

Η συμμετοχή των ασθενών στη λήψη αποφάσεων πολιτικής υγείας: ερευνητικά ευρήματα από την Ευρώπη



Διάλεξη

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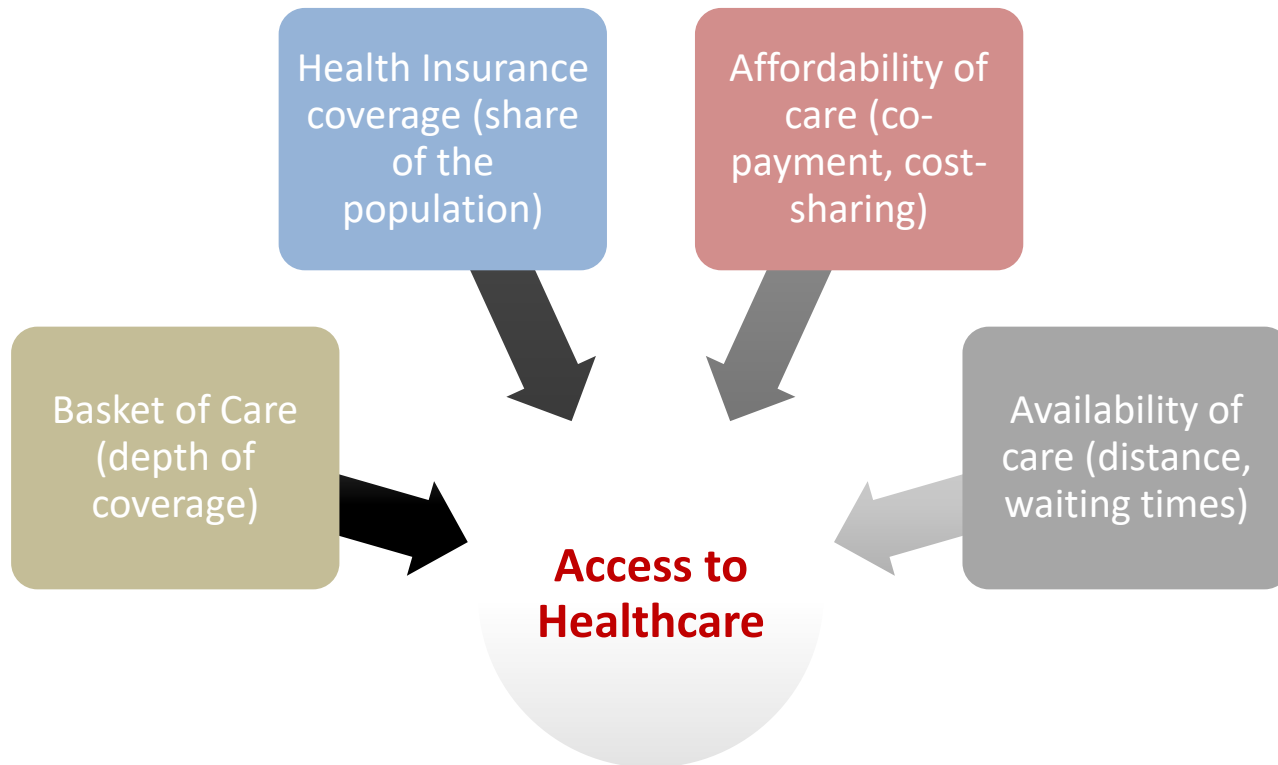
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Source: European Commission, "Communication from the Commission on effective, accessible and resilient health systems", COM(2014)215



Perception I: the PACT project...

- The **primary aim of this project** is to provide policy makers with the tools to assess access to health care services and address any barriers and inequities
- by developing, testing and proposing a **new assessment tool for the evaluation of access to health care services in EU-28**



A Conceptual Framework of Mapping Access to Health Care across EU Countries: The Patient Access Initiative

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Key Words

Access to health care · Stakeholders · Measurement · Health policy

Abstract

Research evidence suggests that access to health care is the key influential factor for improved population health outcomes and health care system sustainability. Although the importance of addressing barriers in access to health care across European countries is well documented, little has been done to improve the situation. This is due to different definitions, approaches and policies, and partly due to persisting disparities in access within and between European countries. To bridge this gap, the Patient Access Partnership (PACT) developed (a) the 'SAs' definition of access, which details the five critical elements (adequacy, accessibility, affordability, appropriateness, and availability) of access to health care, (b) a multi-stakeholders' approach for mapping access, and (c) a 13-item questionnaire based on the 5As definition in an effort to address these obstacles and to identify best practices. These tools are expected to contribute effectively to addressing access barriers in practice, by suggesting a common framework and facilitating the exchange of knowledge and expertise, in order to improve access to health care between and within European countries.

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Introduction

Access to health care is a complex notion used to describe several aspects of utilization and delivery of health care services. Although the terms access, utilization, availability and universal coverage are used interchangeably in the literature in an effort to illustrate whether the health need of a patient is covered in an effective and timely manner, they refer to different elements of access to health care. Utilization appertains to 'the outcome of the interaction between health professionals and patients' [1], while availability to the actual presence of health services delivery in terms of infrastructure, health personnel and utilization [2]. The WHO [3] defined universal coverage as 'ensuring that all people can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship'. Goddard and Smith [4] delineate access as 'the ability to secure a specified set of healthcare services, at a specified level of quality, subject to a specified maximum level of personal inconvenience and cost, while in possession of a specified amount of information'. Despite the efforts of the research community, especially in the last decades, access remains a complicated and vague concept susceptible to various interpretations [5].

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Perception I: the PACT project...

The five A's principles / criteria in defining access:

1. **Availability**: Whether services are available in the first place
2. **Adequacy**: Whether there is an adequate and continued supply of available services
3. **Accessibility**: Whether the services are effectively available for utilization (timeliness)
4. **Affordability**: Whether there is a system for financing health services so people have not financial hardship when using them
5. **Appropriateness**: available health care resources should meet the needs of different population groups



RESEARCH

Open Access



Access to treatment for Hepatitis C among injection drug users: results from the cross-sectional HOPE IV study

Kyriakos Souliotis^{1,2*}, Eirini Agapidaki², Manto Papageorgiou¹, Niki Voudouri³ and Xenophon Contiades^{1,4}

Abstract

Background: Evidence suggests that Greece is among the European countries with increased trend in HCV prevalence among injecting drug users (IDUs) from 2008 to 2014. Nonetheless, the access of IDUs to treatment for Hepatitis C Virus (HCV) is very limited while the risk of co-infection and transmission remains high. In an effort to better understand the inhibitors to HCV treatment, the present study aimed to investigate the main barriers to access in a sample of IDUs.

Methods: The cross-sectional study was carried out between July and September 2015 using a 23-items questionnaire. Participants were recruited from urban primary services, mobile health vans, community health services, day-care centers as well as during street work, located in Athens, Greece. Inclusion criteria were age above 18 years, understanding and speaking Greek sufficiently, HCV diagnosis, intravenous drug use. Data collection was carried out by health professionals of Praksis, a non-governmental organization. For the comparisons of proportions chi-square and Fisher's exact tests were used.

Results: The study sample consisted of 101 HCV patients, 68% male. More than 80% of study participants experienced barriers in accessing their doctor and medication during the past 12 months. The most common obstacles in accessing a doctor were "delay in making the appointment and "difficulties in going to the doctor due to health condition or lack of means of transport". Access to physician or medication was not differed according to gender, but significant differences were found according to economic status and health insurance coverage. 56.1% of participants reported loss or treatment delay due to barriers to treatment. The majority of participants had deteriorated financial status, health status, access to health services and medication, higher financial burden for health services, worse mental health and lower adherence to medical instructions in 2015 compared to 2009.

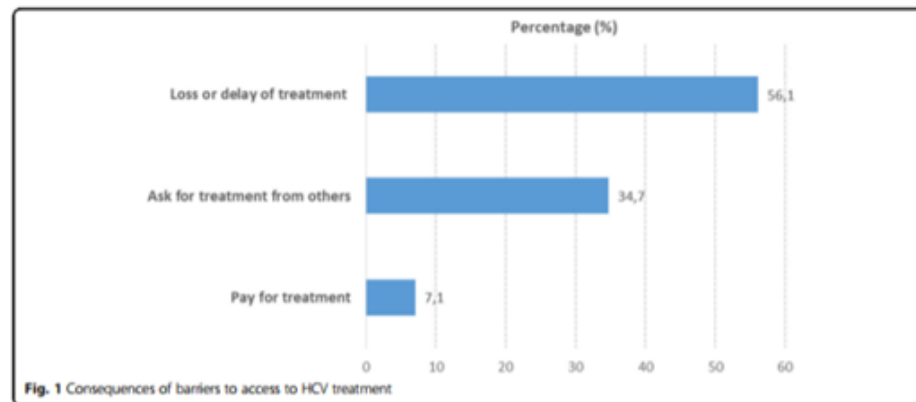
Conclusions: The findings from the present study revealed that the vast majority of IDUs experience significant barriers in seeking HCV care in Greece, thus highlighting the need for immediate action in this particular area due to the high risk of co-infection and transmission.

Keywords: Hepatitis C, HCV, Injecting drug users, Greece, Healthcare, Pharmaceuticals, Barriers, Patient access, Recession, Economic crisis

Table 2 Barriers to access treatment in total sample and according to demographic and socioeconomic determinants

	Total sample	Sex		Monthly income		Self-assessment of economic status		Health insurance	
				≤500	>500	Bad/Very bad	Good/Fair	No	Yes
		%	%	%	%	%	%	%	%
Barriers to physician access	86.9	83.6	93.8	82.4	95.7	81.1*	97.0	85.1	88.5
Delay in making appointment	47.5	50.7	40.6	39.7*	82.6	39.6	60.6	34.0*	59.6
Difficulties due to health reasons or lack of transportation means	46.5	41.8	56.3	50.0	26.1	50.9*	36.4	51.1	42.3
Language barriers	13.1	17.9	3.1	14.7	4.3	17.0	3.0	23.4*	3.8
Barriers to medication access	84.8	80.6	93.8	79.4	95.7	79.2*	97.0	80.9	88.5
Language barriers	14.1	16.4	9.4	14.7	4.3	17.0	3.0	23.4*	5.8

Note: Asterisks indicate significant difference in the proportions





W. Edwards Deming
(1900-1993)

"You can't manage what you can't measure"



Patients' empowerment to shape the future of healthcare

"We need to shift towards more patient-centred healthcare systems. Such type of care models have been shown to be cost-effective as well as improve patients' satisfaction and clinical outcomes" said Ms. Bedlington.

Patients need to be empowered to become these co-producers of their health. An effective empowerment strategy starts with promoting health literacy in order to equip patients with the capacity to obtain, interpret and understand health information to make sound health decisions.



Editorial briefing

Quality in healthcare and the contribution of patient and public involvement: talking the talk and walking the walk?

Kyriakos Souliotis

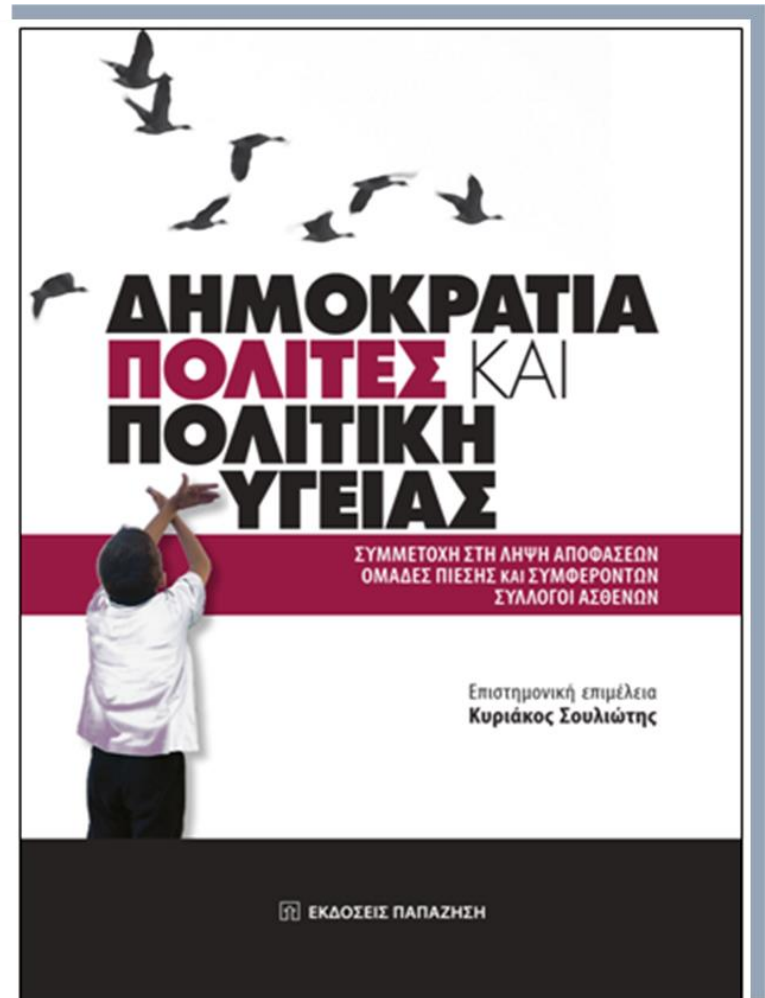
First published: 13 January 2015 [Full publication history](#)

Health Expectations is strongly committed to encouraging patient and public participation in health care and health policy. By publishing high-quality research on such topics, HEX aims to inform policies and practices as well as to advocate for the importance of patient and public participation in the early stages of health research design to ensure it meets real-life health needs of the population.



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HEALTH DEMOCRACY AND PATIENT PARTICIPATION INDEX



Mission: Patient Empowerment – The EMOTION PROJECT

Aim: To help Patient Organisations achieve a formal position in decision making on health (access, reimbursement, budget allocation, health priorities, health reforms, etc)

Evidence from Europe



Σκεπτικό - Κατασκευή Δείκτη

- Η έννοια του “patient-centered care” (φροντίδα με επίκεντρο τον ασθενή)
- «Η συνεργασία ανάμεσα σε επαγγελματίες υγείας και ασθενείς προκειμένου να διασφαλιστεί ότι οι αποφάσεις σέβονται τις επιθυμίες, ανάγκες και προτιμήσεις των ασθενών και ότι οι ασθενείς έχουν την εκπαίδευση και την υποστήριξη που χρειάζεται για να λάβουν οι ίδιοι αποφάσεις και να συμμετέχουν ενεργά στη θεραπεία τους»
- Εφαρμογή στο micro, meso και το macro επίπεδο



ΣΚΕΠΤΙΚΟ

- Η **συμμετοχή των ασθενών** δεν περιορίζεται στο ατομικό επίπεδο, καθώς οι ασθενείς μπορούν συλλογικά να συμμετάσχουν σε διάφορα επίπεδα λήψης αποφάσεων (π.χ. διαμόρφωση ευρύτερων και στοχευμένων πολιτικών για την υγεία, κλινική έρευνα, health technology assessment, διαμόρφωση κατευθυντήριων οδηγιών θεραπείας, κτλ)
- **Συγκλίνοντα ευρήματα** τεκμηριώνουν μια τέτοια συμμετοχή για λόγους: δημοκρατικούς, ενδυνάμωσης και αποτελεσματικότητας και αποδοτικότητας του συστήματος υγείας (π.χ. μείωση δαπανών, καλύτερη ποιότητα φροντίδας, κτλ)



Ενδυνάμωση

- Η **ενδυνάμωση των ασθενών** είναι αλληλένδετη με τη συμμετοχή και την εγκαθίδρυση ενός μοντέλου φροντίδας επικεντρωμένου στον ασθενή
- Στο **Ευρωπαϊκό Καταστατικό των Βασικών Δικαιωμάτων** (European Charter of Fundamental Rights) η ενδυνάμωση των ασθενών έχει κεντρικό ρόλο
- Η **Ευρωπαϊκή Επιτροπή** υποστηρίζει την ενδυνάμωση και συμμετοχή των ασθενών στην υγεία
- Πολλές **χώρες** έχουν μεταρρυθμίσει τις νομοθεσίες τους προκειμένου να εξασφαλιστεί η ενδυνάμωση των ασθενών (“Health Democracy” French Act, 2002)



Δημιουργία Δείκτη

- **Ερευνητικός σκοπός:**

- η δημιουργία ενός δείκτη που θα διερευνά το βαθμό και την επίδραση της συμμετοχής συλλόγων ασθενών στη λήψη αποφάσεων για την υγεία στο μέσο- και μακρο-επίπεδο
- η διερεύνηση των ψυχομετρικών του ιδιοτήτων



Δημιουργία Δείκτη

- Ορίστηκε η **εννοιολογική κατασκευή** βάσει βιβλιογραφικής ανασκόπησης («συμμετοχή συλλόγων ασθενών στη λήψη αποφάσεων πολιτικών υγείας»)
- Ο ορισμός εξετάστηκε από **επιτροπή 35 stakeholders** (μέλη συλλόγων ασθενών, ερευνητές και policy makers)
- Η ίδια επιτροπή εξέτασε και τα **λήμματα** που προέκυψαν από βιβλιογραφική ανασκόπηση
- **Ομάδα εστιασμένης συζήτησης** 12 μελών συλλόγων ασθενών εξέτασαν επίσης τα λήμματα
- Το **ερωτηματολόγιο** χορηγήθηκε σε **δεύτερο χρόνο** σε 440 μέλη ασθενών (στρατολογήθηκαν 553, ποσοστό απόκρισης 74.9%)
- Σε **τυχαίο υπο-δείγμα 100** συμμετεχόντων, το ερωτηματολόγιο **επαναχορηγήθηκε 1 εβδομάδα** μετά



Health democracy in Europe: Cancer patient organization participation in health policy

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Abstract

Background: Patient organization participation in health policy decision making is an understudied area of inquiry. A handful of qualitative studies have suggested that the growing number of patient organizations in Europe and their increasing involvement in policy issues do not result in high political effectiveness. However, existing research is largely country-specific.

Objective: To examine the degree and impact of cancer patient organization (CPO) participation in health policy decision making in EU-28 and to identify their correlates.

Methods: A total of 1266 members of CPOs participated in this study, recruited from a diversity of sources. CPO participation in health policy was assessed with the Health Democracy Index, a previously developed instrument measuring the degree and impact of patient organization participation in various realms of health policy. Additional questions collected information about participants' and the CPO's characteristics. Data were gleaned in the form of an online self-reported instrument.

Results: The highest degree of CPO participation was observed with respect to hospital boards, reforms in health policy and ethics committees for clinical trials. On the contrary, the lowest was discerned with regard to panels in other important health-related organizations and in the Ministry of Health. The reverse pattern of results was observed concerning the Impact subscale. As regards the correlates of CPO participation, legislation bore the strongest association with the Degree subscale, while organizational factors emerged as the most important variables with regard to the Impact subscale.

Conclusions: Research findings indicate that a high degree of CPO participation does not necessarily ensure a high impact. Efforts to promote high and effective CPO participation should be geared towards the establishment of a health-care law based on patient rights as well as to the formation of coalitions among CPOs and the provision of training to its members.

KEYWORDS

health policy decision making, patient-centred care, patient empowerment, patient involvement, patient rights

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	Mean (SD)	Median (IQR)
Does your patient organization take part in reforms or crucial decisions in health policy?	3.4 (1.8)	3 (2-5)
Does your patient organization take part in workshops or panels held at the Ministry of Health?	3.4 (1.9)	3 (2-5)
Does your patient organization take part in workshops or panels in other important organizations, pertinent to health?	3.6 (1.7)	4 (2-5)
Does your patient organization take part in boards of hospitals?	1.9 (1.4)	1 (1-2)
Does your patient organization take part in Ethics Committees for clinical trials?	2.1 (1.3)	2 (1-3)
Does your patient organization take part in Health Technology Assessment procedures?	2.3 (1.6)	2 (1-3)
Does your patient organization is present in the national parliament during decision making for important health policies/issues?	1.8 (1.2)	1 (1-2)
How often do you observe a substantial change in the content of a health policy decision as a result of interference from a patient organization? (yours or another's)	3.7 (1.6)	4 (2-5)
<i>HDI total score</i>	22.2 (8.6)	22 (16-28)



Αξιοποίηση δείκτη

- Ύστερα από προσαρμογή του δείκτη σε διεθνή δεδομένα, χρησιμοποιήθηκε σε συγχρονική επιδημιολογική μελέτη με στόχους:
 - Την καταγραφή του επιπέδου της συμμετοχής των συλλόγων ασθενών στη λήψη αποφάσεων πολιτικής υγείας
 - Την καταγραφή της επίδρασης της συμμετοχής αυτής στις τελικές αποφάσεις
 - Της αξιολόγησης των οργανωτικών και ατομικών χαρακτηριστικών που σχετίζονται με τα παραπάνω





Assessing Patient Participation in Health Policy Decision-Making in Cyprus



Kyriakos Souliotis^{1,2*}, Eirini Agapidaki², Lily Evangelia Peppou³, Chara Tzavara², George Samoutis⁴, Mamas Theodorou⁵

Abstract

Although the importance of patient participation in the design and evaluation of health programs and services is well-documented, there is scarcity of research with regard to patient association (PA) participation in health policy decision-making processes. To this end, the present study aimed to validate further a previously developed instrument as well as to investigate the degree of PA participation in health policy decision-making in Cyprus. A convenient sample of 114 patients-members of patients associations took part in the study. Participants were recruited from an umbrella organization, the Pancyprian Federation of Patient Associations and Friends (PFFA). PA participation in health policy decision-making was assessed with the Health Democracy Index (HDI), an original 8-item tool. To explore its psychometric properties, Cronbach α was computed as regards to its internal consistency, while its convergent validity was tested against a self-rated question enquiring about the degree of PA participation in health policy decision-making. The findings revealed that the HDI has good internal consistency and convergent validity. Furthermore, PAs were found to participate more in consultations in health-related organizations and the Ministry of Health (MoH) as well as in reforms or crucial decisions in health policy. Lower levels were documented with regard to participation in hospital boards, ethics committees in clinical trials and health technology assessment (HTA) procedures. Overall, PA participation levels were found to be lower than the mid-point of the scale. Targeted interventions aiming to facilitate patients' involvement in health policy decision-making processes and to increase its impact are greatly needed in Cyprus.

Keywords: Patient Participation, Health Policy, Decision-Making

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Table 4. Summary Statistics for the HDI Items

	Mean (SD)	Median (IQR)
Does your patient organization take part in reforms or crucial decisions in health policy?	3.54 (1.61)	3.53 (2-5)
Does your patient organization take part in workshops or panels held at the MoH?	3.31 (1.72)	3 (2-5)
Does your patient organization take part in workshops or panels in other important organizations, pertinent to health?	3.71 (1.61)	4 (2-5)
Does your patient organization take part in boards of hospitals?	2.10 (1.59)	1 (1-3)
Does your patient organization take part in Ethics Committees for clinical trials?	2.10 (1.59)	1 (1-2)
Does your patient organization take part in HTA procedures?	2.24 (1.63)	1 (1-3)
Does your patient organization take part in the national parliament during decision-making for important health policies/issues?	2.70 (1.64)	2 (1-4)
How often do you observe a substantial change in the content of a health policy decision as a result of interference from a patient organization? (yours or another's)	3.33 (1.44)	3 (2-4)
HDI total score	23.04 (10.00)	20.00 (15.00-29.00)

Abbreviations: HDI, Health Democracy Index; MoH, Ministry of Health; HTA, health technology assessment.





Assessing Patient Organization Participation in Health Policy: A Comparative Study in France and Italy



Kyriakos Souliotis^{1*}, Eirini Agapidaki¹, Lily Evangelia Peppou², Chara Tzavara¹, Dimitrios Varvaras³, Oreste Claudio Buonomo³, Dominique Debiais⁴, Stanimir Hasurdjiev⁵, Francois Sarkozy⁶

Abstract

Background: Even though there are many patient organizations across Europe, their role in impacting health policy decisions and reforms has not been well documented. In line with this, the present study endeavours to fill this gap in the international literature. To this end, it aims to validate further a previously developed instrument (the Health Democracy Index - HDI) measuring patient organization participation in health policy decision-making. In addition, by utilizing this tool, it aims to provide a snapshot of the degree and impact of cancer patient organization (CPO) participation in Italy and France.

Methods: A convenient sample of 188 members of CPOs participated in the study (95 respondents from 10 CPOs in Italy and 93 from 12 CPOs in France). Participants completed online a self-reported questionnaire, encompassing the 9-item index and questions enquiring about the type and impact of participation in various facets of health policy decision-making. The psychometric properties of the scale were explored by performing factor analysis (construct validity) and by computing Cronbach α (internal consistency).

Results: Findings indicate that the index has good internal consistency and the construct it taps is unidimensional. The degree and impact of CPO participation in health policy decision-making were found to be low in both countries; however in Italy they were comparatively lower than in France.

Conclusion: In conclusion, the HDI can be effectively used in international policy and research contexts. CPOs participation is low in Italy and France and concerted efforts should be made on upgrading their role in health policy decision-making.

Keywords: Patient Participation, Health Policy Decision-Making, Cancer Patient Organizations (CPOs), Scale Development

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Table 3. Descriptive Statistics for the Type of Participation Concerning HDI Items for Italy and France

	Type of Participation	France	Italy	P
		No. (%)	No. (%)	
In reforms or key decisions in health policy	Observer	39 (41.9)	65 (68.4)	< .001 ^a
	Consulted	45 (48.4)	5 (5.3)	
	Vocal participant	9 (9.7)	20 (21.1)	
	Voting member	0 (0.0)	5 (5.3)	
In panels of experts or workshops held in the Ministry of Health	Observer	21 (22.6)	85 (89.5)	< .001 ^b
	Consulted	39 (41.9)	0 (0.0)	
	Vocal participant	33 (35.5)	10 (10.5)	
	Voting member	0 (0.0)	0 (0.0)	
In panels or workshops in other important organizations pertinent to health	Observer	30 (32.3)	80 (84.2)	< .001 ^b
	Consulted	42 (45.2)	0 (0.0)	
	Vocal participant	21 (22.6)	5 (5.3)	
	Voting member	0 (0.0)	10 (10.5)	
In hospital boards	Observer	42 (45.2)	80 (84.2)	< .001 ^a
	Consulted	39 (41.9)	0 (0.0)	
	Vocal participant	9 (9.7)	15 (15.8)	
	Voting member	3 (3.2)	0 (0.0)	
In Ethics Committees for clinical trials	Observer	33 (35.5)	85 (89.5)	< .001 ^a
	Consulted	27 (29.0)	0 (0.0)	
	Vocal participant	27 (29.0)	10 (10.5)	
	Voting member	6 (6.5)	0 (0.0)	
In health technology assessment procedures for the scientific evaluation of new treatments & methods	Observer	60 (64.5)	80 (84.2)	< .001 ^a
	Consulted	24 (25.8)	5 (5.3)	
	Vocal participant	6 (6.5)	10 (10.5)	
	Voting member	3 (3.2)	0 (0.0)	
In health technology assessment procedures for the economic evaluation of new treatments & methods	Observer	78 (83.9)	80 (84.2)	< .001 ^a
	Consulted	15 (16.1)	0 (0.0)	
	Vocal participant	0 (0.0)	10 (10.5)	
	Voting member	0 (0.0)	5 (5.3)	
In the national parliament during decision-making for important health policies/legislation	Observer	63 (67.7)	80 (84.2)	< .001 ^a
	Consulted	27 (29.0)	5 (5.3)	
	Vocal participant	3 (3.2)	5 (5.3)	
	Voting member	0 (0.0)	5 (5.3)	

Abbreviation: HDI, Health Democracy Index.

*Fisher exact test; ^b Pearson chi-square test.

Key Messages

Implications for policy makers

- The first step to ensure patients' participation in shaping health policies is the development and enforcement of relevant legislation.
- The main barriers preventing patients to participate in health and healthcare decisions are: limited knowledge about cancer, the health system and health policies as well as lack of lobbying and advocacy skills. Targeted interventions on these topics would be beneficial in increasing patient participation in every aspect of decision-making.
- Policy-makers should invest in regulations that focus on equal and meaningful participation of patient groups in health policy decision-making. To this end, they should develop online informational and monitoring systems.
- The Health Democracy Index (HDI) is a brief and robust tool which can be used to assess the degree and impact of patients' organization participation in health policy decision-making.

Implications for the public

Patient organization participation allows patients to be an integral part of the health policy decision-making course that influences their health. In recent years, patient organizations have the role of representing groups of patients at various levels (eg, local, national, international). The main objective of patient organizations is not only to participate but also to influence health policy decisions. Evidence from the present study suggests that even though there are cancer patient organizations (CPOs) in Italy and France, they fail to participate successfully in health policy decision-making processes and influence them effectively. Consistent efforts should be made on the part of citizens, patients and their representatives on acquiring a central position in health policy decision-making.



BMJ Open Cancer patients' organisation participation in health policy decision-making: a snapshot/cluster analysis of the EU-28 countries

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ABSTRACT

Objectives Even though patient involvement in health policy decision-making is well documented, studies evaluating the degree and impact of this participation are scarce. This is even more conspicuous in the case of cancer. There is evidence showing that patients with the same type of cancer and at the same stage of the disease will receive different treatments in different countries. Therefore, it is crucial to assess the degree of patient participation in health policy decision-making across Europe, as it may result in health inequalities across countries. In a response to this research call, the present study aimed to provide a snapshot of cancer patients' organisation (CPO) participation in health policy processes in European Union (EU)-28 countries.

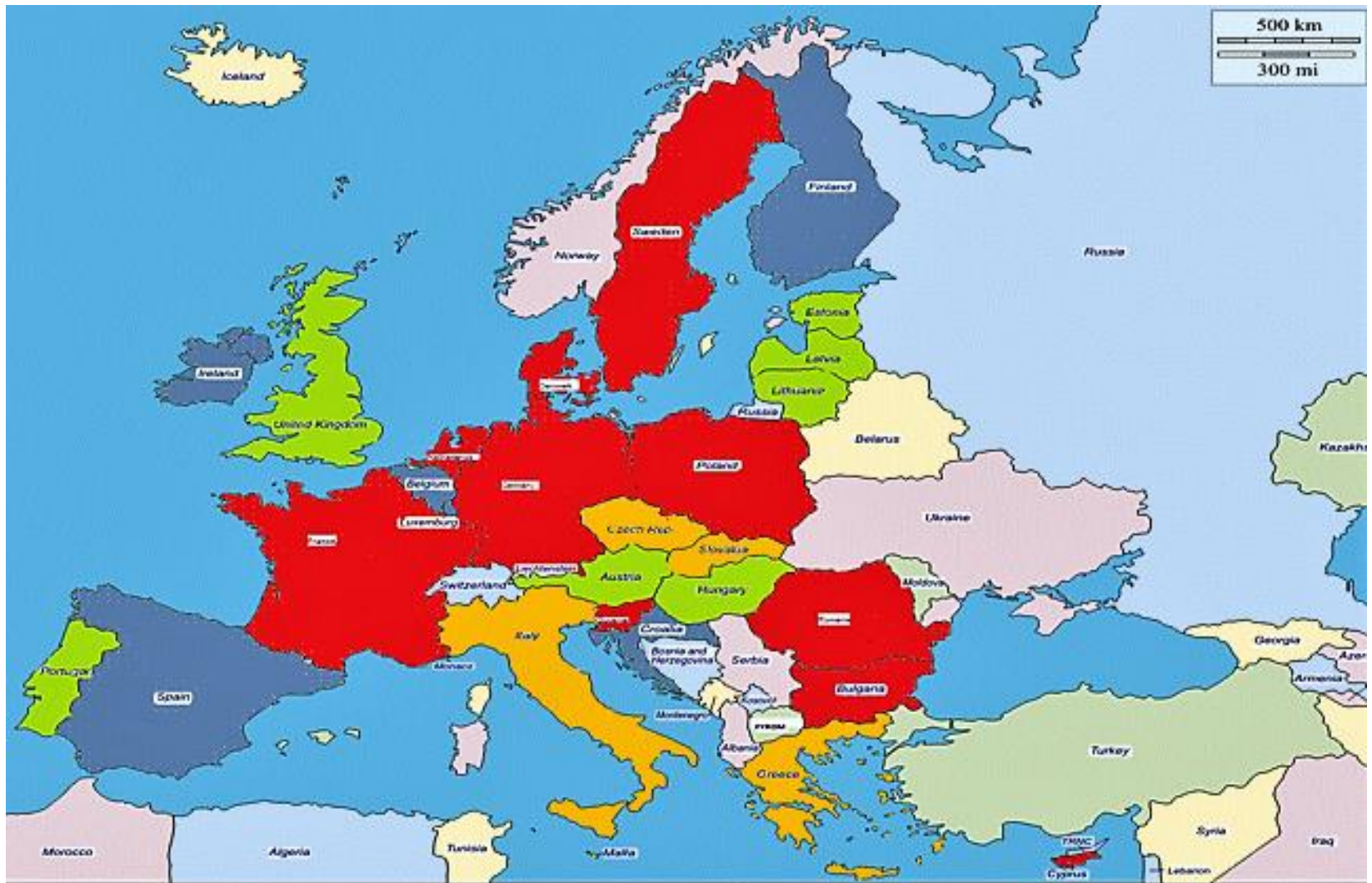
Setting CPOs from the EU-28 countries.

Participants Primary and secondary outcome measures: information about participants' sociodemographic characteristics and their involvement in their CPO was collected as well as data about the CPO. A 17-item index containing questions about the type and impact of participation in various facets of health policy decision-making was used to assess the degree of CPOs participation in health policy decision-making processes and its impact.

Strengths and limitations of this study

- The study included a large sample from the 28 member states of the European Union.
- An innovative and validated tool was employed in order to assess the level of cancer patients' organisations participation in health policy decision-making.
- The cross-sectional design of the study does not allow making causal inferences.
- The convenience sample of the study might have limited the generalisability of the results.



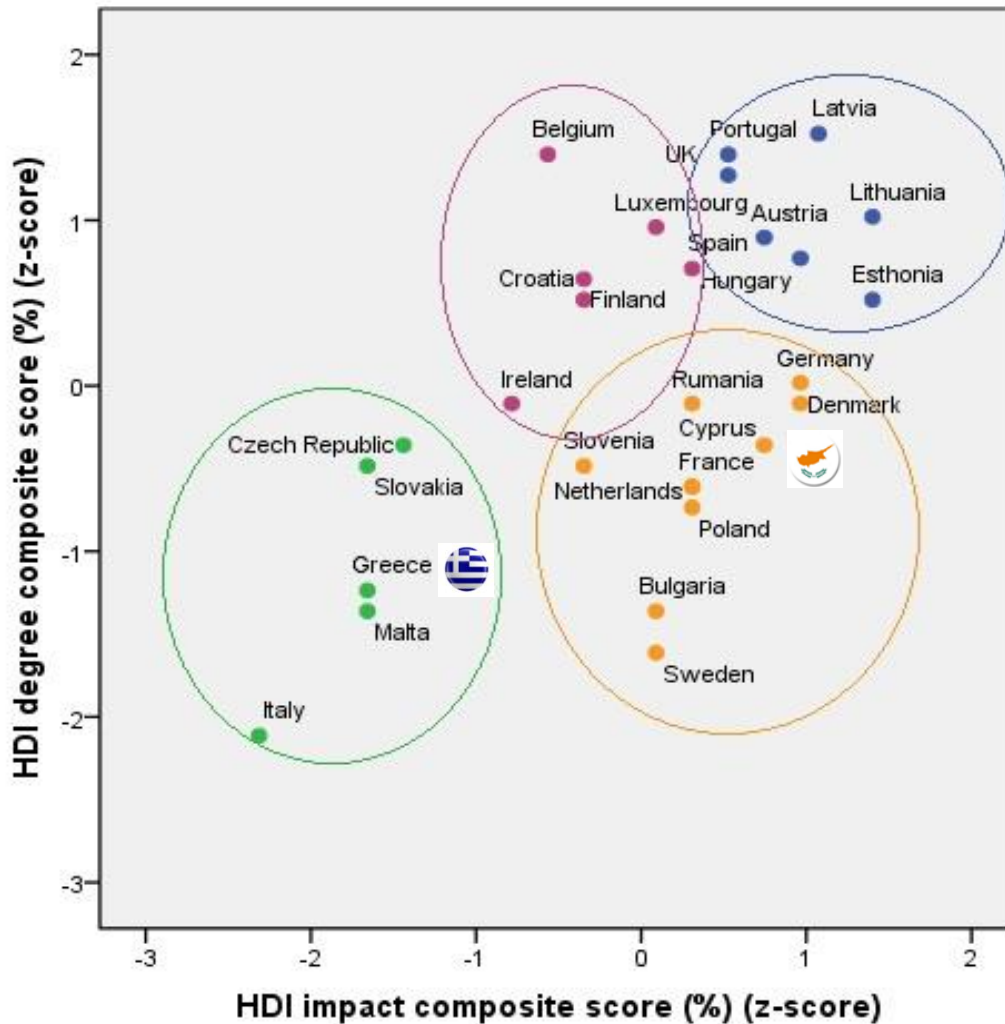


■ high degree - high impact
 ■ high degree - low impact
 ■ low degree - high impact
 ■ low degree - low impact



Patient Empowerment – The EMOTION PROJECT

Degree of Impact & Participation of Cancer Patients Groups in EU-28




Clusters:

- 1) High degree and high impact
- 2) Low degree and low impact
- 3) High degree and low impact
- 4) Low degree and high impact



Health democracy in Europe: Cancer patient organization participation in health policy

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Abstract

Background: Patient organization participation in health policy decision making is an understudied area of inquiry. A handful of qualitative studies have suggested that the growing number of patient organizations in Europe and their increasing involvement in policy issues do not result in high political effectiveness. However, existing research is largely country-specific.

Objective: To examine the degree and impact of cancer patient organization (CPO) participation in health policy decision making in EU-28 and to identify their correlates.

Methods: A total of 1266 members of CPOs participated in this study, recruited from a diversity of sources. CPO participation in health policy was assessed with the Health Democracy Index, a previously developed instrument measuring the degree and impact of patient organization participation in various realms of health policy. Additional questions collected information about participants' and the CPO's characteristics. Data were gleaned in the form of an online self-reported instrument.

Results: The highest degree of CPO participation was observed with respect to hospital boards, reforms in health policy and ethics committees for clinical trials. On the contrary, the lowest was discerned with regard to panels in other important health-related organizations and in the Ministry of Health. The reverse pattern of results was observed concerning the Impact subscale. As regards the correlates of CPO participation, legislation bore the strongest association with the Degree subscale, while organizational factors emerged as the most important variables with regard to the Impact subscale.

Conclusions: Research findings indicate that a high degree of CPO participation does not necessarily ensure a high impact. Efforts to promote high and effective CPO participation should be geared towards the establishment of a health-care law based on patient rights as well as to the formation of coalitions among CPOs and the provision of training to its members.

KEYWORDS

health policy decision making, patient-centred care, patient empowerment, patient involvement, patient rights



TABLE 2 Item descriptives for the HDI degree subscale

	Mean (SD)
Does your patient organization participate	
In reforms or key decisions in health policy	5.36 (1.52)
In panels of experts or workshops held in the Ministry of Health	4.37 (1.62)
In panels or workshops in other important organizations pertinent to health	4.28 (1.59)
In hospital boards	6.21 (1.30)
In ethics committees for clinical trials	5.27 (1.67)
In health technology assessment procedures for the scientific evaluation of new treatments and methods	4.49 (1.75)
In health technology assessment procedures for the economic evaluation of new treatments and methods	4.45 (1.76)
In the national parliament during decision making for important health policies/legislation	5.07 (1.85)
HDI score (sum)	24.59 (9.49)



	Mean (SD)
How would you rate the outcome (impact) of this participation	
In reforms or key decisions in health policy	2.72 (1.30)
In panels of experts or workshops held in the Ministry of Health	3.24 (1.25)
In panels or workshops in other important organizations pertinent to health	3.27 (1.18)
In hospital boards	1.97 (1.17)
In ethics committees for clinical trials	2.46 (1.24)
In health technology assessment procedures for the scientific evaluation of new treatments and methods	2.93 (1.31)
In health technology assessment procedures for the economic evaluation of new treatments and methods	2.75 (1.30)
In the national parliament during decision making for important health policies/legislation	2.51 (1.18)
How often do you observe a substantial change in the content of a health policy decision as a result of the involvement of your patient organization?	2.59 (1.27)
HDI score (sum)	24.60 (7.82)

TABLE 3 Item descriptives for the HDI impact subscale



TABLE 4 Multivariate regression analysis for the HDI degree subscale

	β	SE	β^*	P	R ²
Personal characteristics					
Rate your familiarity with the disease	-0.003	0.01	-0.02	.714	.06
Rate your knowledge about treatment options/country's health-care system/country's reimbursement processes	-0.001	0.01	-0.02	.591	
What is your position in the organization?	0.05	0.01	0.34	<.001	
How long in years have you been a member?	0.002	0.001	0.09	.002	
Rate your personal involvement in the organization	-0.002	0.01	-0.01	.745	
Organization characteristics					
I receive information materials	-0.004	0.01	-0.01	.733	.16
I receive training	0.01	0.01	0.01	.724	
My PO is a member of a national cancer federation	0.08	0.01	0.21	<.001	
My PO is a member of a national federation for chronic diseases	0.07	0.01	0.20	<.001	
My PO is a member of a national federation for people with disabilities	-0.01	0.02	-0.02	.580	
Country characteristics					
Health-care law is based on patient rights					
Low, reference					
Medium	0.15	0.02	0.22	<.001	.29
High	0.24	0.02	0.49	<.001	

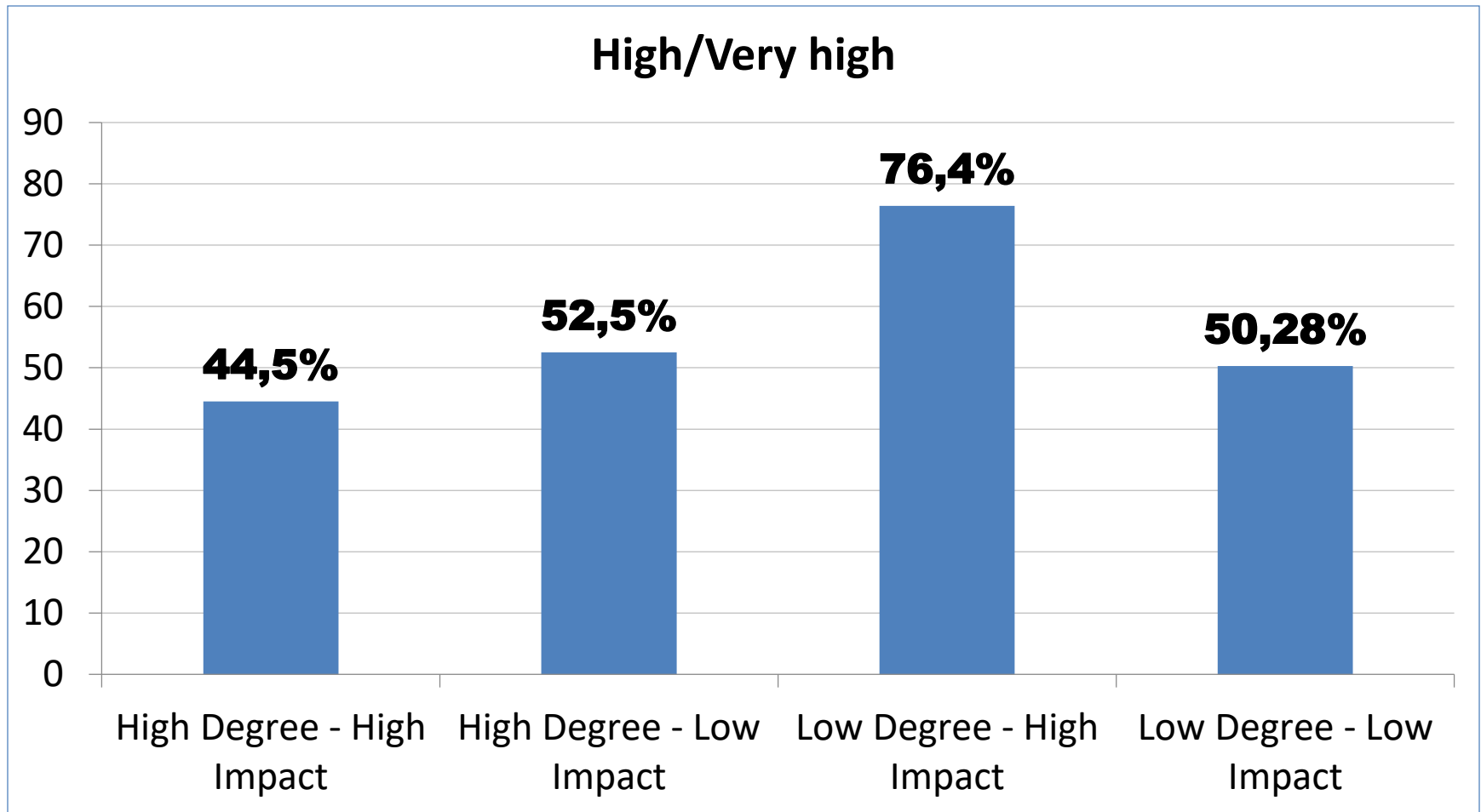
Bold values is smaller than $P < .001$.

β = regression coefficient; SE = standard error; β^* = standardized regression coefficient;

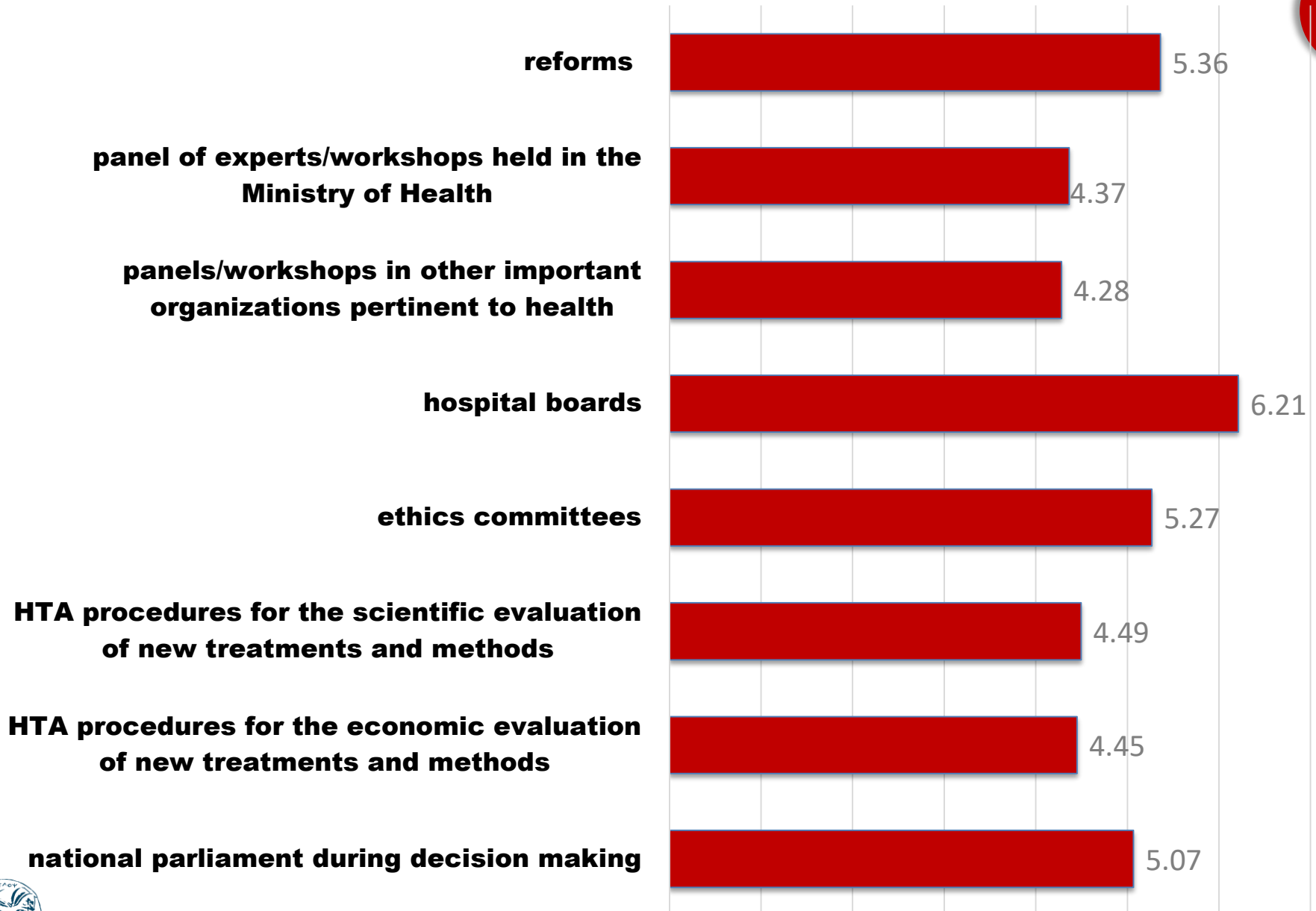
R² = coefficients of determination.



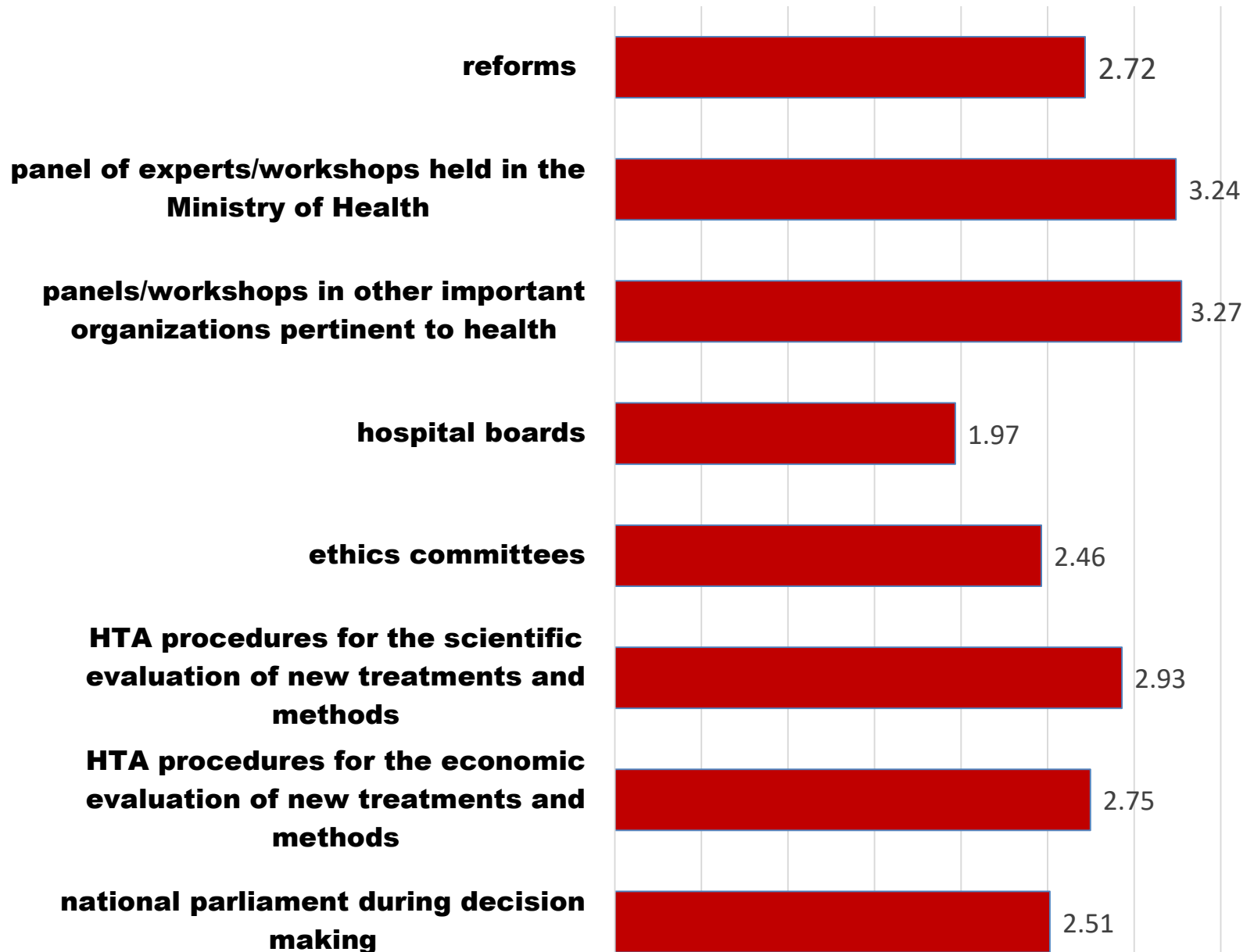
Personal involvement in the organization (N=1266)



Degree of participation in:



Impact of participation in:



Outcome variable: degree of participation

	β	SE	β^*	P	R ²
<i>Personal characteristics</i>					
Rate your familiarity with the disease	0.00	0.01	-0.02	0.714	0.06
Rate your knowledge about treatment options/country's healthcare system/country's reimbursement processes	0.00	0.01	-0.02	0.591	
What is your position in the organization?	0.05	0.01	0.34	0.000	
How long in yrs have you been a member?	0.00	0.00	-0.09	0.002	
Rate your personal involvement in the organization	0.00	0.01	-0.01	0.745	
<i>Organization characteristics</i>					
I receive information materials	0.00	0.01	-0.01	0.733	0.16
I receive training	0.01	0.01	0.01	0.724	
My PO is a member of a national cancer federation	0.08	0.01	0.21	0.000	
My PO is a member of a national federation for chronic diseases	0.07	0.01	0.20	0.000	
My PO is a member of a national federation for people with disabilities	-0.01	0.02	-0.02	0.580	
<i>Country characteristics</i>					
Healthcare law is based on Patients Rights					
Low, reference					
Medium	0.15	0.02	0.22	0.000	0.29
High	0.24	0.02	0.49	0.000	



Outcome variable: impact of participation

	β	SE	β^*	P	R ²
<i>Personal characteristics</i>					
Rate your familiarity with the disease	0.01	0.01	0.05	0.248	0.08
Rate your knowledge about treatment options/country's healthcare system/country's reimbursement processes	0.00	0.01	0.01	0.880	
What is your position in the organization?	0.02	0.00	0.15	0.000	
How long in yrs have you been a member?	0.00	0.00	-0.02	0.441	
Rate your personal involvement in the organization	0.04	0.01	0.25	0.000	
<i>Organization characteristics</i>					
I receive information materials	0.05	0.01	0.19	0.000	0.18
I receive training	0.02	0.01	0.07	0.018	
My PO is a member of a national cancer federation	0.03	0.01	0.12	0.000	
My PO is a member of a national federation for chronic diseases	0.04	0.01	0.14	0.000	
My PO is a member of a national federation for people with disabilities	0.00	0.01	0.00	0.918	
<i>Country characteristics</i>					
Healthcare law is based on Patients Rights					
Low, reference					
Medium	-0.03	0.02	-0.05	0.165	0.21
High	0.03	0.01	0.08	0.033	



Βασικά Ευρήματα

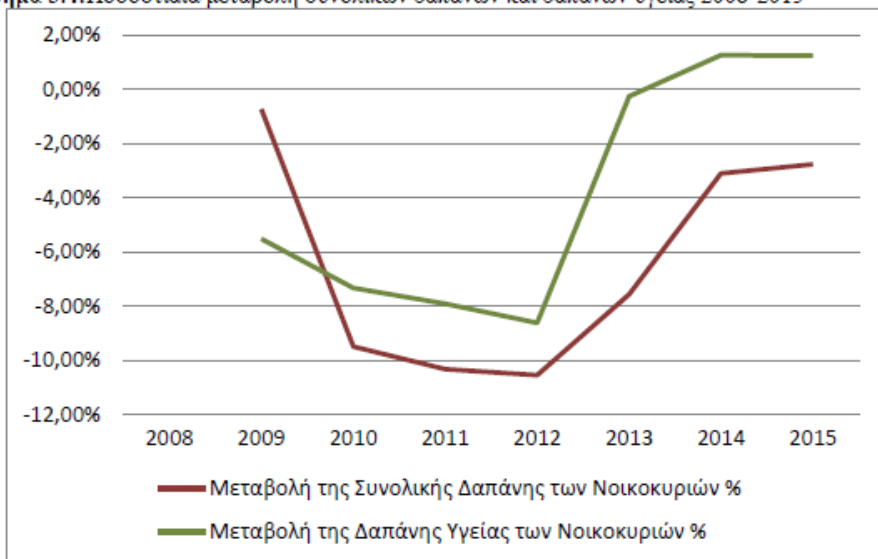
- Όσον αφορά το **επίπεδο συμμετοχής**, ως κρίσιμος παράγοντας αναδεικνύεται το θεσμικό πλαίσιο
- Η ύπαρξη «οργανισμού – ομπρέλα» καταγράφεται ως υποστηρικτικός ως προς της συμμετοχή παράγοντας
- Όσον αφορά την **επίδραση της συμμετοχής στις τελικές αποφάσεις**, ως κρίσιμος παράγοντας αναδεικνύεται το θεσμικό πλαίσιο
- Επιπλέον, ως κρίσιμοι για την επίδραση της συμμετοχής στις τελικές αποφάσεις παράγοντες, καταγράφονται η ευαισθητοποίηση των μελών, η εκπαίδευση αλλά και η ύπαρξη «οργανισμού – ομπρέλα»



ΣΤΡΕΒΛΩΣΕΙΣ ΑΠΟ ΤΗ ΜΗ ΣΥΜΜΕΤΟΧΗ ΤΩΝ ΑΣΘΕΝΩΝ: ΕΛΛΑΔΑ

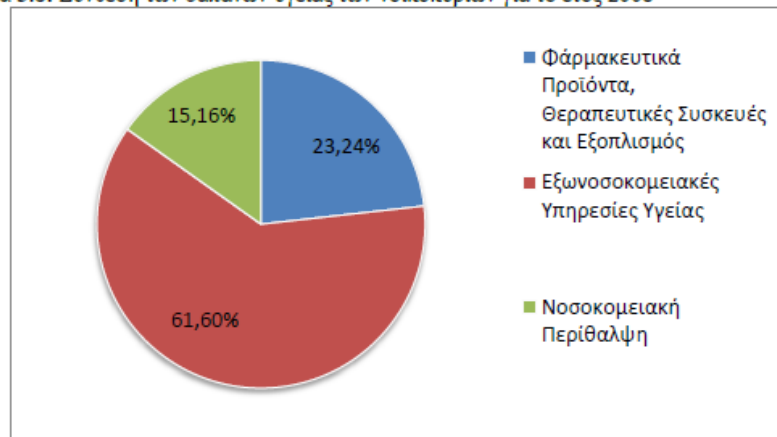
Δαπάνες υγείας των νοικοκυριών: μια διαχρονική ιδιαιτερότητα

Γράφημα 3.4: Ποσοστιαία μεταβολή συνολικών δαπανών και δαπανών υγείας 2008-2015

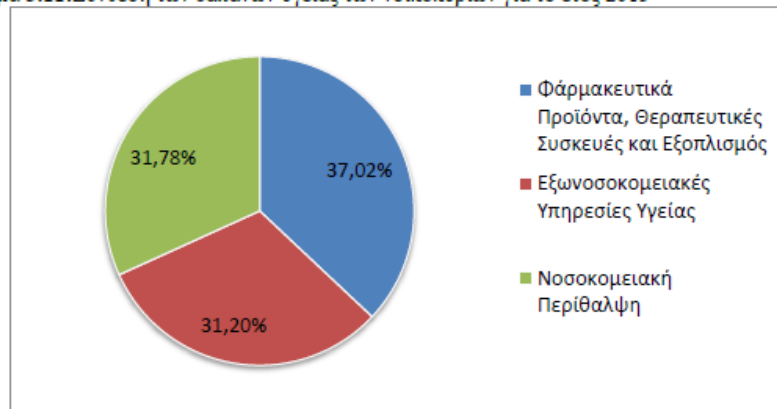


Πηγή: Επεξεργασία μικροδομημένων Έρευνας Οικογενειακών Προϋπολογισμών 2008-2015, ΕΛΣΤΑΤ

Γράφημα 3.8: Σύνθεση των δαπανών υγείας των νοικοκυριών για το έτος 2008



Γράφημα 3.11: Σύνθεση των δαπανών υγείας των νοικοκυριών για το έτος 2015



Πηγή: Επεξεργασία μικροδομημένων Έρευνας Οικογενειακών Προϋπολογισμών 2008-2015, ΕΛΣΤΑΤ

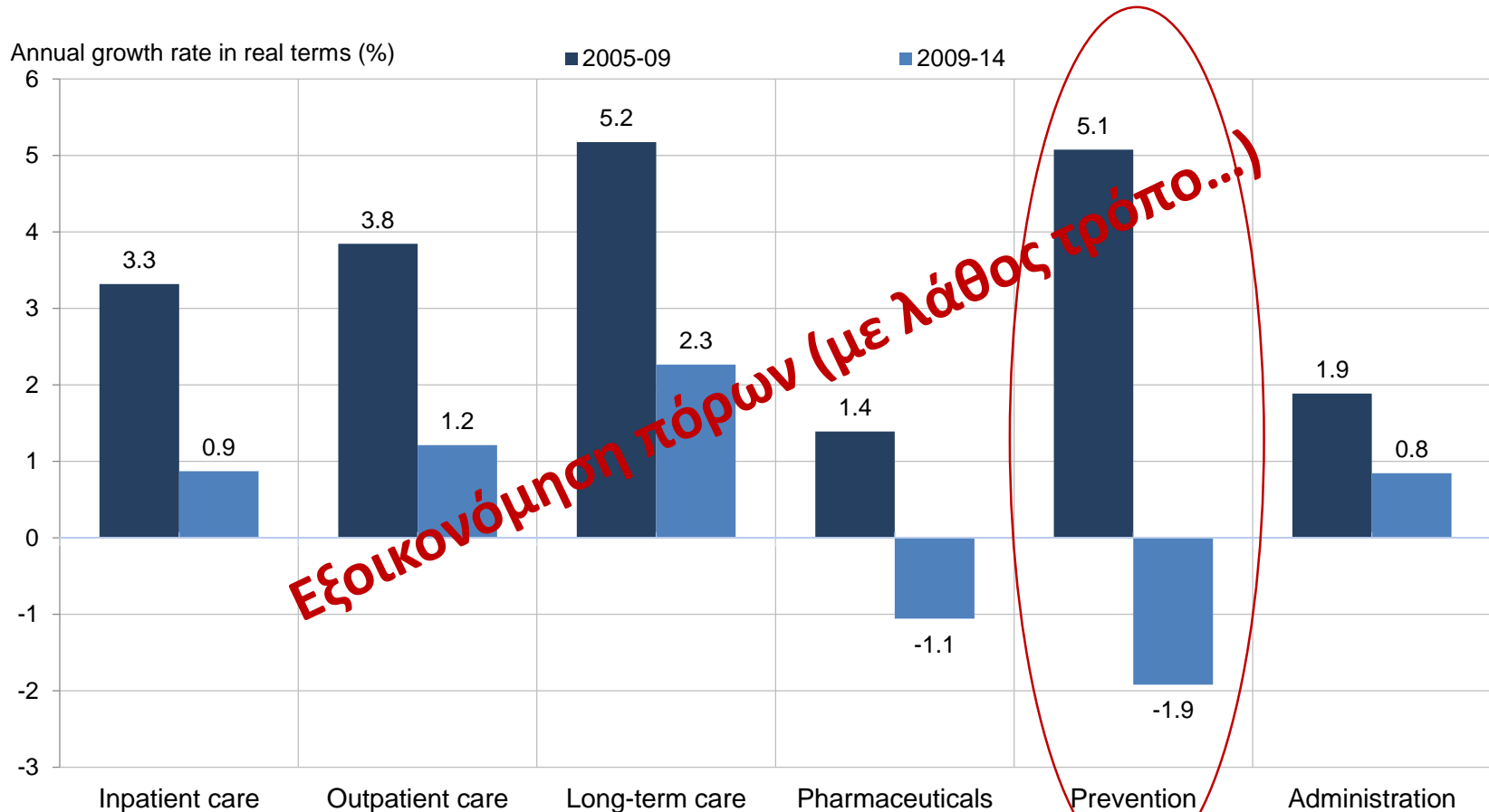
Πηγή: Χριστάκης και Σουλιώτης, *Ανισότητες στην Υγεία: Οι Ιδιωτικές Δαπάνες Υγείας κατά την Διάρκεια της Οικονομικής Κρίσης στην Ελλάδα, 2017* (υπό δημοσίευση).



ΣΤΡΕΒΛΩΣΕΙΣ ΑΠΟ ΤΗ ΜΗ ΣΥΜΜΕΤΟΧΗ ΤΩΝ ΑΣΘΕΝΩΝ: ΟΟΣΑ

Οι (λαθεμένες) πολιτικές προτεραιότητες στην υγεία διεθνώς

Growth of health spending for selected functions per capita, EU average, 2005-14



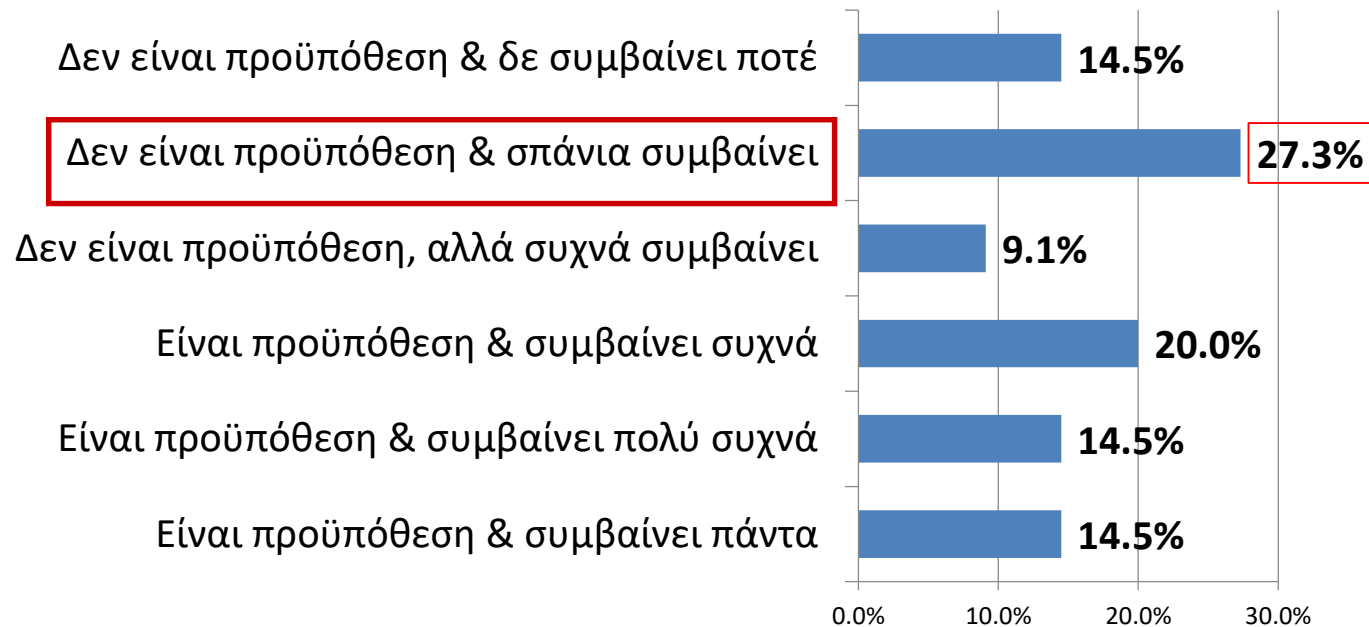
Source: Health at a glance 2016



Από την έρευνα στην παρέμβαση: το παράδειγμα της Κύπρου



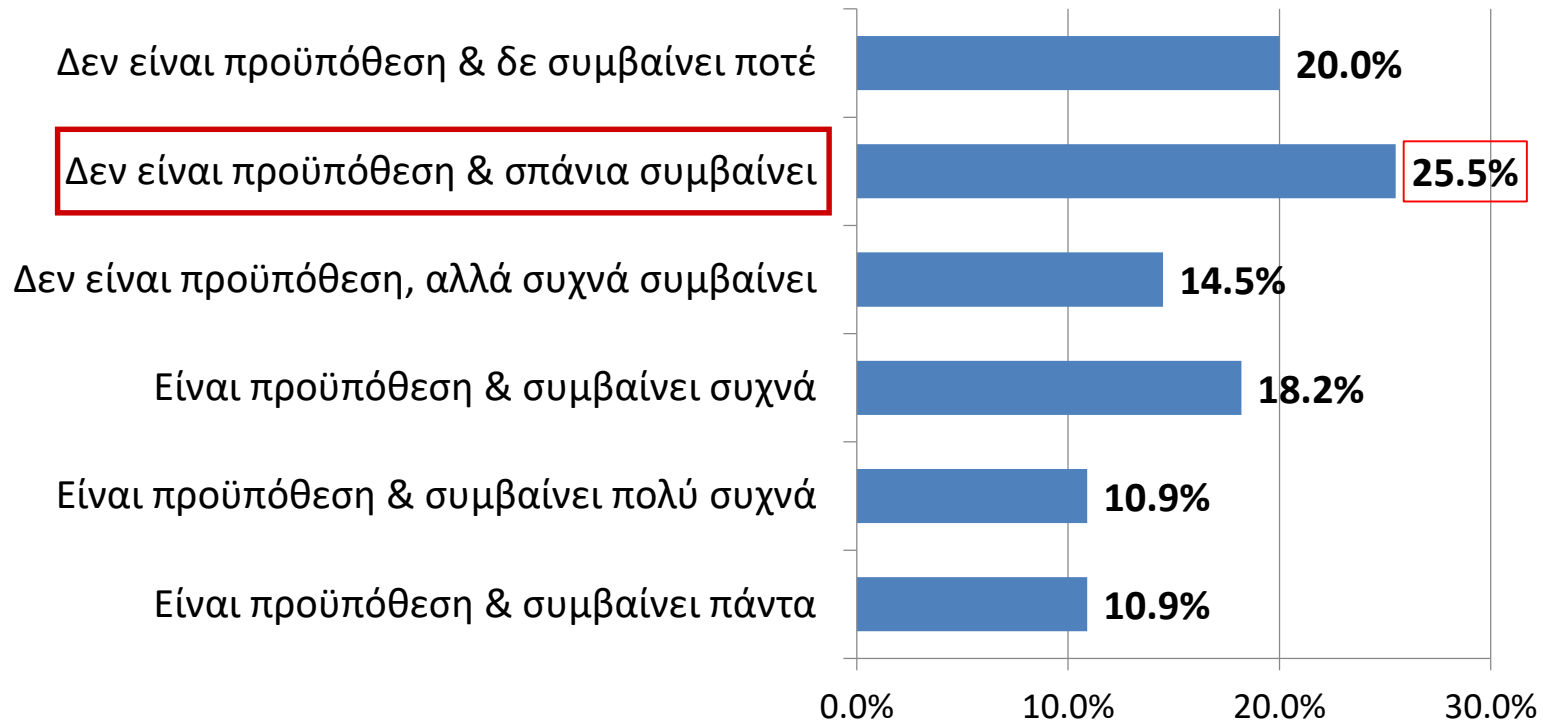
Ο σύλλογός σας συμμετέχει σε διεργασίες μεταρρυθμίσεων
ή κρίσιμων αποφάσεων πολιτικής υγείας;



Από την έρευνα στην παρέμβαση: το παράδειγμα της Κύπρου



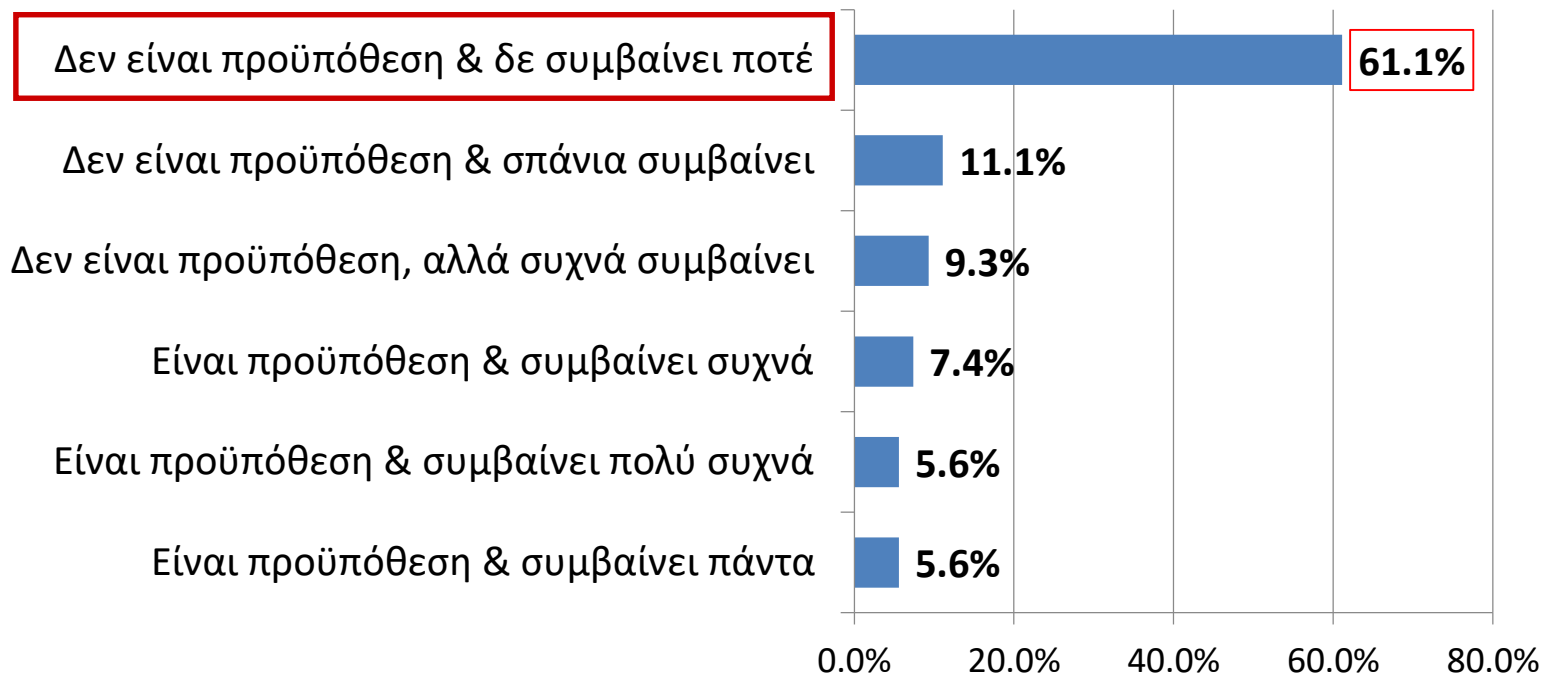
Ο σύλλογός σας συμμετέχει σε ομάδες εργασίας του
Υπουργείου Υγείας;



Από την έρευνα στην παρέμβαση: το παράδειγμα της Κύπρου



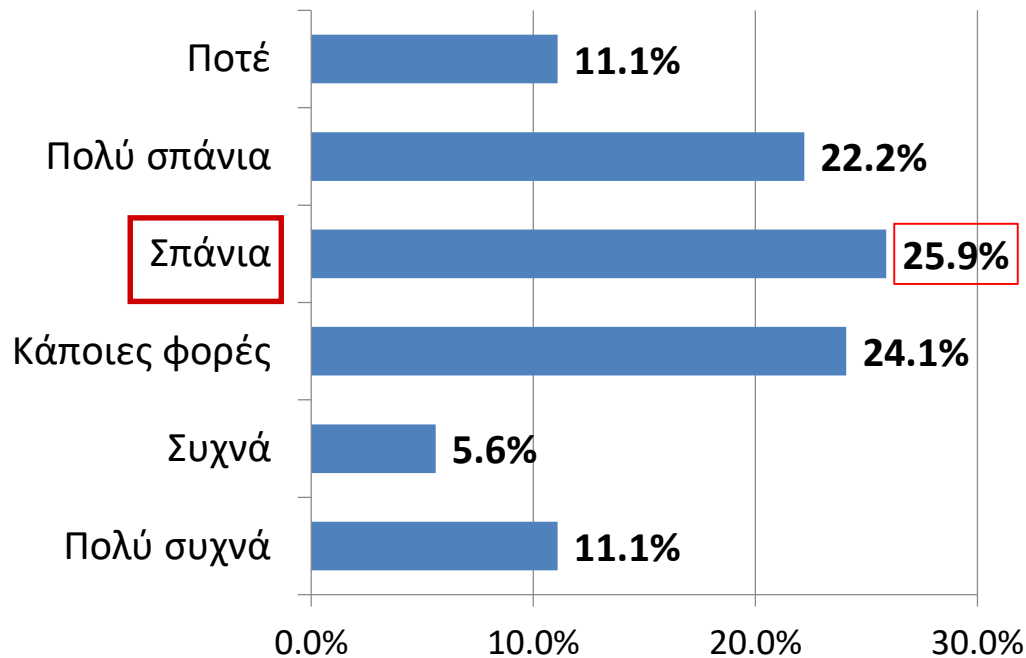
Ο σύλλογός σας συμμετέχει σε διοικητικά συμβούλια νοσοκομείων;



Από την έρευνα στην παρέμβαση: το παράδειγμα της Κύπρου



Πόσο συχνά παρατηρείται μια ουσιαστική αλλαγή στο περιεχόμενο μιας απόφασης που σχετίζεται με τις πολιτικές υγείας, ως αποτέλεσμα παρέμβασης από τον σύλλογό σας ή κάποιον σύλλογο ασθενών γενικότερα;



Με νόμο η συμμετοχή των ασθενών στις πολιτικές υγείας

07.04.2016 19:54 Κύπρος SigmaLive



Η Ολομέλεια της Βουλής ψήφισε ομόφωνα σε νόμο την πρόταση νόμου που κατέθεσε η Βουλευτής του ΔΗΣΥ Στέλλα Κυριακίδου με την οποία θεσμοθετείται η διαβούλευση κάθε υπηρεσίας που ασκεί δημόσια εξουσία για θέματα που αφορούν ομάδες ασθενών με την Παγκύπρια Ομοσπονδία Συνδέσμων Πασχόντων και Φίλων και καθιερώνει την εν λόγω ομοσπονδία ως κοινωνικό εταίρο του κράτους για τα θέματα αυτά.





Ευχαριστώ πολύ για την προσοχή σας!

soulioti@hol.gr

