ORIGINAL PAPER

Cross-national diagnostic analysis of patient empowerment in England and Greece

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Abstract

Background: Different NHS patient empowerment policies have been adopted in England and Greece; the voluntary sector development and its influence also differ. Although various aspects of patient empowerment have been explored in England, the patient empowerment systems' application is under-researched. In Greece, the few relevant attempts looking at patients' experiences focus on patient satisfaction, with only one study exploring the public hospitals managers' perspectives on user involvement. However, patient empowerment questions may be similar in both countries.

Aims and Objectives:The study aimed to explore and compare the general patient empowerment settings in the two countries, with main objectives to:

a. identify and explore the relationships of national voluntary and governmental organisations,
b. explore the cross-national challenges and facilitators, and make cross-national recommendations.

Methodology:This is a cross-national comparative research study. A 'diagnostic analysis' approach, an assessment of potential and actual barriers and facilitators, including the context and potential change, was chosen. The methods used were:-

a. a network analysis of national voluntary and governmental organisations;
b. semi-structured interviews with key representatives of these, and
c. documentary analysis.

Results: The network analysis revealed the potential of English organisations to influence more people, with extensive memberships and stronger interrelationship between them than the Greek organisations. Different levels of awareness, knowledge and perceptions of application of the national patient empowerment policies, systems and mechanisms were identified; being generally good in England, limited in Greece. Variable general information provision, with good verbal information in England, and limited, written and verbal, information in Greece was also identified. Although the commonest cross-national perceived challenges were organisational, the Greek culture, professional systems and attitudes were also challenges in Greece. National relevant policies and professional attitudes in England, and integrated working in Greece were perceived facilitators. Changes in professional attitudes and cultures, information awareness / provision, and national drivers were common cross-national facilitators. Greek participants called for better function of patient empowerment systems within hospitals; while hearing the patients 'voice' and non-tokenism were highlighted in England.

Conclusions: Notwithstanding its limitations, this analysis identified factors and complexities likely to influence patient empowerment change. The influence of the voluntary sector and well-developed policies in England was evident, while in Greece there was lack of knowledge and awareness. Nonetheless, it seems that the need for better non-tokenistic systems is cross-national.

Keywords: patient empowerment, England, Greece, cross-national comparative study, patient involvement, patients' rights, diagnostic analysis, network analysis

Introduction

Theoretical concepts

Patient involvement and empowerment are terms used frequently in health services. There are many definitions for involvement, participation or empowerment. *'Patient involvement'* refers to the active participation of patients and their carers, as partners in their own care and treatment. It can be at various levels, planning, service delivery, quality monitoring and development of health services (Kelson, 1997). Involve (2005) summarises participation as *'everything that enables people to influence the decisions and get involved in the actions that affect their lives.'*

'Patient empowerment' refers to the mechanisms enabling patients to gain control and make choices in their health and health interventions (O'Cathain et al, 2005). More choice, more information, more personalised care may be some of the elements that lead to real empowerment of patients. The concept of *empowerment* in health care is described as the act of conferring authority, ability or control:

'the process (or processes) of redressing the balance of power in health care between the individual receiving care and the health care professional in a provider setting… people obtaining the knowledge and skills to make it possible for them to become active partners, with professionals, in making informed decisions and choices about their own treatment and care; and of enabling communities to exert informed influence on NHS service planning, development and delivery' (Farrel and Gilbert, 1996).

Other concepts used are *'engagement', 'partnership', having 'voice', 'patient-centred', 'patient-focus', 'patient-led'* services, *'co-production'*; all concepts may express different patient involvement level, type or acts that the participation is sought, but sometimes they are used interchangeably. '*Patients' rights*' is also considered as means of empowering patients. Patients' rights have been introduced in many countries, i.e. in Greece, as an extension of human rights in health. Fundamental rights are the rights of information and complaining; the underpinning values of all rights are respect for the '*voice'* and '*choice'* of the individual citizen (Fallberg and Mackenney, 2004). Many theoretical models exist, most of them presenting information as the lowest level and empowerment as the highest of involvement (Poulton, 1999; Department of Health, 2003).

England - Overview

The non-profit sector has been playing an important role in patient involvement and empowerment since the mid 1960s and has influenced policy directions and practice. The first generic patient organisation, the Patients Association, was established in the 1960s (The Patients Association, 2005), followed by other generic or umbrella patient organisations. They have voiced patients and carers concerns on treatment, care, and delivery of services since then (The Patients Forum, 2005). Specific condition or subgroup organisations, i.e. Mind, Age Concern, have been also advocating, voicing patient concerns, and influencing national policy directions. In many areas, voluntary bodies became the national expertise centres; it was eventually recognised among others, that users might be able to command more information than professionals, i.e. with the notion of the '*expert patient'*(Appleby, Harrison and Devlin, 2003).

NHS policies have started talking about patient-centred services and patients' rights since 1990; they have increasingly put patients at the centre of services since then. Notable drivers for patient and public involvement (PPI) have been the NHS Plan (Department of Health, 2000) and the legal duty to involve and consult the public (Department of Health, 2003). To enable policy implementation, the NHS has adopted the *'Involvement Continuum'* (Department of Health, 2008). Within this, strategies encompass information provision, education, consultation, knowledge sharing, active participation, choice, engagement, managing and monitoring expectations and satisfaction with care and treatment.

National structures and bodies designed to involve patients and the public in the healthcare services have / had been in place for many years, i.e. the *Commission for Patient and Public Involvement in Health* (CPPIH).There have also been other bodies and structures at the local or hospital level, i.e. *Overview and Scrutiny Committees (OSCs), Patient Advice and Liaison Services (PALS), Patient and Public Involvement Forums (PPIFs).* In terms of hospital systems, there is usually a PPI structure with

a PPI Lead or Director, a PALS office/team, a Complaints office/team, and perhaps PPI project officers. They work closely with the *Independent Complaints Advocacy Service (ICAS), OSCs, PPIFs* (existent at the study's time) and voluntary/community organisations.

Greece - Overview

Unlike England, non-profit organisations representing patients have been developed only recently - most in the early 1990s -, and their activities have been limited (Michailidou, 2005). Although there are national specific disease organisations, i.e. Hellenic Cancer Society, Diabetes Association (Forthnet Greek Directory, 2006), an umbrella or generic organisation has yet to be established.

In Greece, taking into consideration the successive attempts for health care reforms of the 1990s as well as the 2001, no legislation has addressed patient involvement in an explicit way (Greek Parliament, 1992; Abel-Smith et al, 1994; Greek Parliament 1997 & 2001). The Conservatives reform in 1992 introduced patients' rights, based on the European Charter of Patients' Rights. The legislation led to the 1997 health care reform also emphasised patients' rights and effective hospital management which would use user views as an input in decision-making processes through the establishment of statutory bodies for patients' rights protection at national and hospital level. The 2001 health care reform focuses on Greek citizens and their interests.

Two national statutory bodies to protect patients' rights at the macro-level were introduced in 1997: the *Independent Patients' Rights Protection Service (IPRPS) (Αυτοτελής Υπηρεσία Προστασίας Δικαιωμάτων Ασθενών*) and *the Patients Rights' Protection and Control Committee (PRPCC) (Επιτροπή Ελέγχου Προστασίας Δικαιωμάτων Ασθενών).* Two hospital-based statutory bodies were also established in 1997 and were reinforced with the other reforms: the *Offices for Communication with Citizens (OCC) (Γραφεία Επικοινωνίας με τον Πολίτη)* and *Citizen's Rights Protection Committees (CRPCs) (Τριμελής Επιτροπή Προστασίας Δικαιωμάτων του Πολίτη).*

Background

Various aspects of patient involvement and empowerment have been explored in many studies in England; it has been shown that many patients want more involvement in care decisions and better information about health problems and conditions, treatment and lifestyle issues. Patients are moving towards obtaining control, rather than being given control or choice; they no longer accept being simply spectators, but expect to actively participate and to be partners themselves in their own healthcare provision (Anderson, Tritter and Wilson, 2007). The balance of power is shifting between individual patients and their clinicians and between local communities and health commissioners to identify ways of working together (Farrel and Gilber, 1996). However, there is lack of evidence about how patient empowerment systems are perceived and applied in practice (Sang, 2009).

Research in health care services is limited in Greece; the few attempts to look at patients experiences focus on patient satisfaction (Niakas, Gnardellis and Theodorou, 2004; Gnardellis and Niakas, 2005; Niakas, 2005). One study only was identified exploring professional perspectives, the Greek public hospitals managers' perspectives on user (no patient) involvement (Michailidou, 2005).

Although the development of policies and the influence of the voluntary sector appear to be different, patient empowerment questions may be comparable and similar in both England and Greece - as in other European countries. A major research study covering eight European countries recently - including U.K. but not Greece - found remarkable similarities of patients' views about their health care, including issues on involvement (Coulter and Magge, 2004). An analysis of patient surveys data revealed significant weaknesses in patient engagement, including organisational and professional culture barriers, in the UK in comparison to other six developed countries (Coulter, 2006). Greek NHS has introduced patients' rights legislation for years, but its application and how they empower patients have not investigated. In England, policy developments may relate directly to hospital patient involvement systems and structures, but their application has also not been examined sufficiently.

Research aims and objectives

A cross-national diagnostic analysis has been undertaken, aiming to explore and compare the general settings of patient empowerment in the two countries.

The *main objectives* were to: identify key national voluntary and governmental organisations with a patient empowerment role (patient involvement, patients' rights)

- explore the relationships and potential national influence of these organisations
- explore views and perceptions of key national stakeholders
- explore the cross-national patient empowerment challenges and facilitators, and
- make cross-national recommendations.

Methodology

A) Design

This is a *cross-national comparative research study*; systematic comparisons and analyses are made of two or more societies. Data about nations and about their specific conditions within context is gathered, and by illuminating, interpreting and explaining similarities and differences, a deeper understanding of social reality, and a generalisation about relations between variables is sought (Hantrais, Mangen and O'Brien, 1994).

There is no methodology specific to the comparative method, it does not make use of different analytical tools, but exploits all the available techniques (Berthoin Antal, Dierkes and Weiler, 1987; Hantrais, Mangen and O'Brien, 1994; Ovretveit, 1998). A *'diagnostic analysis'* approach was chosen; it is an assessment of potential and actual barriers and facilitators, including the context and potential users and change (Stetler, 1994; Harrison, 2005; Rycroft-Malone and Bucknall, 2010).

B) Overview of methods and tools

There is no universal model for diagnostic analysis; the methods used may vary, involving a combination of routine data analysis, interviews and informed judgment (NHS Centre for Reviews and Dissemination, 1999; Harrison, 2004; Hamilton, McLaren and Mulhall, 2007). The methods used here were:-

- a network analysis of voluntary and governmental organisations;
- semi-structured interviews with key representatives of these organisations, and
- documentary analysis.

A network analysis of voluntary and governmental organisations was utilised to identify relevant groups and organisations, their activities in the field, their connections and relations; potential external barriers to change and likely external enabling factors (Scott, 2000). The notion of network is used here to describe the system of organisations that work and interlink at the same area, i.e. patient involvement, patients' rights (Abercrombie, Hill and Turner, 1984). The network perspective emphasizes structural relations as its key orienting principle, where social structure consists of *'regularities in the patterns of relations among concrete entities'*; entities here are groups and organisations. Its central objectives are to measure and represent these structural relations accurately (Knoke and Yang, 2008). The network approach is particularly suitable for understanding interactions, the mechanisms via which structure influences attitudes, beliefs and behaviours (Pescosolido, 1994).

Semi-structured interviews were chosen to explore the perceptions of individuals within these organisations. Qualitative interviews have the advantages of collecting personal information without the fear of interviewee being judged or reveal things in front of others and also talking about personal experiences in more depth than a group setting (Kvale and Brinkmann, 2009).

Documentary analysis was also chosen to identify further issues, by examining published records or documents; it is an unobtrusive way of identifying issues. Notwithstanding its limitations, i.e. subjectivity and impressionism, its advantages include their relative non-reactivity with the investigator, convenience and low cost comparing with other research methods (Bowling, 2000).

D) Processes, sampling and analysis

Network analysis

Seven national organisations with a strong patient empowerment remit, i.e. patient involvement, patients' rights, patient-centred services or representation of patient interests, were identified in each country through national lists, websites and personal contacts. Invitation letters with study information sheets were sent to their Chief Executives or Directors; being followed by telephone calls. From those, six organisations in England and five organisations in Greece agreed to participate in consultations, involving interviews and documentary search. Consultations were conducted between September 2006 and April 2007.

Network analysis was based on highlighting existing ties between the organisations; focusing primarily on the relationships between the organisations. The relational structure was measured according to organisation's size (the number of members or staff), density (the degree of interrelationship between organisations) or homogeneity (the similarity between them according to their patient empowerment' remit), and the content of interactions (the mechanisms via which structures influence attitudes, beliefs and behaviours and social support offered) (Carpentier and Ducharme, 2005).

Semi-structured interviews

An invitation letter, information sheet and consent form were compiled in English; they were then translated into Greek. The interview topic guide was informed by the literature and policy review. The translated topic guide was slightly modified to correspond to policy issues and terminology used in Greece, following preliminary discussions with key informants; the main topics remained the same.

All potential participants received the above and were followed by telephone calls or visits to provide further study information and arrange an appointment. Those who refused to participate sited as main reasons workload and lack of time; if appropriate, they nominated someone else. Interviews took place in convenient times and private and comfortable locations within the participants' organisation. They lasted approximately 30-60 minutes. They were digitally recorded and transcribed verbatim using professional transcribing services; in addition written notes were kept. The transcriptions were checked and amended when necessary by MB; they were then sent to participants for validation, inclusion or exclusion of extracts and further comments.

Documentary search and analysis

Documentary search, i.e. yearly reports of the participating organisations, organisational strategies, press-releases, mass media records, were also conducted, prior, during or after the interviews.

Framework analysis

Qualitative data derived from both interviews and documents were analysed using framework analysis in the language conducted; they then translated into English by MB. Framework *is an analytical process, which involves distinct though highly interconnected stages*, systematic process of sifting, charting and sorting material according to key issues and themes. The method has key features, central to its development: it is grounded or generative, dynamic, systematic, comprehensive, enables easy retrieval and is accessible to others. It was chosen for these key features and because it provides an audit trail: the analytical process is documented, accessible and transparent, the synthesis retains links back to the original data (Ritchie and Spencer, 1994; NatCen Learning, 2006; NatCen Learning, 2007; Ritchie, Spencer and O'Connor, 2007).

Synthesising and triangulating evidence were important analytical elements.

Data obtained and analysed was compared by country to obtain a synthesis of similarities and differences and a cross- national picture. The methods of analysis, explanation and argument building involve understandings of complexity, detail and context to produce

rounded and contextual understandings on the basis of rich, nuanced and detailed data (Mason, 2002).

D) Validity and reliability

Validity and reliability have been enhanced in several ways, for example:

a. Concept validity in cross-languages and cross-cultures, with testing of the tools in the different settings.
b. Construct validity, with the pilot of the translated interview topic and subsequent amendments in terminology to reflect the terms used in Greece
c. Quality of interviews, with the review of randomly selected extracts from English interviews and translated extracts from Greek interviews from all authors.
d. Translation construct validity and reliability for Greek interviews, with another bilingual researcher checking translations of randomly selected interview extracts.

E) Ethics

The study was approved by a University Ethics Committee. The main ethical principles governing research of information giving, informed consent, confidentiality, voluntary participation, autonomy and beneficence (Bowling, 2000c; BSA, 2002) were safeguarded; these explained both verbally and in writing in the information sheets and informed consent forms. The British Sociological Association Statement of Ethical Practice (2002) was obeyed; all work was conducted within the legal obligations imposed by the Data Protection Act 1998 (ICO, 1998).

Results

A) Participation

Six organisations participated in England, but four interviews were conducted as two stakeholders represented two organisations each. Five organisations participated in Greece. Participants were either Directors / Chairpersons or associated with patient involvement or activities, i.e. Co-ordinator of Patient Activities or User Involvement Officer *(Table 1).*

Sixty one documents were collected in England and seventy four in Greece. A lot of the documentation was easily accessible online through their websites and contained general organisational information, aims, remit and activities / actions for all. Summaries of projects, reports on specific issues, annual reports were available for some organisations (7) on paper or online in both countries. Other common information was organisational structure (2), membership information (2) in England; information on heath service user / patient rights (3) and patient responsibilities (3) in Greece.

B) Cross-national network analysis

The network analysis identified some similarities and differences at the national settings of the two countries. The participating organisations in both countries were relative small but all influenced patients somehow; three English organisations, however, had extensive membership, thus the potential to influence member organisations and a wider number of people *(Table 2).*

In addition, more generic organisations were identified in England, while most of organisations were condition-specific in Greece *(Table 3).* Thus the density (the interrelationship between different organisations) was weaker in Greece and the organisations were less homogeneous (similar) than the organisations in England. In addition, the three non-specific condition English organisations with the highest degrees of density presented strong boundary penetrations relations, i.e. they had overlapping membership between them, and good communication relations. On the other hand, the Greek organisations did not have overlapping membership, committee or board members, and had week communication relations.

All relationships between organisations in both countries were *non-directed*, were mutuality occurs, e.g. conversing between organisations. Although their actions were *directed* to patients and their members, all of them had membership, patient representatives or worked directly with patients and the

public, so there was conversation and interaction between them and members / patients *(Figure 1 & Figure 2).*

These differences in structural relations between the various organisations in the two countries consist part of the national settings for patient empowerment and may well influence the patient empowerment systems and their application nationally.

Table 1. Participation in the cross-national diagnostic analysis

Cross-national diagnostic analysis (September 2006 - April 2007)					
England (September 2006 – April 2007)			***Greece (September 2006 – January 2007)***		
a) Network analysis (September 2006 – December 2006)			*a) Network analysis (September 2006 – December 2006)*		
b) Consultations with organisc (n=6) (Feb. 2007 - April 2007)	*Interviews (n=4)*	*Documents (n=61)*	*b) Consultations with organisc (n=5)* (Dec. 2006 – Jan. 2007)	*Interviews (n=5)*	*Documents (n=74)*
Organisation A1 & A2	1	17	Organisation E	1	16
Organisation B	1	18	Organisation F	1	11
Organisation C	1	10	Organisation G	1	10
Organisation D1 & D2	1	16	Organisation H	1	11
			Organisation K	1	26
Total	***4***	***61***		***5***	***74***

Table 2. The ties between organisations and their characteristics – England

National organisations	***Organisation's patient empowerment remit and priority***	***Size*** (staff and membership)	***Density*** (1: Weak interrelationship, 5: Strong interrelationship)	***Homogeneity*** (1: Less similar, 5: Most similar)
A1: Generic organisation	Strong patient empowerment - mostly project work around information and choice	7 associates and staff (3 managers-associates, 4 staff)	2	1
A2: Generic umbrella / networking organisation	Strong patient empowerment remit - sharing information, involving members, influencing policy-makers	1 chair, 1 project assistant, 53 members-organisations	4	4
B: Generic organisation	Strong patient empowerment remit - campaigning for patients	5 staff members, 48 member-organisations	3	3
C: Specific-condition organisation	Strong patient empowerment remit - representing and involving patients with the condition	9 Board of Trustee members, 120 national and local staff members	3	2
D1: Specific-conditions umbrella / networking organisation	Strong patient empowerment remit - individual and collective PPI level	6 staff members, 109 member organisations	4	3
D2: Generic EU-funded organisation	Strong patient empowerment remit - national policy and guidelines	6 staff members	2	1

Table 3. The ties between organisations and their characteristics – Greece

National organisations	***Organisation's patient empowerment remit and priority***	***Size*** (staff and membership)	***Density*** (1: Weak interrelationship, 4: Strong interrelationship)	***Homogeneity*** (1: Less similar, 4: Most similar)
E: Generic governmental organisation	Strong patients' rights protection role – protecting NHS service users' rights and resolving issues	36 staff members	4	1
F: Specific-condition voluntary organisation	Strong patients and carers' empowerment role – improvement of quality of life, psychosocial support, information	6 staff members, 12 council members	2	3
G: Generic governmental organisation	Strong patients' rights protection role - protecting patients' rights	1 manager	4	1
H: Specific-condition voluntary organisation	Strong patient empowerment role – practical and psychosocial support, information and awareness, influencing policy	6 staff members	2	3
K: Specific-condition voluntary organisation	Strong patient empowerment remit – information and awareness	2 staff members, 11 council members	2	3

Figure 1: A sociogram of interactions between organisations - England

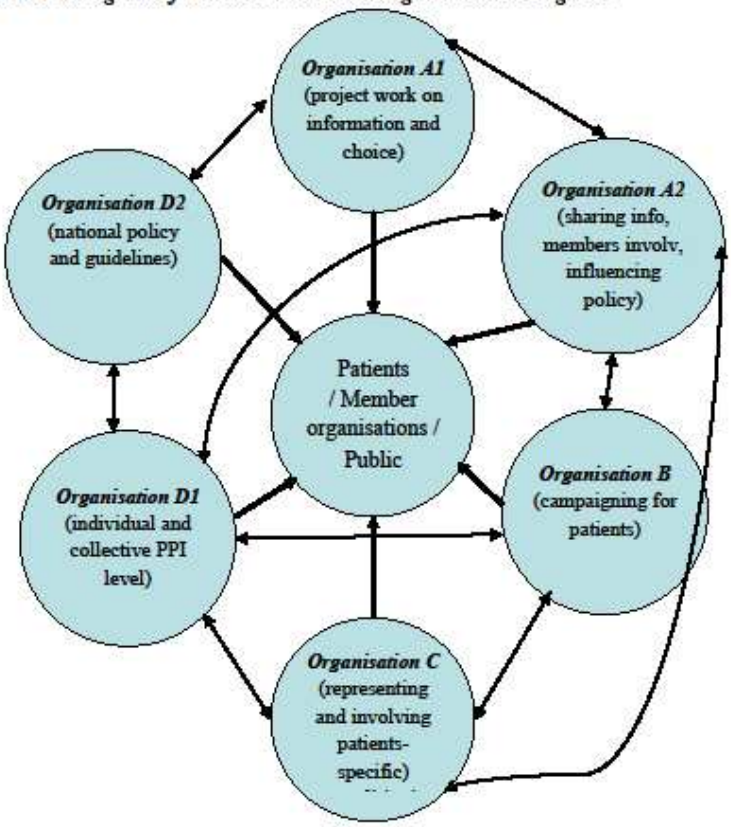
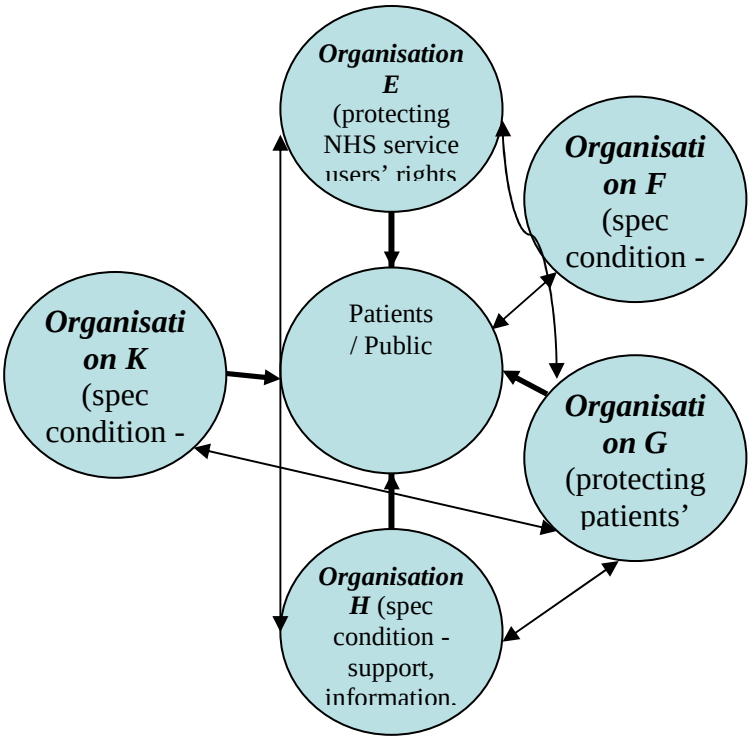


Figure 2: A sociogram of interactions between organisations – Greece



C) Cross-national perceptions of patient empowerment systems and mechanisms (Table 4)

a) Awareness, knowledge and perceptions of application of the national patient empowerment policies

In England, all participants were aware and knowledgeable of PPI in general and the main PPI documents and policies in particular. It was recognised that without clear guidelines, no structures in place and many not-well thought changes, the policies implementation was difficult. However, it was acknowledged that all these policies brought a shift in direction towards patient-centred services and PPI. It was also recognised that certain mechanisms, i.e. the OSCs and reforms of complaints procedures had been more successful than others.

On the other hand, most representatives of Greek voluntary organisations were unaware of the relevant legislation. Some participants, however, felt that awareness and knowledge had been increasing for both health professionals and the public. Some representatives were not even aware of national organisations with a patient empowerment role. The most well-known organisation was the Greek Ombudsman; the PRPIS was very little known.

b) Perceptions of patient empowerment systems and mechanisms within Trusts / hospitals

Again, most participants in England were aware of the general PPI activities, the existing mechanisms of PPI Leads, PALS and Patients Forums; they viewed them positively. There were concerns about the vulnerability of PPI mechanisms, i.e. not being NHS priority, and being allocated somebody's responsibility, thus not being considered as everyone's job. PPI was perceived as still being tokenistic, with very complicated PPI / PALS systems and a 'gentle' work approach. Although PALS was recognised as a good service, offering good customer care, information and support to patients, it was also acknowledged that its development and good function depended on appropriate resources and adequate staff training. Central hospital funding, the consequent lack of PALS independence, and the non-existence of PALS staff central list were considered its weaknesses. PPI Forums were also recognised as doing very good work, but concerns were expressed about the PPI commissioning through the Forum Support Organisations, and the flexibility in their development.

In Greece, on the contrary, awareness and thus perceptions of the OCC, its mechanisms and the CPPR was very low among the voluntary organisations' representatives.

c) Information provision

In England, the internet was recognised as a general information source, easily available, accessible, and empowering to people; concerns were expressed about the quality of information. Health professionals, however, were perceived as the principal source of information for patients. Within Trusts / hospitals, participants believed that information provision varied. Some had excellent information provision, with dedicated officers, groups and information across various conditions; others provided only basic information and even this was sometimes hard to acquire. Information was considered patchy even within the same hospital. Health professionals were thought to have different practices towards information provision; some of them might provide very good and appropriate information, while others might not. It was believed that although appropriate written information was not provided to patients; most health professionals provided verbal information.

Internet was not discussed among Greek participants; voluntary organisations were perceived as playing a big role in general information provision about specific conditions, with production and distribution of written information and support material. They also organised public educational events, i.e. seminars and talks, to promote awareness about the conditions to professionals and the public. Within hospitals, national governmental organisations were believed to distribute only limited information. Voluntary organisations played again an informational and educational role with events, written material or participation in other relevant hospital actions. In general, most participants felt that sufficient information about patients' health status and risks was not given. Acknowledging the lack of information and support, their provision was sometimes the voluntary organisations' role. Participants mentioned the availability of written information at specific clinics only; consisting of leaflets produced by voluntary organisations, commercial and pharmaceutical companies and information about relevant events and seminars. Examples were given when appropriate written information about risks of particular procedures was given, but the timing of information was not

right. One of the participating organisations produced its own patients' rights leaflet; however, its availability was limited to few hospitals only. Verbal information was not provided in any formal way and was not considered adequate. In addition, opportunities were not given to patients to ask questions, request information or participate in decision-making.

Table 4. Cross-national perceptions of patient empowerment systems and mechanisms

England	***Greece***
Awareness, knowledge and perceptions of application of national Patient and Public Involvement (PPI) / patients' rights policies	
General awareness of PPI	• ***Limited awareness of patients' rights policies*** • ***Awareness and knowledge has been increasing***
Awareness of main PPI documents and policies ***Negatives:*** - no clear guidelines - no structures in place - many not well-thought policy changes ***Positives***: - a shift in direction towards patient-centred services and PPI	***Limited awareness and perceptions of national patient empowerment organisations***
Perceptions of patient empowerment systems and mechanisms within Trusts / hospitals	
• ***General awareness of PPI systems and mechanisms*** • They were considered ***positively*** • ***Concerns***: - the vulnerability of PPI mechanisms - PPI being somebody's responsibility - PPI still being tokenistic	***Limited awareness and perceptions of national empowerment organisations***
Internal Trust / hospital mechanisms	
PALS: - good service, customer care, information and support - depends on appropriate resources and staff training - weaknesses: central hospital funding, lack of independence, non-existence of staff central list	***Limited awareness of OCC and its mechanisms***
PPI Forums: - good work - concerns: commissioning through Forum Support Organisations, flexibility in their development	***Limited awareness of CPPR***
Information provision	
General information - ***Internet***: accessible, empowering people, but concerns about information quality - ***Health professionals***: the principal source of information for patients	***General information*** - ***Voluntary non-profit organisations:*** information provision about specific conditions
Information in Trusts / hospitals	
General - Information provision varies - Health professionals have different practices ***Written*** - Appropriate written information is not provided ***Verbal*** - Most health professionals provide verbal information	***General*** - Some information, events, seminars, leaflets from voluntary organisations - Sufficient information about health status and risks is not given ***Written*** - Availability of some leaflets in some clinics only - Appropriate information about certain risks - Limited availability of patients' rights leaflets ***Verbal*** - Not adequate and not in any formal way - Opportunities to ask questions are not given

D) Changing the patient empowerment systems and culture

a) Perceived challenges (Table 5)

Table 5. Perceived challenges and facilitators

England	***Greece***
Perceived challenges	
Challenges linked to PPI systems and mechanisms - Organisational: vulnerability of PPI mechanisms, PPI being tokenis tic, PALS' lack of independence, ineffective support, organisation of PPI Forums - Lack of awareness and complexity of PPI systems *...the average patient I don't think has heard of them at all and doesn't find them useful because they are just too gentle in the way they are supposed to be fighting for patients. The whole business of how a patient can change things, how a patient can complain is constantly on the move, just as they may have understood what the system is, it changes again and it is unbelievably complicated compared to a complaints system for any other organisation. (EN023, p2, 19-25)* ***Challenges for information*** - Organisational: decisions about provision, leadership, organisational priorities - Varied attitudes of health professionals - Patients not retaining verbal information ***Challenges for staff*** - Organisational: workload, lack of time, resources - Staff attitudes: staff hardening up - Lack of staff support and supervision ***Challenges for patients*** - Patient/carers attitudes: fear of retribution - Patients' personalities, socio-demographics - old age - Both patients and staff attitudes: challenging towards collaboration.	***Challenges linked to patients' rights policies*** - Greek culture and its idiosyncrasies, related to visiting times, curiosity and protectivism - Organisational issues: under-staffing, inadequate cover of patient needs *Because in Greece when you go to a hospital and you say to them 'go out, because the visiting time has run out and the relatives have to go', eeeh, people grudge very much. If you say to an English hospital, for example, that we allow half the family in, 45 people, past the visiting time, it seems incomprehensible.… Thus, I want to say, that obviously, there is a different culture, which is linked to our inadequate structures. (GR001, p16, 4-11)* ***Challenges for information*** - Inappropriate use of leaflets ***Challenges for staff*** - Organisational issues: under-staffing, heavy workload, lack of coordination - Overall professional system and cultures, paternalistic and protective individual staff attitudes - Professional sub-cultures and staff attitudes - Lack of staff' support and training ***Challenges for patients*** - Greek culture and its characteristics, i.e. individualism, indifference, non-public participation - Patients' attitudes: fear of anything related to health, lack of awareness for the holistic role of doctors.
Perceived facilitators	
Facilitators linked to PPI systems and mechanisms - National PPI policies and documents - Organisational: initiatives bringing awareness about services, leadership - Personalities and commitment of individuals *… the other thing is personality of course and capabilities and you will have individual PPI Leads, and in some cases you will have a director level people or there is a director with direct responsibility for it, and you will have somebody who is very good, who gives it high priority and you will have somebody just tacked on to their role and it is just something that they do in their spare time almost. (EN021, p8, 4-8)* ***Facilitators for information*** - Attitudes and personalities of health professionals - Appropriate manner, tailored to individual needs ***Facilitators for patients*** - Changes in public attitudes; morbidity patterns	***Facilitators for information and staff*** - Integrated working and collaboration of multi-professional teams *And for this and at the diagnoses, namely always when there are announcements, we always try to have somebody else with the parents, he will be either a social worker, or he will be, I don't know, some nurse, to be in combination. (GR002, p8, 29-32)* ***Facilitators for patients*** - Specific socio-demographic characteristics, i.e. younger age and higher educational level

In England, the perceived challenges linked to PPI systems and mechanisms were mainly organisational: the vulnerability and tokenism of PPI mechanisms, PALS' lack of independence, ineffective support and PPI Forums organisation. Lack of awareness and the complexity of PPI systems were also mentioned. *Challenges for information* were organisational decisions and priorities, leadership, various attitudes of health professionals, patients not-retaining verbal information.

Challenges for staff were organisational issues such as workload, lack of time, resources and financial stress. Staff attitudes were also perceived as challenging; staff harden up, shut their emotions up, thus they are less prone to listening and actively involving patients. Lack of sufficient staff support and supervision, counselling or help in dealing with emotional issues and complaints were also mentioned.

Challenges for patients were their certain attitudes; patients being afraid of retribution, especially as inpatients. These attitudes were thought to be reinforced by the imbalance of power between patients and health professionals. Involvement also depended on patients' personalities and some characteristics, i.e. age. Finally, both patients and staff attitudes may be challenging towards collaboration and partnership.

In Greece, perceived challenges linked to application of policies were the Greek culture and its idiosyncrasies, related to visiting times, curiosity and protectivism; organisational issues such as under-staffing and inadequate cover of patient needs by staff. An additional *challenge for information* was the inappropriate use of leaflets by patients and carers. *Challenges for staff* were organisational issues such as staff shortages, workload, lack of coordination and organisation between different staff, clinics and departments. The overall professional system and cultures, paternalistic and protective individual staff attitudes, professional sub-cultures and staff attitudes together with lack of appropriate support and training were additional challenges. The Greek culture and its characteristics, i.e. individualism, indifference, a tendency not to participate in public processes; and particular patient attitudes, such as a fear about anything health-related and lack of awareness of the holistic role of doctors were perceived as *challenges for patients*.

b) Perceived facilitators (Table 5)

Facilitators linked to PPI systems and mechanisms in England were the national PPI policies, organisational drivers and initiatives to bring awareness about services; leadership, personalities and commitment of individuals. *Facilitators for information* were the attitudes and personalities of health professionals, appropriate manner and being tailored to individual needs. *Facilitators for patients* were changes in public attitudes and morbidity patterns.

In Greece, facilitators for information and staff were the integrated working and collaboration of multi-professional teams. *Facilitators for patients* were specific socio-demographic characteristics, such as younger age and better educational level.

c) Recommendations (Table 6)

In England, participants presented numerous recommendations for effective patient empowerment, including *changes in attitudes and relationships of health professionals and patients*; *appropriate provision of information and choice*, encapsulating appropriate manner, communication, variety of ways and times of provisions. *Hearing the patients' 'voice' at all levels*, moving on to non-tokenism, involving hard to reach groups, recognising that patients and carers are individuals and recognising the importance of different levels of involvement were also suggested. *National drivers*, such as the government restoring credibility and confidence, and responsiveness of NHS and organisations to people' needs and expectations were additional recommendations.

In Greece, awareness and knowledge of patients' rights, mechanisms and empowerment aspects such as communication and information from all staff - and health professionals in particular -, patients and the public were considered essential. *Changes in attitudes and professional cultures*, i.e. medical and nursing staff, working towards appropriate communication and information tailored to individuals; appropriate training in communication and dignity issues, were suggested. *Better function of OCCs and CPPRs*, with good monitoring, evaluation and production of regular statistics was recommended. *Information provision* about treatment, care and support, including resources and payment for

Table 6. Towards a change

England	***Greece***
Recommendations – Similarities	
- ***Changes in attitudes and relationships of health professionals and patients*** *…the sort of stereotypical attitude that people have from the last century is that we have professional services that can cure you and therefore the individual can disconnect from their health condition and go to the witch-doctor… the principal job of health services is to help people live their life with their illness, if you want to take a medical term I would say, with their long term condition. And so attitudes need to change so that people understand that their quality of life and their outcomes depends on what they do themselves more than it depends on what any health service professional can do. (EN028, p1, 30-43)* - ***Appropriate provision of information and choice, with appropriate manner, communication, variety of ways and times of provision*** *I think in an ideal world if there are more than, if there's more than one option, then yes they should be given a choice as to what would suit them the most… And so it's possibly more a question of that they should be given the information on what options are available, and whether there are enough options to make a choice… (EN024, p10, 13-19)* - ***National drivers: government restoring credibility and confidence, responsiveness of NHS and organisations to people's needs and expectations*** *...saying we have got so busy in the health service about everything that we're actually forgetting the patient is the most important thing. We're busy doing everything else except focussing on the patient and making sure that we are the health servant for them as it were. We call it a National Health Service but I always say 'where are the national health servants'. (EN023, p9, 44-48)*	- ***Changes in attitudes and professional cultures*** *I do not know if I am going to name it 'respect'. Nobody considers how this person who has a body part removed, as mine, a leg, a breast, feels. I do not blame the doctors. They are oncologists, they are surgeons, they are pathologists, they are, they are…But they are not specialists nor they have been trained to respond to this. There should be specialists or they should have been trained. It requires special treatment and information. It's not simple at all... We ask the patients 'Have you been informed?' 'No' they answer… (GR005, p13, 35-42)* - ***Appropriate provision of information, including resources and payment for specific treatments*** *… So paying the time of the radiotherapy and taking the receipt. The money is a lot, so I was pleased that the hospital, with the first visit, said to go through a leaflet that we leave at the patient's table, so that he knows that he pays this and this, not the radiotherapy, the partial things that have been built into, as a simulator, as, as, and that he can take from his insurance this amount with the receipt given to him. Then it is an individual matter for everyone. (GR005, p10, 35-41)* - ***National drivers: general NHS organisational improvements, better function of primary care services, state responsibility for patients' rights application, related national / district organisations*** *Basically, health has to be de-centralised. It cannot be that everyone comes for a cold to a third-degree hospital… for example, filters should be created, filters at regional level and the Greek provinces, but also at Athens districts, with health centres that however will function properly. They exist in paper, but there are not manned or they do not preserve clients or people have not been informed and will never go there. (GR010, p12, 46-51)*
Recommendations – Differences	
- ***Hearing the patients 'voice' at all levels, moving on to non-tokenism, involving hard to reach groups, recognising that patients / carers are individuals*** *Because obviously there is a conversation, we've left out, there is some way, we are talking about patients here, but there are carers and then of course that conversation between patients, carers, healthcare providers, people higher up, health service, government – of course what we have left out is the public element and obviously there does need to be in relation to what an individual person needs, there is a balancing to be done between, you know, that person coming in and saying well I'd like herceptin and all these people out here who are paying for it and may have other needs. (EN021, p10, 23-29)*	- ***Awareness and knowledge of patients' rights, mechanisms and empowerment aspects*** *Furthermore, they could have at the admission offices, namely where the patient' admission is, - for this reason we also sent posters – written material. Written material, posters, leaflets… Signs, 'ask us for your rights and we will tell you'…And all these. (GR001, p12, 31-38)* - ***Better function of OCCs and CPPRs, with good monitoring, evaluation and statistics*** *Now for the issue of patients' rights it would be very important, in my personal opinion, the CPPRs within the hospitals to function and their actions to be monitored… at a regional level (ΔΗΠΕ), not necessarily at Ministry level, so that there will be local mechanisms for the propagation of patients' rights… this is not something to be done centrally, but something to be done in regional and local level. (GR001, p8, 37-48)* - ***Formalisation of carers' role***

specific treatment was also suggested. *National drivers*, such as improvements to the general NHS organisation, better function of primary care services, state responsibility for patients' rights application, development of national or district organisations with responsibility for OCCs and CPPRs, and national and local networking and hospitals and voluntary organisations' collaboration were considered very important. Finally, the *formalisation of carers' role* was suggested.

Discussion

A) Limitations

Issues that affect cross-national, cross-cultural and cross-language research have to be taken into account. This research is more demanding of conceptual and practical research skills than many other types of research. Problems are linked with theoretical, methodological, organisational issues and also issues relating to policy relevance (Berthoin Antal, Dierkes and Weiler, 1987; Ovretveit, 1998). The definition of boundaries may be influenced by the availability of data and its comparability, and in turn affects the reliability and validity of measurement; all of which are linked to problems of equivalence of meaning and concepts, often across language barriers and giving rise to difficulties of cross-cultural communication (Hantrais, Mangen and O'Brien, 1994). The understanding of concepts, terms used and questions posed may differ; translated terms, even if they are technically correct, may not be appropriate in providing the same meaning and understanding. For example, although there are equivalent concepts to '*empowerment*' and '*involvement*' in Greek, i.e. '*ενδυνάμωση*' and '*συμμετοχή*', they are not used extensively in health services, thus participants were not familiar with them. The term '*voluntary organisation*' also brings different cultural connotations, as their level of activities and development varies in the two countries and cultures.

Additionally, the participating organisations and participants in Greece, were not familiar not only with research in general, but with organizational or patient empowerment research in particular. This caused unwillingness to participate, several delays and the need to explain the research issues and topics in length.

B) Reflections

In this study, MB being bilingual and having in-depth knowledge of both cultures, she adopted the dual role of researcher / translator, having dual perception of meanings and dual commitment to ethical paradigms; being involved fully and exercising the right to use her judgment (Hoffmeyer-Zlotnik and Harkness, 2005; Shlavor, 2007). This offers opportunities that are not open to other researchers; the researcher can use the translating experience to discuss points in the text where she has had to stop and think about the meaning (Temple and Young, 2004). However, the pilot study was utilised to clarify appropriate terminology in the design and data collection in Greece. Another bilingual researcher checked selected extracts in both languages to validate the translations and maintain research analytical integrity.

C) Summary and conclusions

The network analysis revealed similarities and differences in structural relations between the various organisations in the two countries. It revealed the potential of English organisations to influence more people, with extensive memberships and stronger interrelationship between them than the Greek organisations. This, in the content of interactions, it help us understand the mechanisms of systems' application.

The perceptions of patient empowerment systems shed light on their national applications at the two countries. There were different levels of awareness, knowledge and perceptions of application of the national policies, systems and mechanisms; in England it was generally good, while in Greece it was limited. This may, however, relate to the late development of such systems, i.e. legislation and enforcement of patients' right legislation, in Greece and the existence of a number of

guidelines in England. General information provision was perceived as variable, with good verbal information in England, while in Greece information, both written and verbal was perceived as limited. This is a somehow interesting finding, as the existence of information systems may depend on organisational issues, i.e. funding and leadership, cross-nationally. In Greece, this may also relate with weak policies and weak voluntary sector.

Although the commonest perceived challenges were organisational issues cross-nationally, the Greek culture and its idiosyncrasies, professional systems, cultures and attitudes were discussed frequently as challenges in Greece. In England, national PPI policies, which are well-developed, and professional attitudes, that may have been influenced by policies, were referred to as facilitators, while integrated working was highlighted in Greece. Interestingly, common recommendations were changes in attitudes and professional cultures, awareness and provision of information, and national drivers. As the patient empowerment systems appear to be underdeveloped in Greece, participants called for their better function within hospitals; while hearing the patients 'voice' and moving further on to non-tokenism were highlighted in England.

Notwithstanding its limitations, this cross-national diagnostic analysis explored patient empowerment systems in the two countries. It identified national and cross-national factors and complexities likely to influence patient empowerment change; it provided us with an understanding of the settings and context, actual barriers and facilitators. The influence of the voluntary sector and well-developed policies in England was evident, while in Greece there was lack of knowledge and awareness of legislation and systems. Nonetheless, it seems that even taking into account the difference developmental levels of systems, the need for better function and non-tokenistic systems is cross-national.

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