

# Expert patient program Institut Català de la Salut: From passive to active patient

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**ABSTRACT:** The main objective of the Expert Patient Program at the Institut Català de la Salut is to enhance self-care using a multi-disciplinary collaboration between patients and health professionals. It aims to improve the quality of life for chronically ill patients and their families, involving them with the decision-making as part of the care process. The program consists of 9 ninety-minute sessions which are carried out over a period of about 2 ½ months. What is innovative about the program is that the chair of the meetings is a patient who has first-hand experience of the symptoms and the problems encountered. The chair is, therefore, in a unique position to counsel others who have suffered or are suffering from similar problems. The healthcare professional develops a role as an observer, but can intervene and redirect the meeting if necessary.

**KEYWORDS:** patient expert, chronic diseases

## Introduction

In recent decades we have experienced changes and transformations in society. We find ourselves in a social context where patients have facilitated access to information and a greater ability to decide for themselves. This reality is changing the doctor-patient relationship. The role of the patient is no longer passive and they are becoming increasingly involved and responsible when it comes to making

decisions about their health and / or their illnesses.

This new social reality, combined with the increase of chronic diseases contracted by the ageing population, has led to the search for new formulas in the management of the Health System and a new approach in developing the daily activity of professionals in primary health care. That is why the Institut Català de la Salut, pushing for a new model of clinical management in primary care in coordination with the referral hospitals, launched the Project Management of Heart Failure Pathologies in the Primary Care of the City of Barcelona. It was considered that heart failure had to be the first disease to be included in the project, as the leading cause of hospitalization in people over 65 and for being the third leading cause of cardiovascular death in Spain.

It is within this Project and with the aim of promoting the integration of care services, ensuring continuity of the process, reducing variability, improving efficiency and lending coherence to the final user's satisfaction and enhancing their self-care, where the Expert Patient Program Institut Català de la Salut (hereafter: Expert Patient Program ICS) is integrated.

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The design and development of the Expert Patient Program ICS is based on evidence from other countries, including Britain, where it has shown to have positive effects on health.

The Expert Patient Program ICS focuses primarily on the person suffering from chronic disease and it is geared towards the enhancement of self-care. It is a multidisciplinary initiative based on patient/health professional collaboration and teamwork, which seeks to improve the quality of life for patients and families of patients suffering from a chronic illness, sharing with them the decision-making as part of the care process.

As experts we understand that, to those affected by a chronic disease, it is the ability to take responsibility for their own illness and self-care that allows them to manage the impact on a physical, emotional and social level. Being able to recognize and respond to symptoms and acquiring the tools that helps them will, therefore, improve their quality of life.

### Objectives

The Expert Patient Program of the ICS aims to improve the understanding of chronic disease by patients through the exchange and transfer with the expert patient's knowledge. This promotes change in habits to improve their quality of life and coexistence with the disease.

To serve the purpose of the Expert Patient Program ICS, 8 specific objectives have been set: 1) Getting the involvement of patients themselves, 2) Finding out the degree of patient satisfaction, 3) Improving the quality of perceived life of patients, 4) Improving the patient's knowledge about the disease, 5) Improving the degree of self-care to acquire a correct handling of the disease, 6) Improving therapeutic compliance, 7) Reducing the number of visits to the family doctor/nurse, 8) Reducing hospital admissions and emergency visits caused by the disease.

### Methodology

The Expert Patient Program ICS consists of 9 sessions of one hour and thirty minutes in the course of

about 2 ½ months. The sessions include both theoretical guidance and one practical class. The number of participants has been limited to 10 in order to ensure a smooth and effective communication between partakers in the group.

The expert patient, serving as the chair of the meetings, is selected among the group of patients suffering from the chronic pathology part of the Program, and must meet criteria for voluntary, self-care capacity and lack of mental disabilities. Their skills of empathy, concern to help, motivation and communication skills are also valued after a personal interview. Their initial training is carried out by healthcare professionals from the primary care team, acting as observers.

One aspect of this model to highlight is that the chair of the meetings has experienced first-person symptoms and problems dealt with and is, therefore, in a better position to speak to others who have suffered the same experiences. The health professional, doctor, nurse or social worker, develops a role as observer, who can intervene to redirect the meeting in the case that it is required.

This program falls within the gradual transition, varying from an unidirectional health education (often biological depending on the healthcare professional), to another health education, which provides two-way discourse on social and experimental aspects where the patient is more autonomous.

### Results

In the process of assessing the Expert Patient Program of the ICS, two phases are identified. The assessment of the first phase takes place during the development process of the group meetings through to its termination. The second phase takes place after 6 and 12 months to finalize the group meetings.

In both phases the assessment carried out takes into account quantitative and qualitative factors. On the one hand we have the foreground measures, valuing the change in habits and lifestyles, the degree of self-care and satisfaction of the participants. On the other hand we look at the use of health care services

in relation to visits to the family doctor and nurse, emergency services and hospital admissions by acute symptoms, conducting a study that looks at the differences one year after the completion of the Program by comparing it with the year before it began. Until now, there have been 10 groups of heart failure patients in the primary care teams of Roquetes, Gotic, Besòs, Montnegre and Marina of the Primary Health Care Centers of the ICS in Barcelona city. The total number of participants was 78 (41 women and 37 men). From the analysis of the results of the first groups which convened between 2006 and 2007, when the Program ended, it showed a 21% lifestyle improvement and a 9.2% foreground. After 6 months, we have seen an improvement of 38.7% in lifestyle and 13% in knowledge, considering the results at the start of the intervention. The qualitative results show a high degree of satisfaction with participants as seen in the satisfaction surveys and comments made by patients:

*"...health professionals know much, but sometimes we do not understand what we are told..."*;

*"...with this program we understand the mechanism of the disease since the examples are simpler..."*;

*"...and we are not alone and we have freedom to ask things when we desire..."*;

*"...we are not bound by the rush of visits..."*;

*"...it is the patient's disease not the doctor's disease..."*;

*"...helps us to understand the chronic illness otherwise..."*.

## Discussion

From the experience of the first groups of Expert Patient Program ICS we can say that the implementation process has included a deep involvement on the part of all contributors: expert patients, patients and professionals.

Early results show that Expert Patient Program ICS is in line with that of other countries where such practices are extant and we therefore feel very satisfied with the development of the Program.

At present, the Institut Català de Salut has extended

the program to patients with chronic obstructive pulmonary disease and oral anticoagulant therapy. Further work is being done with the aim of extending the Expert Patient Program ICS to other chronic diseases such as diabetes mellitus (DM) and anxiety, among others.

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