



## **Patient Involvement in the Scientific Literature:**

### **A Review**

## Introduction

A literature review is often carried out in projects to better understand issues and trends and to help set the framework of a project. As part of the Value+ assessment of patient involvement in projects, a literature review was completed to get the bigger picture of the involvement of patients both at individual level as well through representative patient organisations in health policy, healthcare systems, service delivery and of course projects.

Patient involvement is the focus of this review with a particular eye on “meaningful” involvement and also on the gender dimension of patient involvement. The result of this analysis determines the state of the art of research in the literature pertaining to this topic.

## Objectives

The main objective for doing this work was to draw some guidance on how to frame the research to be done in Value+ mainly through a qualitative approach. The findings of the review would tell us which issues and problems should be addressed in the questionnaire survey, focus groups, workshops and interviews.

Through the comprehensive literature review we wanted to find answers to the following questions:

- How is patient involvement in health perceived?
- Which are the main areas and mechanisms of patient involvement in health?
- To what degree do the diverse stakeholders accept patient involvement?
- To what degree do barriers inhibit patient involvement in health?
- What is the impact of patient involvement on the health policy making process?
- How does patient involvement vary at the national, European, and international levels?
- Which countries serve as models for patient involvement?
- Which recommendations have experts provided to improve patient involvement at the national, European, and international levels?

What we found out directly from current or completed EC-funded projects matched well with what we had learnt from the literature.

## Methodology

MEDLINE forms the basis of the literature research on patient involvement. Further relevant

documentation has been obtained from the EU, World Health Organization (WHO), OECD documentations, national health ministries, patient organisations, and patient-centred academic institutions. A total of 650 patient involvement and participation documents were analysed based on four categories of patient involvement: actors, health, action, and output.

## Conclusions

### *Definitions and Concepts*

- ❖ The term *patient* is often used interchangeably with others apparently similar such as: user, citizens, health users, service user, lay person, client, people, communities or the wider public. This ambiguity adds to the complexity of patient involvement because a term is associated to ways of seeing and portraying people and their relationships with the healthcare system
- ❖ A specific definition of *patient* is important because the definition determines the quality and effectiveness of the whole process of involvement from five point of views: “*Who to involve* (the representativeness), *the reason for their involvement* (the focus and nature of the involvement), *their role and responsibilities* (the level, comprehensiveness and depth of involvement and participation); *how decisions will be made* (democracy, transparency and accountability of involvement) and *the evaluation of their involvement*” (Pivik, 2002<sup>i</sup>; Tritter, 2006<sup>ii</sup>; Boote, 2006<sup>iii</sup>)
- ❖ While there is diversity across European and non-European countries about the manner to interpret and implement patient involvement into the healthcare system, there is still a common challenge concerning the concept of *meaningful* patient involvement
- ❖ The growing emphasis on patient involvement is linked to the emerging of concepts like *patient-centred healthcare* and *patient empowerment*. The first called for a new, more humanistic approach to healthcare that would take into account not only the disease but also the patient’s experience of it. The literature indicates that among the core principles of any patient-centred healthcare model, patient involvement and participation are always present despite the differences of models.

### *Patient Involvement and Democracy*

- ❖ While patient involvement is considered as a right in matters of clinical and medical decisions making – and thus is included in patients’ rights legislations – it is rarely seen as such in other contexts, e.g. health policy making and therefore lacks proper regulation
- ❖ Countries with a greater focus on patient involvement are the same across time. The literature shows also that the countries producing the major number of publications on this topic are, at the same time, those with a longer tradition in democracy, patient rights and citizen’s participation.
- ❖ The increasing interest on patient involvement coincides in the time with the renaissance of public’s health policy debates on the redefinition of the concept of shared decision-making provoked by the appearance of a new term from the French healthcare system: the participatory democracy. Shared decision making is one of the most recent and standardised models fostered by European and international healthcare research to denote

patient involvement, but in a limited way of intervention: the clinical and medical encounter. It is for this reason that the main concern for the literature research still remains the difficulty to have a comprehensive and systematic approach to patient involvement in a broader context than the medical one that would include policy making.

### ***The Gender Dimension of Patient Involvement***

- ❖ An analysis of the gender dimension of patient involvement is clearly lacking
- ❖ Patient involvement and gender have in common the gap between theory and reality especially in decision-making bodies and processes

### ***Elements Supporting Meaningful Patient Involvement***

- ❖ Despite the complexity of involvement, the literature shows a remarkable degree of convergence in the elements considered key for a successful involvement of patients:
  - Political and relevant stakeholders' commitment to patient involvement
  - Development of a patient involvement agenda at health policy and research levels
  - Comprehensiveness of involvement so as to guarantee the integration of patients at all levels of the healthcare system (macro, meso and micro)
  - Adequacy of involvement to the patient-centred-dimensions of healthcare
  - Development and implementation of the involvement according to patients' values, needs, preferences and expectations
  - Assessment of the quality, effectiveness and sustainability of patients involvement
  - Accountability on patient involvement by the healthcare systems at local, national and European levels.
- ❖ The literature indicates three important concerns in relation to the realisation of patient involvement in a systematic way:
  - a) The **opportunities** offered by healthcare systems: despite the increasing interest from the beginning of the 1970s through until the 1990s by European healthcare systems to integrate patients and citizens 'at the core' of the system, the major problem evidenced by the literature is the high level of dispersion and fragmentation. Because of this, at the present moment, it is not possible to talk about patient involvement without talking about the opportunity to implement this in practice
  - b) The **type of involvement** (direct *versus* indirect): although patient involvement is generally associated with a democratic approach, the dominant method of

- engagement is indirect, instead of direct
- c) The level of **fragmentation** or **decentralization** of health system: patient involvement is more successful in centralised health systems (France, Germany, the Netherlands, UK), or in those that are decentralised but in fact operate in a centralised way (Belgium and Canada).

### *Challenges*

- ❖ Recurrent challenges were summarised by the literature and reported by individual countries. There is a high level of consensus irrespective of countries, experts and stakeholders in the following areas:
  - **Legal:** In general, although a high level of individual patient rights is guaranteed in the EU Member States, there is a gap in the view of patient involvement as a right. This applies especially to involvement in contexts other than individual clinical decision making
  - **Political:** The lack of, or poor political commitment to patient involvement at all levels in the healthcare system and especially at policy making decision level is one of the strongest barriers
  - **Administrative:** Patient involvement can be seen as inconvenient and time-consuming that interrupts the smooth operation of a hierarchical, bureaucratic organisation, especially if there is little or no knowledge on practices of involvement
  - **Professional:** Despite progress towards acceptance of a more important role of patients, attitudes of health professionals remain a strong barrier
  - **Communication:** Language, in terms of health literacy and especially use of technical terms, is an important barrier to good communication which is key for patient involvement
  - **Personal:** Characteristics of patients like ethnicity, age, disease and other relevant aspects may lead to discrimination, and therefore lower opportunities for involvement
  - **Resources:** There are two key aspects: a) throughout the history of involvement the added value of patient involvement has not been quantified in economical terms and, thus has not been adequately compensated and b) meaningful patient involvement requires resources.

### **Theory and Practice**

- ❖ Despite the acknowledgement of patient involvement as a core principle of patient-centred healthcare, the problem that remains unsolved by health stakeholders is the effective

translation from theory to practice; from a theoretical patient involvement definition to its empirical implementation

- ❖ There is a high and uniform recognition of patients as central to the achievement of better efficiency, effectiveness and quality of healthcare systems. However the level of impact of patient involvement varies due to a complex set of variables that are responsible for a major or minor openness to patients and patient organisations' engagement
- ❖ Little comparative analysis has been done with respect to the evaluation, effectiveness and impact of patient and public involvement on health systems
- ❖ The approach and mechanisms used to involve patients have a consequence on the quality and impact of involvement. The majority of healthcare systems and countries choose information and consultation as a preferable mechanism to public involvement rather than the most formal and influential forms, that is to say delegation and control
- ❖ Patient empowerment is still very weak, undeveloped and, for some aspects, 'artificial' and ineffective. Even if we can distinguish three levels of patient involvement, only one of these is sustainable in the time; that is the higher level of patient involvement where patients are part of the decision-making process.

### How the Literature Review Fed into the Value+ Project

The findings from the literature led Value+ to explore the following issues in the questionnaire survey, the focus groups, workshops and interviews:

- The ambiguity of definitions of patient involvement and the concept of 'meaningful', and the definition of a specific framework to refer to
- Approaches to patient involvement and good practices
- Challenges and barriers as perceived by the various stakeholders engaged in the patient involvement process
- Factors supporting patient involvement
- The gender dimension of patient involvement in health related projects

Value+ used this knowledge also to shape the content of its deliverables: the Toolkit for patients and patient organisations, the Handbook for project coordinators and the Policy Recommendations to the EU Institutions.

---

<sup>i</sup> Pivik, J.R. Practical strategies for facilitating meaningful citizen involvement in health planning. Ottawa: University of Ottawa, 2002.

<sup>ii</sup> Tritter, J.Q.; McCallum, A. The snakes and ladders of user involvement: moving beyond Arnstein. *Health Policy* 2006;76:156-168.

<sup>iii</sup> Boote, J; Barber, R; Cooper, C. Principles and indicators of successful consumer involvement in NHS research: results of a Delphi study and subgroup analysis. *Health Policy* 2006;75:280-297.