

A critical analysis of national policies, systems, and structures of patient empowerment in England and Greece

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Background: Comparison of patient empowerment (PE) policies in European countries can provide evidence for improvement and reform across different health systems. It may also influence patient and public involvement, patient experience, preference, and adherence.

Objective: The objective of this study was to compare PE within national policies, systems, and structures in England and Greece for achieving integrated people-centered health services.

Methods: We performed a critical search and review of policy and legislation papers in English and Greek languages. This included 1) general health policy and systems papers, 2) PE, patient and/or public involvement or patients' rights policy and legislation (1990–2015), and 3) comparative or discussion papers for England and/or Greece.

Results: A total of 102 papers on PE policies, systems, and structures were identified initially; 80 papers were included, in which 46 were policy, legislative, and discussion papers about England, 21 were policy, legislation, and discussion papers about Greece, and 13 were comparative or discussion papers including both the countries. In England, National Health Service policies emphasized patient-centered services, involvement, and empowerment, with recent focus on patients' rights; while in Greece, they emphasized patients' rights and quality of services, with recent mentions on empowerment. The health ombudsman is a very important organization across countries; however, it may be more powerful in Greece, because of the nonexistence of local mediating bodies. Micro-structures at trusts/hospitals are comparable, but legislation gives more power to the local structures in Greece.

Conclusion: PE policies and systems have been developed and expressed differently in these countries. However, PE similarities, comparable dimensions and mechanisms, were identified. For both the countries, comparative research and these findings could be beneficial in building connections and relationships, contributing to wider European and international developments on PE, involvement, and patients' rights and further impact on patient preferences and adherence.

Keywords: patient empowerment, patient involvement, patients' rights, England, Greece, national health policies

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Introduction

Patient empowerment (PE) and its benefits^{1–6} have been recognized internationally and in Europe; empowerment and engagement are goals of a global strategy on the achievement of integrated, people-centered health services between 2016 and 2026.¹ The Tallinn Charter recognized the importance of making health systems more responsive to patients' needs, preferences, and expectations, committing WHO

Table 1 Patient empowerment concepts and definitions

Concept	Definitions
Patient empowerment (PE)	Inclusive term, encompassing different levels, strategies, methods, and dimensions of involvement/participation, including patient involvement and patients' rights across countries. ¹⁸ Refers to all mechanisms enabling patients to gain control and make choices on their health and health interventions; the act or process 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. ¹⁹
Patient involvement (PI) or patient and public involvement (PPI)	Patient involvement (PI) or patient and public involvement (PPI), a term commonly used in England, refers to active participation of patients/carers and the public, as partners in their own care and treatment at various levels, ie, health services planning, service delivery, quality monitoring, development. ²⁰
Patients' rights	Patients' rights, entitlements, and duties are what citizens can expect of health systems and providers of care, and what is expected from them. ²¹ Fundamental rights are those for information and complaining. Respect for the individual citizen's "voice" and "choice" are the underpinning values of all rights. ¹⁴

Member States in Europe to strengthening health systems.⁴ The European Community White Paper (2008/2013) recognized citizens' rights to be empowered in relation to health and health care, encompassing participation and influence on decision-making and competences needed for well-being.⁵ The value of patient engagement and empowerment has been discussed in international forums, bringing forward proposals for strengthening national approaches to patient engagement and the advocacy capacity of patients.⁷ Recently, WHO called for action on PE,⁸ recognizing that patient, family, and community engagement are assets for building capacity and quality of care.⁹

Diverse models of PE have been adopted internationally encompassing patients' rights legislation (the Netherlands and Greece), introducing ombudsperson services (Austria, Finland, Hungary, Norway, Greece, and England) and increasing patient participation in care decision-making in England.^{6,10-14} A developing consensus recognizes that PE is increasingly important to health governance, resulting in better system responsiveness to health consumer's views, preferences, and self-management of health. Both England and Greece, which have not been compared in relation to empowerment before, are engaged in professional, political, and public discussions about PE, sharing common European health policies, standards, and targets.^{1,4} Both the countries have recognized the benefits of making health systems and are more patient-centered and responsive by adopting PE strategies.¹⁵ It is acknowledged that they may have different health and welfare systems, PE national policies, systems, and development. This diversity can only be helpful in providing evidence for improving policies, organizational

systems, management, professional practices, and patient experiences. Comparison of PE policies across two different health and welfare systems can illuminate similarities and differences, providing evidence for improvement and reform.¹⁶⁻¹⁸ It can also influence patient and public involvement in such policies and systems and impact on patient preferences and adherence.

The term "patient empowerment" is used as an inclusive term here, encompassing different levels, strategies, methods, and dimensions of involvement/participation, including patient and public involvement (PPI) and patients' rights across countries. It refers to all mechanisms enabling patients to gain control and make choices in their health and health interventions,¹⁹ the act or process of conferring authority, ability, or control.²⁰ More choice, more information, and more personalized care may be elements leading to better health literacy, informed decision-making, and real empowerment of patients to improve their health, health services, and systems. There are many concepts and definitions relating to PE (Table 1); these have been discussed elsewhere and we do not revisit them in this paper.^{14,19-22} This paper aimed to compare PE within national policies, systems, and structures in England and Greece.

Methods

A wide-ranging critical policy and legislation review of papers in English and Greek language, using a structured approach was undertaken. Three categories of papers were reviewed: 1) general health policy and systems papers; 2) PE, PPI, or patients' rights policy and legislation (1990-2015); and 3) comparative or discussion papers, for England and/or

Greece. Inclusion criteria were the terms “patient empowerment,” “patient (and public) involvement,” “patients’ rights,” “patient engagement,” and “patient participation;” papers in English and Greek languages were included.

The review was conducted between April 2006 and September 2015. Combination of the following terms were searched: “patient empowerment,” “patient (and public) involvement,” “patients’ rights,” “patient engagement,” “patient participation,” “citizenship,” “health policy” (implementation of health policy), and “organizational systems” (strategies, systems, structures, or mechanisms). The following databases, search engines, and websites were used:

- Department of Health in England, Ministry for Health and Social Solidarity (MHSS) in Greece, National Health Services (NHSs) in both countries and other governmental.
- King’s Fund, Picker Institute Europe, World Health Organisation, European Community, Greek National Centre for Social Research (Εθνικό Κέντρο Κοινωνικών Ερευνών – ΕΚΚΕ), Greek National Documentation Centre (Εθνικό Κέντρο Τεκμηρίωσης).
- Electronic databases: Medline, CINAHL, Greek medical databases, that is, Iatrotek.org, MedNet.gr.

All papers were screened by MB; summaries and any data considered dubious were discussed with the other co-authors. Only papers agreed by all the three authors were included. Exclusion criteria were that 1) they did not contribute to new knowledge in relation to the terms and aims and 2) they were not about Greece or England.

Results

Initially, 102 papers on PE policies, systems, and structures were identified. Of them, 80 papers were used and analyzed in the following sections: 46 were policy, legislative, and discussion papers about England; 21 were policy, legislation, and discussion papers about Greece; and 13 were comparative or discussion papers including both the countries. A short introduction about the general organization of the English and Greek NHSs is first presented, followed by the PE policies, systems, and structures in the two NHSs.

The NHSs

England

Established in 1948, the NHS centralized system, funded through national taxation, delivers services through public providers, devolving purchasing responsibilities to local bodies, that is, primary care trusts, clinical commissioning groups (CCGs).^{23,24} Health care spending is 9.1 of GDP (2013), medium compared to other countries and arguably

equitable.^{11,25–27} Public health funding is high; private out-of-pocket funding is moderate.²⁶ All citizens and residents are insured, but have limited provider choice or access to specialists. Only 10% have private health insurance, which gives higher quality care access and reduced waiting times.^{11,28} Initiatives focused on improving efficiency, responsiveness, and equity of the system, that is, foundation hospitals (2004) have greater management, financial responsibilities, and freedoms. Such measures aimed to reduce waiting lists, improve quality of provision, increase funding and staff numbers, encourage innovation, and extend patient choice.²³ Despite these, it has been argued that patients are prevented from taking control of their health care and frontline professionals from revolutionizing services for patients’ benefit.²⁹ Although UK health policy has focused on controlling spending, the system faces serious financial strains, waiting lists, and explicit rationing for some types of care¹¹ (Table 2).

Greece

The NHS inception in 1983 guaranteed free health care for all residents; introduced state responsibility for health care services provision, equal access, decentralization of planning, primary care development, exclusive employment of health care staff, and unification of main insurance funds.³⁰ Health care spending is 9.8 of GDP (2013), medium compared to other countries.²⁷ The system is characterized by a public–private mix for funding and delivery, high out-of-pocket payments, and little regulation of access to health care providers.^{11,26,31} Types of coverage available are the NHS, health insurance funds (occupation-based), and private health insurance.²³ Most Greeks (95%–97%) have private insurance for hospital care. The health insurance system is employer-based; employers enroll their employees in a “social” payer system, the ministry controls employee contribution rates, insurance benefits and the doctors’ social insurance funds.¹¹ NHS services are provided through a public hospital network, delivering to inpatients and outpatients. Advances in accessing health care services include development of rural surgeries, primary health centers, and public and regional teaching hospitals. There are many challenges, that is, integrating primary care services, high level of pharmaceutical expenditure and modernizing NHS management.²³ Public primary health care services are insufficiently developed, with the exception of some rural areas. Long waiting times for NHS care are partly due to provider shortages caused by low reimbursement rates.^{11,32,33} The system is characterized by over-centralization, fragmentation of coverage (with many insurance funds), regressive financing extensive

Table 2 Main characteristics of the English and Greek National Health Services

Characteristics	England	Greece
Funding	Centralized, comprehensive, single-payer system, funded by general tax revenues Moderate private out-of-pocket payments	Public and private mix for funding Ministry regulation: single-payer system High out-of-pocket payments
Delivery	Mainly public delivery of services; devolved purchasing responsibilities to local bodies, ie, PCTs, CCGs Wide network of public hospitals Strong public primary health care	Public and private delivery of services Wide network of public hospitals (inpatients and outpatients) Public primary health care insufficiently developed
Insurance	National insurance: all citizens and residents Only 10% of people have private insurance	Employer-based health insurance system, “social insurance funds” Coverage types: NHS, health insurance funds (occupation-based), and private health insurance Most people (95%–97%) have private insurance
Provider choice	Choice of public provider and access to specialists	Choice of public/private provider and health professionals
Principles/initiatives	Equal access to services by all, efficiency, responsiveness	Equity, solidarity, equal access to services
Challenges	Efficiency, quality, equality need strengthening Financial strains, waiting lists, explicit rationing (selective) for some types of care, ie, kidney dialysis, open heart surgery, and some other expensive procedures and technologies	Lack of primary care services; high pharmaceutical expenditure, waiting lists Modernization of management; over-centralization/fragmented service coverage Extensive user’ charges and informal payments

Abbreviations: PCT, primary care trust; CCG, clinical commissioning group.

user charges and informal payments, inefficient resource allocation, perverse incentives for providers, and heavy reliance on unnecessarily expensive inputs^{26,32,35} (Table 2).

PE policies

England

NHS policies emphasized the need for patient/user input to service planning, development, delivery at all levels, monitoring, evaluation, audit, and their outcomes in the 1990s.^{35–39} The Patients Charter presented the first “aspirational” vision for hospital patients; the standards were not legal rights, but “major and specific standards” encompassing respect for privacy, dignity, religious and cultural beliefs, continuity of care, and quality of nursing.³⁵ Other “rights” addressed waiting times, information (about cancellations), and timely responsiveness to complaints.³⁵

The NHS Plan and “Shifting the Balance of Power” were the first patient-centered strategies in the 2000s encapsulating a vision where patients had more say about health care provision, marking the need for organizational and cultural change.^{40,41} Subsequently, significant policies, legislations, and frameworks aimed to empower patients and the public.^{24,43–53} Importantly, patient and public involvement in planning, development, and making decisions affecting services operation became a duty enacted in the Health and Social Care Acts in 2001 and 2003.^{43,54} A subsequent Act (2006) placed a legal duty on health organizations to involve users/representatives through consultation, providing

them with information about planning services, proposals for change, and decisions affecting service operation⁵⁵ (Table 3).

The Next Stage Review (2008) placed quality at the heart of care, concentrating on patient-reported outcome measures, detailing elements of PE encompassing more information, choice, partnership working, and quality of care.⁵⁶ Other guides and programs supported community, patient, and public engagement in health care.^{57,58} The NHS Constitution brought together and explained patient’s rights and public, patient, and staff responsibilities, thereby empowering all, for the first time in 2009.⁵⁹ The Health Act 2009 placed a duty on all NHS providers to have regard to the Constitution, proposing measures to improve care quality, service performance, and public health.⁶⁰ In 2013, new rights for both patients and staff were added, and patient involvement was updated in the Constitution⁶¹ (Table 4).

In the 2010s, the NHS White Paper Equity and Excellence envisioned “an NHS genuinely centered on patients and carers” encompassing an information revolution, greater choice and control through shared decision-making, increased patient control over records, and equity for everyone.⁶² The NHS 2010–2015 Plan together with more recent operating frameworks are even more empowering, emphasizing driving change through patient influence and integrating information around patients.^{63,64} A key tenet is “people must be given rights and entitlements, with greater control over their own health and care;” explicitly referring to rights, full choice of

Table 3 A summary of patient empowerment policies and legislation in England and Greece (1990–2015)

	Policy and legislative focus	Legislative/policy frameworks: documentary sources
Empowerment policies and legislation 1990–1999		
England	Need for patient input to the planning, development, delivery of services Patients charter: “major and specific standards” rather than “rights” User involvement in monitoring, evaluation, services audit, and outcomes	The Patients Charter, 1991; ³⁵ Local Voices, 1992; ³⁶ A Service with Ambition, 1996 ³⁷ The Patients Charter, 1991 ³⁵ A Service with Ambition, 1996 ³⁷
Greece	Introduction of patients’ rights, based on the European Charter of Patients’ Rights Emphasis on rights and hospital management; statutory bodies for patients’ rights protection established at national and hospital level	Conservatives Reform and Law, 1992 ⁶⁹ Health Care Reform and Law, 1997 ⁷⁰
Empowerment policies and legislation 2000–2009		
England	First patient-centered policy reforms on shifting balance of power Legislation in health and social care enacted, placing a legal duty involving users Giving service users a stronger voice at national/local level in planning, development, and commissioning of services Engagement of service users in achieving “high quality care for all” Guidance on community engagement to improve health; a support programme to support patient and public engagement in health care Explanation of patients’ rights and responsibilities in new NHS Constitution; legislation places a duty on NHS providers to observe new constitution	NHS Plan, 2000; ⁴⁰ Shifting the Balance of Power, 2002 ⁴² Health and Social Care Acts 2001, 2003, 2006, 2009 ^{43,54,55,60} A Stronger Local Voice, 2006; ⁴⁹ Our Health, Our Care, our Say, 2006; ⁵⁰ World Class Commissioning, 2007 ⁵¹ Next Stage Review, 2008 ⁵⁶ Community Engagement, 2008; ⁵⁷ PP Engagement Support Programme, 2009–2010 ⁵⁸ NHS Constitution, 2009; ⁵⁹ Health Act, 2009 ⁶⁰
Greece	Citizens and their interests; reinforcement of the Office for Patient’s Reception Quality, effectiveness, and efficiency: explicit NHS policy goals Quality improvement in health services, living conditions in public health context Collaboration of hospitals and non-profit organizations reinforced Reinforcement of equity, service quality, protection of patient’s rights Enhancing/promoting citizens’ health by providing appropriate information, empowering to remain healthy and best usage of health and social care services	Health Care Reform and Law, 2001 ⁷¹ Health Care Reform and Law, 2005 ⁷² Ministry of Health and Social Solidarity’s Mission, 2008 ⁷³ National Action Plan for Public Health, 2008–2012 ⁷⁴
Empowerment policies and legislation 2010–2015		
England	Driving change through patient influence and integrating information around patients Information revolution, greater choice, and control through norms of shared decision making, increased patient control over records, and equity for everyone More patient choice enacted in law, with individual/public participation duties Empowerment with access to electronic medical records. Involving diverse communities and citizens directly in decisions about future health and care	NHS 2010–2015 Plan “From Good to Great” ⁶³ Equity and Excellence: Liberating the NHS, 2010 ⁶² Health and Social Care Act, 2012 ⁶⁵ NHS 5-year Forward View, 2014; ⁶⁷ NHS England Business Plan, 2015–2016 ⁶⁶
Greece	Reinforcement of patient empowerment bodies Empowerment mirroring positive health, emphasizing social and individual capacities	Ministry of Health and Social Solidarity’s Circulars and Targets, 2010 ⁹¹ National Action Plan for Human Rights, 2013 ⁷⁵

primary and secondary care services, more personal health responsibility, all increasing patient satisfaction. A significant proportion of provider income is linked to patient experience and satisfaction by linking payment to patient satisfaction, giving providers incentives to understand and improve.⁶³ With the Health and Social Care Act (2012), NHS duties to offer more patient choice were enacted in law, including individual and public participation.⁶⁵ The Health and Care System

(2013) gave local communities more say in care through health and well-being boards, envisioning that “everyone has greater control of their health and their wellbeing, supported to live longer, healthier lives by high quality health and care services that are compassionate, inclusive and constantly-improving.”⁶⁶ The NHS 5-year Forward View emphasized a new relationship with patients and communities, that is, empowerment with access to electronic medical records.⁶⁷

Table 4 A summary of patients' rights and entitlements in England and Greece

Rights/entitlement	England ^a	Greece ^b
Access to health care	<p>Access health services free of charge (limited exceptions by Parliament)</p> <p>Never refused on unreasonable grounds</p> <p>Expect NHS to assess community requirements and put services in place</p> <p>No unlawful discrimination in NHS service provision</p> <p>Access certain services commissioned by NHS bodies within maximum waiting times, or NHS to take reasonable steps to offer range of suitable alternative providers</p>	<p>Access the most appropriate hospital services for the disease/condition</p> <p>Collaboration between hospitals and non-profit health organizations^c</p> <p>Equity in service delivery^c</p>
Quality of care/environment	<p>Treatment with a professional standard of care, by appropriately qualified and experienced staff, in an organization meeting required levels of safety/quality</p> <p>Expect NHS organizations to monitor, make efforts to improve, the quality of health care</p>	<p>Efficiency and quality^c</p>
Approval of treatment, drugs, programs	<p>Use of drugs and treatments recommended by NICE^f if doctor states clinically appropriate</p> <p>Local decisions on funding of other drugs/treatments: following proper consideration of evidence</p> <p>Local NHS must explain decision not to fund drug/treatment that patients/doctors think appropriate</p> <p>Receive approved vaccinations under an NHS-provided national immunization program</p>	<p>Give/refuse consent to diagnostic/therapeutic procedures^e</p>
Respect, consent, confidentiality	<p>Be treated with dignity and respect</p> <p>Accept/refuse treatment, and not be given any examination/treatment without valid consent</p> <p>Be given information about proposed treatment in advance, including any significant risks/alternative treatments available, and risks without treatment</p> <p>Privacy/confidentiality: NHS to keep confidential information safe/secure</p> <p>Access to own health records</p>	<p>Receive care^d with due respect for dignity as human beings</p> <p>Give/refuse consent to diagnostic/therapeutic procedures^e</p> <p>Procedures only performed with consent. Patients entirely free to decide whether or not to agree to collaborate for the purposes of research or training. Consent to such collaboration is their own right and they may withdraw at any time</p> <p>Privacy/confidentiality must be guaranteed for content of documents concerning patient and the file in which medical notes are recorded. (Access to own health records is not explicitly stated)</p> <p>Have religious and ideological beliefs respected</p>
Information, informed choice, involvement in own health care and NHS	<p>Choose GP practice and be accepted unless reasonable grounds to refuse exist</p> <p>Express preference for choice of doctor within GP practice; practice to try to comply</p> <p>Make choices about NHS care based on supporting information</p> <p>Involvement in discussions/decisions about one's health care; be given information to enable one to do this</p> <p>Involvement, directly or via representatives, in planning health services, development/consideration of proposals for changes in service provision and decisions affecting service operation</p>	<p>Request information regarding health status. Guaranteed information provided is comprehensive and accurate</p> <p>Choice of public/private provider and health professionals</p> <p>Patients can obtain accurate picture of medical, social, and financial parameters of health status and participate in decision-making process likely to affect their life</p> <p>Patients/representatives informed in advance of risks likely to arise as a result of unusual or experimental diagnostic/therapeutic procedures</p>
Rights of redress	<p>Have complaints dealt with efficiently and properly investigated</p> <p>Know outcome of complaint investigation</p> <p>Refer complaint to Health Service Ombudsman, if dissatisfied with NHS process/outcome</p> <p>Claim for judicial review if directly affected by an unlawful act/decision of an NHS body</p> <p>Compensation if harmed by negligent treatment</p>	<p>Present complaints/objections</p> <p>Be fully informed on effects and outcomes of complaints</p> <p>Refer complaint to Health Service Ombudsman, if dissatisfied with NHS process/outcome</p>

Notes: ^aNHS Constitution (2009) (incorporating 2010, 2012, and 2013 updates).^{84,86} ^bGreek Parliament (2071/1992 Law).⁹³ except otherwise specified. ^cGreek Parliament (3370/2005 Law).⁹⁶ ^dCare covers practice of medicine, nursing, services of allied health care personnel, appropriate accommodation, treatment, administrative and technical services. ^eIf suffering from total/partial mental incapacity, exercise of this right devolves upon person legally acting on their behalf. ^fNational Institute for Clinical Excellence.

Abbreviations: NHS, National Health Service; GP, general practitioner.

Subsequently, the NHS England Business Plan (2015–2016) commits to innovative engagement with diverse communities and citizens, placing citizens at the center of design for new services and care models⁶⁸ (Table 3).

Greece

Health care reforms in the 1990s and 2000s utilized legislation addressing patients' rights and service quality.⁶⁸ The Conservatives' Reform in 1992 introduced patients' rights based on the European Charter; the most significant being rights of information, complaint, appropriate services, respect, and choice/refusal of treatment⁶⁹ (Table 4). The Health care Reform in 1997 also emphasized patients' rights and effective hospital management of utilizing user's views in decision-making, through establishment of statutory bodies for rights' protection at national and hospital level⁷⁰ (Table 3).

The following Health care Reform (2001) focused on Greek citizens and their interests, reinforcing the statutory bodies established in 1997 (below).⁷¹ This reform aimed to a patient-centered NHS, incorporating basic measures of universal coverage and equity in service delivery, efficiency, and quality.³⁴ Reforms were to be achieved through the establishment of National Health Institute's Regional Health Authorities and improved public hospitals with appointment of professional managers. The later Health care Reform (2005) addressed living conditions in the wider public health context; health priorities emphasizing equal access and need satisfaction. Official endorsement of collaboration of hospitals and nongovernmental health organizations was given.⁷² Patients' rights continued to be reinforced in 2008 with the MHSS' mission emphasizing equality, quality of services, and protection of individual and social rights.⁷³

Despite subsequent lack of reforms, recent National Action Plans were patient empowering. The National Action Plan for Public Health (2008–2012) explicitly mentions "information" and "empowerment of citizens."⁷⁴ The National Action Plan for Human Rights (2013) explains rights to health and refers to "empowerment" as mirroring positive health, emphasizing social and individual capacities.⁷⁵

PE systems and structures

England

National organizations, systems, and initiatives

National organizations' monitoring, regulating, and inspecting health care services, that is, the Care Quality Commission (2009), replacing the Health Care (2004) and the Mental Health Act Commissions (1983), have been active since the 1980s.^{76,77} National organizations empowering, protecting,

and strengthening patients and public have also been active; of these, the Health Service Ombudsman, established in 1973, considers complaints that the NHS has not acted properly, fairly, or provided a poor service.⁷⁸ This statutorily independent investigator has powers to summon witnesses and access records, breaches of which can be treated as akin to contempt of court.^{14,78} Other bodies now abolished, that is, the Commission for Patient and Public Involvement in Health (CPPIH) (2004–2007) and the National Resource Centre for Patient and Public Involvement (2006–2009), aimed to promote PPI value, and the latter to create a single point for information and advice (Table 5).^{79,80}

Changes implemented at the macro level included several choice initiatives, that is, the "Choose and Book" service, enabling patients requiring elective care to see information about hospitals and book first appointments through general practice surgeries or a booking service.⁸¹ Patient feedback was facilitated via annual hospital patient surveys, undertaken by NHS acute hospital trusts between 1997 and 2013. Over time, surveys expanded to include topics of public and/or political interest, that is, waiting times, single sex wards, and cleanliness. Wider annual national surveys were undertaken for inpatients (2002–2007) and outpatients (2003, 2004/2005) together with surveys on specific services or conditions.⁸² In 2013, the Friends and Family Test was introduced, asking service users if they would introduce a service to friends and families.⁸³ A new NHS Citizen Program was co-designed (2013), enabling NHS England to directly engage citizens in a publicly accountable and transparent forum, providing a framework for citizens to engage commissioners and providers of services, offering views, insights, and solutions, holding them to account. Since the program began, NHS England has facilitated workshops and regional events, with face to face and digital participation.⁸³

Local and trust/hospital systems and structures

Systems empowering patients and the public at the micro local/hospital level are also prevalent (Table 5). Community Health Councils (1974), the first formal structures to represent public interests locally, were abolished in 2003.⁸⁴ Their role was taken over by other services:

- Overview and Scrutiny Committees (2000), a statutory service, established to look at the local NHS work with local authority councillors having the powers to review and scrutinize the planning, provision, and operation of health services and to make improvement in recommendations.⁸⁵

Table 5 A summary of NHS patient empowerment systems and mechanisms in England and Greece (1973–2015)

England	Greece
National organizations (macro-level)	
Health Services Ombudsman (1973)	Ombudsman for Health and Welfare (2004)
National Resource Centre for Patient and Public Involvement (2006–2009)	Non-existent
Commission for Patient and Public Involvement (2004–2007)	Non-existent
NHS Citizen (2013–2015)	Patients' Rights Protection Independent Service (PRPIS) (1997–2015)
Non-existent	Patients' Rights Protection and Control Committee (PRPCC) (1997–2015)
Initiatives (macro-level)	
"Choose and Book" Choice of provider	Formal "choice" initiatives: non-existent
Annual Hospital Patient Surveys (1997–2013)	Choice of public/private provider and health professionals
National Surveys (2002–2007)	National Inpatient Survey (2002 only)
Family and Friends Test (2013–2015)	No other national surveys
Local and trust/hospital organizations, systems, and mechanisms (micro-level)	
Overview and Scrutiny Committees (OSCs) (2000–2013)	Non-existent
<ul style="list-style-type: none"> Reviewed NHS/local authority work Empowered to review planning, provision, operation and make recommendations for improvement of services 	
Independent Complaints Advocacy Services (ICAS) (2003–2013)	Non-existent
<ul style="list-style-type: none"> Independent support to patients/carers wishing to complain about their local NHS treatment/care 	Complaints to the office for communication with citizens/ chief executive
PPI Leads/Heads designated (managed by directors of Nursing)	Non-existent/responsibility of chief executives
Patient Advice and Liaison Services (PALSs) (2002–2015)	Offices for Communication with Citizens (OCCs) (1997–2015)
<ul style="list-style-type: none"> Provides accessible support, advice, and information to patient/carers in NHS settings Provides reports/statistics on advice and support given Several committees have involved members of PPIFs'/LINKS/Healthwatch (2003–2015) NHS Citizen/NHS Citizen Development Sites (2013–2015) 	<ul style="list-style-type: none"> Questionnaires and questionnaire boxes Posters with patient's rights Three-monthly/annual statistics reports
Patient and Public Involvement Forums (PPIFs) (2003–2008) ^a	Citizen's Rights Protection Committees (CRPC) (1997): patient member mandatory
<ul style="list-style-type: none"> Independent volunteers, monitored NHS quality from the patient perspective 	No formal patient representation in forums/committees apart from CRPC
Local Involvement Networks (LINKS) (2008–2012)	
<ul style="list-style-type: none"> Provided communities with involvement opportunities and greater ownership by influencing local health and social care services 	
Healthwatch England and local Healthwatch (2012)	
<ul style="list-style-type: none"> Gathers/represents public views 	
NHS Citizen/NHS Citizen Development Sites (2013–2015)	
<ul style="list-style-type: none"> Create opportunities to bring public voice to NHS England Board 	

Note: ^aPPIFs were replaced by LINKS (2008) and more recently with Healthwatch England and local Healthwatch (2012, 2013).

- Independent Complaints Advocacy Service (ICAS) (2003), another statutory service, launched aiming to provide independent support to patients/carers wishing to complain about their NHS treatment and care locally.⁴⁵
- Patient Advice and Liaison Services (PALS) (2002) established aiming to provide accessible support, advice, and information to patient/carers in NHS settings.⁴⁰
- Patient and Public Involvement Forums (PPIFs) (2003), independent bodies made up of volunteers, set up to monitor the NHS quality from the patient perspective. PPIFs were supported by the CPPIH.⁴⁰

Recently, NHS Citizen Development Sites (2014) provide opportunities for people in local areas to make links with the NHS Citizen Program, bringing public voice to the board of NHS England.⁸⁶

Greece

National organizations, systems, and initiatives

The Health and Welfare Inspectorate, established to provide good quality services to citizens, has been active since 2001.⁸⁷ It has a repressive and preventative role by conducting checks and audits and suggesting imposition of

punishments or staff disciplinary control, simultaneously checking relevant procedures and making propositions. Although under the jurisdiction of the MHSS, it has full inspection independence collaborating with the Patients' Rights Protection and Control Committee (PRPCC) (below).⁸⁸ Other national bodies promote, protect, and strengthen patients' rights. The Greek ombudsman for Health and Welfare, established in 2004⁸⁹ as part of the Greek Ombudsman duties,⁷⁰ is the most prevalent. It suggests measures to the ministry for restoration and protection of patients' rights; elimination of bad management, improvements in health and social welfare services, and relationships with citizens⁸⁹ (Table 5).

National statutory bodies to protect patients' rights were introduced in 1997.⁷⁰ The Patients' Rights Protection Independent Service (PRPIS) was established to monitor patients' rights protection, investigate formal written complaints, and report progress to the Ministry's Secretary General. It requires annual hospital reports on their Office for Communication with Citizen (OCC) activities encompassing annual complaints, their resolution, time spent on complaint investigations, and decisions taken. PRPIS has the right to suggest solutions, request further investigations, and make recommendations. Although part of the MHSS, it has independent status.⁷⁰ PRPIS proposed establishment of reception desks (welcome points) in all public hospitals, staffed by OCCs, to make available information leaflets on patients' rights and PRPIS functions.⁷¹

The PRPCC was also established (1997) to ensure hospital compliance with patients' rights regulation and conduct in-depth, national investigations of complaints.⁷⁰ It comprises a State Legal Council representative and representatives of 13 professional Greek institutions from a spectrum of professions. Once a decision regarding a patient complaint is made, the Ministry's Secretary General is notified and ensures that appropriate actions are taken by hospital management. However, it has been under-functioning since 2005.

In 1999, two new bodies answering directly to the ministry were launched within the PRPIS: an "Office for the Protection of Individuals with Psychological Disorders" to protect the rights of these individuals and a "Special Committee for the Rights of Individuals with Psychological Disorders" to ensure compliance with the Office."⁸⁹ A national inpatient survey (2002) was also introduced following the 2001 reforms, aiming to evaluate public hospitals by measuring users' satisfaction;⁹⁰ plans for ongoing annual surveys, however, were not materialized.

Hospital systems and structures

Statutory bodies were also established within all hospitals in 1997.⁷⁰ OCCs acted as information points for patients/service users, registering complaints, operating under direct supervision of hospital chairmen/chief executives.⁷¹ They became "Offices of Patients' Reception," and their role changed slightly to welcoming and directing patients, accompanying them to the appropriate hospital services in 2001; thus, reception desks (welcome points) were created in all public hospitals.⁷¹ In 2010, MHSS' circulars and targets included commencement of quality monitoring processes and reinforcement of the OCCs.⁹² A circular reminded all hospitals that "an Office of Patients' Reception – Office of Communication with Citizen, staffed suitably, should exist in visible location near the entrance in every infirmary."⁹³ Their aim was the reception, information, update, direction, and support of all patients and those accompanying them, about complaint procedures and information on hospital rules. Thus, a double more inclusive role with extensive responsibilities was allocated to the offices. The same year they were renamed to "Offices for Citizen's Support," responsible for the patient welcoming, information, movement control, administrative support, management and dispatch of concerns, complaints, and overall protection of patients' rights.⁹⁴

Citizens Rights' Three-member Protection Committees (CRPCs), established in 1997, investigated complaints and protected and promoted patients' rights in collaboration with the OCCs for which it had a monitoring function. Its membership should include a user representative; the Board of Directors should ensure that all hospital patients were aware of their rights. CRPCs membership comprised a hospital manager/chair, the directors of medical and nursing services (user representative details not stated). In addition, other structures were introduced in 2010 reinforcing patient organizations and volunteering, and also evaluation, monitoring, and reporting, that is, Consultation Councils for Transparency and Monitoring in Health and Social Welfare, the "Registry for Volunteering in Health and Social Care."⁹⁴

Cross-national analysis and discussion

This is the first paper to compare national policies, systems, and structures for PE in England and Greece. Notwithstanding its limitations, that is, based on a critical policy and legislation review in English and Greek language, and not taking into account patients, public, and other stakeholders'

perspectives and preferences, it has highlighted the important differences and similarities.

The NHSs and PE policies

English and Greek NHSs, having been developed differently, have diverse characteristics and face substantive challenges (Table 2) with significant implications for PE. Both NHSs, committed to equity in service access, face serious financial strain, patients experience disempowering effects of waiting lists (both), rationing (England), extensive user charges, and informal payments (Greece). Despite these challenges, both the countries have recognized the benefits of making health systems more patient-centered and responsive by adopting PE strategies and have invested in infrastructures to support policy implementation despite financial constraints.¹⁵

In England, policies and legislation have focused on patient-centered quality services, explicit PPI, engagement, empowerment, and more recently on patients' rights. In Greece, the policy and legislative focus has been on patients' rights, statutory bodies to protect rights and quality of services, with only a very recent focus on "empowerment" (Table 3). Patients' rights encompass human, social, and individual rights, addressing quality and accessibility of health care as well as basic consumer rights, balancing the partnership between providers and individual receivers of care.⁹⁵ Common dimensions of PPI and patients' rights are information and complaining. Patients' "voice" and "choice" are other common dimensions, requisite for PPI and underpinning values for all rights.^{14,21,96} Although these may be comparable elements, their focus, emphasis, and implementation may differ, that is, information, complaining, "choice," and "voice" may have different meanings and take different forms in the two countries. The timing and the development of patients' rights also differ greatly; since the introduction of patients' rights in 1992, there have not been great developments in Greek legislation, perhaps with the exception of the most recent introduction of the term "empowerment," while patients' rights have been developed and expanded greatly since the NHS Constitution in 2009 in England (Table 4). However, there may be recent convergence of policies; patients' rights were introduced as important PE mechanisms in England in 2009 and have been strengthened since then; and PE has been emphasized in Greek policies more recently.

Challenges existed in implementing PE policies and reforms in both the countries slowing down the pace of change. In England, reports noted barriers to patients taking control of their health and health professionals

revolutionizing services.^{11,29} In Greece, a need exists to modernize organizational management, tackle sources of over centralization/fragmentation of services and resolve factors which led to a hiatus in reforms post 2008.^{31,25,29} The recent economic crisis has severely affected the implementation of policies in health and health care in Greece, that is, health care budgets have been slashed; in England, recent health budget cuts are also evident.^{97,98} However, in both the countries, recent developments suggest positive attempts to move policy implementation forward, that is, the National Action Plan for Human Rights⁷⁵ in Greece explains and emphasizes on rights to health, and the recent NHS England Business Plan influences empowerment and engagement of citizens in decisions about future service design.⁶⁶

These developments may not be surprising, as policy makers are expected to implement human-centered approaches, safeguarding dignity and rights to face financial cuts and crisis.^{99,100}

PE systems and structures

Diverse systems and structures have been implemented in both the countries to support PE, patient and public involvement, and patients' rights (Tables 4 and 5). At a macro-level, the independent health ombudsman role is of vital importance in both the countries. However, in Greece because of the nonexistence of local independent organizations or mediating bodies, its role assumes greater importance. National organizations/committees have been set up to protect rights in both the countries, that is, PRPIS and PRPCC in Greece and the NHS citizens in England.

At trust/hospital micro-level, committee structures with patient representation have also been implemented in both the countries to support PE. Although PALSs and OCCs' functions are comparable, PALS have been stable over the years, but legislation in Greece continues to devolve power to OCCs, although one could argue that their name change and slightly diminished role may have created confusion among staff and patients, limiting their functions (Table 5). Furthermore, policy recommendations and implementation guidance for local organizations have been weak in England and required improvement; in contrast, in Greece some guidance and monitoring systems for OCCs is in place. Other PE mechanisms at the local level, that is, the ICAS in England and the Citizen's Rights Protection Committees (CRPCs) in Greece are acknowledged as areas of difference between the two systems. Important systemic and cultural connotations for PE, essential in dealing with the deficiencies of each system and alternative coping mechanisms are highlighted

elsewhere, that is, the role of the voluntary sector in both the countries and the family's role in Greece.^{101,102}

At both macro- and micro-level, monitoring, audit and evaluation investigating PE issues from both patient and professional perspectives is helpful in providing evidence for improving policies, organizational systems, management, professional practices, and the patient experience. In both the countries, patient surveys (Table 4) have been utilized for these purposes, most frequently and consistently in England; in Greece, greater use of survey research or use of alternative feedback forums (currently lacking) would give greater weight to policy development and reform.

Conclusion

The NHSs policies and legislations linked to PE were very different in England and Greece; in turn, PE systems, structures, and mechanisms reflect these influences in England and Greece. Different language and terminology have been used, that is, “patient (and public) involvement” and “engagement” in England, “patients’ rights” and “responsibilities” in Greece. However, PE similarities, comparable dimensions, and mechanisms were also identified.

Future studies could draw on these findings and explore how the implementation of PE policies and legislation may influence PE within organizations, that is, hospitals, in both individual and organizational levels. Further research in implementation of national systems, structures, and mechanisms, investigating PE from both patient and professional perspectives could provide evidence for improving policies, organizational systems, management, professional practices, and patient experience, preference, and adherence. For both the countries, comparative research could be beneficial in building connections and relationships, help to bridge the gap between research and policy implementation and contribute to wider European and international developments on PE, involvement and patients’ rights. Furthermore, the importance of patient and public involvement in such developments and how these factors impact on patient preference and adherence should be explored and highlighted.

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