group, General population - 18-30 years old)

- **PATIENTS' ROLE IN THE CARE OF THEIR OWN HEALTH: RIGHTS AND RESPONSIBILITIES.**

**Patients' attitudes towards the care of their own health.**

The members of the focus groups showed a range of attitudes towards taking responsibility for their own health. They were sometimes unwilling to take the most elementary measures, not just preventive steps, but also those related to their own condition.

From the information provided, two groups of attitudes were found:

- **Active attitudes:**

This group of patients took responsibility for aspects of their own healthcare:

- They visited the doctor whenever they felt ill, even with supposedly minor ailments
- They were active in their demand for information on the disease, treatments and drugs.
- They followed the drug treatments, following doctors' indications.
- They requested information for making decisions.
- They wanted to keep control over the choice of treatment alternatives.
- They took into account lifestyle recommendations.
- They had check-ups.
- They played an active and controlling role in their relationship with the doctor.

- **Passive attitude:**

This group of patients showed a lack of control over their own healthcare.

- Reluctance to visit the practitioner: *"I'll go soon"*.
- They preferred not to know: *"What will be, will be"*.
- Did not dare to request information or accepted partial and simplified medical explanations
- Did not request information on alternative treatments.
- Did not comply with the prescribed medication.
- Did not adapt their lifestyles.
- Did not have regular check-ups such as screening tests: *"they always find something"*.
- They showed a less confident attitude in their relationship with their doctor.
- They ignored the effect of certain lifestyles on disease and its prevention.

*"I would have to get a check up that would tell me: you have to do that and that and do not eat because you have a predisposition to those diseases"*

*"I am very passive. I wait until something happens"*

(Rural population - 18-30 years old)

*"--- they give me 3 or 4 pills and I take them 2 or 3 times or I do not follow the schedule. You have to take it at 4:00 A.M. and you take it at 8:00 A.M. It is the same. You don't comply with doctor's orders..."*

(Alicante, Chronic diseased population - 30-50 years old)

*"I had surgery and the doctor tried to explain the treatment to me. I did not understand anything and I told him: I trust you ....Do not tell me anything more. Prescribe me what would cure me"*

(Madrid, Chronic diseased population - 50-65 years old)

*"I disagree that we have to accept every doctor's order. It is not possible because sometimes they get it wrong. Sometimes you have to get a second opinion"*

(Madrid - General population - 18-30 years old)

### **Attitudes towards the use of genetic tests for screening diseases.**

As these tests are not widely available, focus group participants tended to adopt a more theoretical attitude to these possibilities. On the positive side, tests are preventive:

- If a predisposition to a disease were found, treatment could be offered to avoid its occurrence.
- They could extend life expectancy.

However, there was no sign that these patients would agree to take such tests.

The most common attitudes found were:

- They prefer not to know out of fear.
- They prefer not to know if they suspect predisposition to a particular disease.
- They would prefer to know to prevent illness.
- They would prefer to know to prevent the possible transmission of a disease to their children

*"...the study of chromosomes is out there..... and it helps to prevent future diseases, it is a great advance"*

*"...if doctors had this (information), that might help them to know at what age you can have the disease and, thus, they can help to avoid it"*

*"It would provide important and vital information and I do think people would live longer"*

*"... I prefer to know. It is silly (to wait for the disease to come) because is better to avoid rather than to cure"*

(Barcelona, General population - 30-50 years old)

*"It helps to know your predisposition"*

*"I prefer to ignore a predisposition to cancer...."*

*"I am going to have children...yes, I would like to know"*

*"If you told a person that he is going to have a heart attack at 30 years it might affect him .... and he might have the attack at that moment... due to psychological disturbance"*

(Rural population - 18-30 years old)

*"I do not take responsibility for considering my propensity to cancer"*

*"If you feel good, you are good, and therefore you don't take any tests."*

(Alicante - Chronic diseased population - 50-65 years old)

### **Rights and obligations of patients.**

In the consideration of their rights and obligations as patients, the participants tended to repeat the views they expressed about their relationship with doctors and public health institutions.

### **Patient Rights**

The following were noted:

**Reasonable waiting times:** *“The right to receive care within reasonable time”*

- In the context of primary care.
- Specialist care.
- Surgical care
- Emergency care

**In the doctor-patient relationship:** *“The right to be well attended.”*

- To request and receive information in understandable terms about one’s disease and alternative treatments available
- To make a decision based on the information received

**Obligations:**

Participants focused on compliance:

Regarding treatments and their follow-up:  
Regarding dosage and duration of treatments.  
Regarding diet and lifestyles.

Obligations on prevention and lifestyles were only stated in a theoretical way.

● **THE ROLE OF OTHER PROFESSIONALS HEALTH CARE.**

Apart from doctors, the patients in the focus groups also relied on pharmacists and nurses..

**Pharmacists:**

As noted before, pharmacists have an important role in healthcare. They:....

- play a complementary role to that of doctors,
- have some information doctors may not have,
- can give better drug advice than doctors,
- have the role they are supposed to,
- should not prescribe.

(Rural population views - 18-30 years)

Which implies...

- a familiar relationship,
- a close counsellor,
- they are acquainted with the family
- an advisor

(Madrid, Chronic diseased population - 50-65 years old)

- they are more trustworthy than doctors.
- the pharmacist is my friend
- gives information and advises you

(Barcelona, Chronic diseased population - 50-65 years old)

### **Perception of nurses**

The nurse's role was also clearly defined by patients .

- **They are a complement to doctors:**
  - They provide supplementary information.
- **They reassure patients:**
  - They are a familiar figure that softens the medical setting:
  - They are supportive in distressing situations. They are easier to talk to than doctors.
- **They care for patients in hospital:**
  - They are attentive and caring
  - They are in closer contact with the patient than doctors.

### **Alternative medicines.**

Alternative medicines were seldom mentioned spontaneously. Occasionally, they were seen as a valid complement to more conventional treatment. Homeopathy, acupuncture and natural medicine were mentioned.

The arguments in favour of this type of therapy were mainly based on:

- The problems that some patients had had with drug therapies.
- The supposed lower cost.

In no case was this type of treatment proposed or viewed as an alternative to medical advice.

## **4. CONCLUSIONS**

1.- The most pressing issues for all focus group participants, whether chronic patients or average health care users were:

- Excessive waiting times in primary and specialist health care
- Lack of interpersonal and communication skills in the doctor-patient relationship
- Importance of continuity of care
- Competence of health professionals
- Emergency services as the way to faster access to healthcare

2.- Regarding the information revolution, the most important results found were:

- The Internet was viewed as a helpful way to get information but serious concerns were raised about its impact on the doctor-patient relationship

- Smart cards were viewed as useful and practical information tools although some concerns were expressed about confidentiality
- Doctors were considered the most important and trustworthy source of information

3.- Regarding attitudes to self-care, the following reactions were noted:

Focus group participants had varying attitudes towards self-care that might be qualified as active and passive, and they did not particularly value access to alternative therapies

Specific obligations to comply with treatment regimes

4.- Regarding focus group participants' perceptions of other health professionals, the following views were noted:

Pharmacists were seen as good counsellors and advisors on health care

Nurses were viewed as good professionals, providing patient support and care

- Alternative therapists did not get specific mention but participants did not see them as a replacement for conventional care