

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

Kyriakos Souliotis,<sup>1,2</sup> Lily-Evangelia Peppou,<sup>3</sup> Chara Tzavara,<sup>2</sup> Eirini Agapidaki,<sup>1</sup> Dimitrios Varvaras,<sup>4</sup> Oreste Buonomo,<sup>4</sup> Dominique Debais,<sup>5</sup> Stanimir Hasurdjiev,<sup>6</sup> Francois Sarkozy<sup>7</sup>

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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.

## INTRODUCTION

Cancer is the most common and severe non-communicable diseases, impinging substantially on both health and healthcare.<sup>1</sup> Patients with cancer have to cope with the stress and the dramatic changes in their lifestyle and quality of life as well as the procedures and bureaucracy (eg, reimbursement processes) often involved in the treatment of the illness.<sup>2</sup> Although public spending on health and long-term care has increased in the majority of European Union (EU) countries, needs of patients with cancer remain largely unmet.<sup>3</sup> An illustration of this point is waiting times in cancer care in Ireland, which in 2015 were found to be higher than their

## 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.

counterparts in Albania.<sup>4</sup> Increased public spending is a necessary but not sufficient condition to ensure effectiveness and sustainability of the healthcare system.<sup>5</sup>

In an effort to provide more effective and appropriate services, the healthcare system philosophy has shifted from a biomedical approach (which is doctor focused) to a more holistic and self-managed one.<sup>6</sup> Many programmes, tools and models have been implemented in order to empower patients with cancer and facilitate their participation in the delivery of healthcare services.<sup>7</sup> In this frame, the physician is no longer considered to be the 'expert' or just the provider and the patient only the receiver. Rather, there is shared decision-making in clinical practice. No one knows better the nature of a disease and the needs deriving from it but the patients themselves.<sup>8</sup>

This is not limited to the individual physician-patient relationship, as patients may collectively participate in decision-making in various realms, including guideline development, government policy and research agenda setting, among others.<sup>9-11</sup> Patient participation at the collective level is primarily justified on the grounds of democratic values. Patients are affected by the



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For numbered affiliations see end of article.

## Correspondence to

Professor Kyriakos Souliotis;  
[info@ksouliotis.gr](mailto:info@ksouliotis.gr);  
[ksouliotis@uop.gr](mailto:ksouliotis@uop.gr)

consequences of certain decisions, and therefore they should have a say in the process. Concomitantly, their subjective knowledge of a disease and its treatment may enhance the quality of healthcare decision-making,<sup>12</sup> upgrading the overall effectiveness and efficiency of the healthcare system.

While patients' collective action is increasingly recognised as an important driver of health policy and service provision, there is paucity of research on their association. The De Montfort study in the UK has substantiated increased contact between patient groups and policy-makers during the past years, while professional bodies and pharmaceutical companies were found to have involved patient groups in discussions on policy proposals to a larger extent than in the past.<sup>13</sup> Nonetheless, according to the researchers, the available evidence could not shed enough light on the influence exerted by patient groups, as their heightened participation is not necessarily translated into high political effectiveness. In a similar vein, while the Dutch model in Netherlands allows patient organisations to be an equal party in health policy processes to a large extent; this is not met in practice.<sup>14</sup> Moreover, evidence from Mixed Advisory Committees in Italy highlights the limited influence of users' voice on decision-making by health authorities.<sup>15</sup> In 2006, a workshop with 22 academic researchers and two representatives of patient organisations documented high involvement of patient groups with policy-makers and political institutions; however, marked diversity among European countries was stressed.<sup>16</sup>

The initiatives undertaken by most EU countries to establish and increase patient participation in health policy decision-making are reflected on legislation level<sup>17</sup>. Nonetheless, based on information provided by the European Health Consumer Index,<sup>18</sup> countries display important differences in terms of the degree to which their healthcare law is based on patient rights. Additionally, noteworthy variation is also observed in the degree to which patient organisations are involved in decision-making.<sup>18</sup> This in turn may create health inequalities across countries. As a corollary of this, there is an imperative need to investigate the degree and impact of patient organisation participation in health policy decision-making in the EU. This need becomes even more pronounced in the case of cancer, as the disease has a multifaceted impact and can be a chronic and fatal disease depending on the quality of treatment.<sup>19</sup> In response to this research call, the present study aimed to provide a snapshot of cancer patients' organisation (CPO) participation in health policy decision-making in EU-28 countries.

## METHODS

### Instrument

For the purpose of the study, a self-reported questionnaire was developed, entailing the following sections:

### Respondents' characteristics

Data were collected on participants' sociodemographic characteristics (gender, age, educational attainment, self-reported economic status) and their involvement in the CPO. In particular, participants had to rate their degree of familiarity with cancer and their knowledge about its treatment/their country's healthcare system/their country's reimbursement process (rating options: very low to low moderate to high- to very high). Moreover, they had to rate their degree of involvement in the organisation (rating options: absent-very low to low moderate to high to very high). Data were also gleaned with regard to their position in the organisation (president/or other board members—employed by the organisation—voting member—non-voting but active member—non-active member) and the duration of their membership.

### Organisational characteristics

Information was also collected concerning their CPO. Specifically, participants had to indicate whether their organisation provided information material to its members (yes–no) and training (yes–no). Furthermore, they were asked whether their organisation was a member of a national cancer federation (yes–no).

### Health Democracy Index

Moreover, the questionnaire encompassed the Patient Participation and Health Democracy Index (HDI), an original scale measuring the degree of patient organisation participation and its impact on shaping health policy. The HDI consists of 17 questions: eight items investigate CPOs level of participation (degree of participation) in processes such as: reforms, panels at the ministry of health, hospital boards, ethics committees in clinical trials, health technology assessment procedures (two items: one for the scientific evaluation of new treatments and methods and one for the economic evaluation) and the national parliament. Each question may have one of the following answers: (1) it is not a legal requirement and it never happens, (2) it is not a legal requirement and it rarely happens, (3) it is not a legal requirement but it often happens, (4) it is a legal requirement and it never happens, (5) it is a legal requirement and it often happens, (6) it is a legal requirement and it happens very often and (7) it is a legal requirement and it always happens. Concomitantly, the HDI entails nine items tapping the impact of CPOs participation on the aforementioned eight realms (reforms, ministry of health, other health-related organisations, hospital boards, ethics committee, HTA and national parliament), which are rated on a six-point scale ranging from absent to very high. In addition, the impact of participation subscale entails a ninth item enquiring about the frequency by which a substantial change is observed in the content of a health policy decision as a result of the involvement of the patient organisation. The particular item

**Table 1** Number of respondents per country

Country	N	%
Austria	47	3.7
Belgium	34	2.7
Bulgaria	31	2.4
Croatia	46	3.6
Cyprus	37	2.9
Czech Republic	45	3.6
Denmark	44	3.5
Estonia	35	2.8
Finland	45	3.6
France	93	7.3
Germany	44	3.5
Greece	63	5
Hungary	33	2.6
Ireland	51	4
Italy	95	7.5
Latvia	32	2.5
Lithuania	38	3
Luxembourg	30	2.4
Malta	32	2.5
Netherlands	42	3.3
Poland	44	3.5
Portugal	47	3.7
Rumania	45	3.6
Slovakia	38	3
Slovenia	41	3.2
Spain	42	3.3
Sweden	43	3.4
UK	49	3.9

is rated on a six-point scale ranging from never to very often.

Higher composite scores on the subscales denote higher degree and impact of participation. Both subscales displayed good internal consistency (Cronbach's  $\alpha=0.879$  and Cronbach's  $\alpha=0.874$ , respectively). Converging evidence has substantiated the psychometric properties of the HDI.<sup>20</sup>

Specifically, the development of the index has followed the subsequent steps: (1) definition of the construct (ie, patient organisation participation in health policy decision-making), (2) review of the construct definition, (3) item drafting, (4) item review and (5) pilot testing of its psychometric properties (internal consistency, test–retest reliability, construct validity and convergent validity). As the index was originally developed in Greece,<sup>21</sup> an international working group consisting of European stakeholders (policy-makers, members of patient organisations and researchers with background on patient empowerment) held various meetings

**Table 2** Sample demographics

	N	%
Age, mean (SD)	54.6 (14.8)	
Sex		
Men	534	42.2
Women	732	57.8
Education level		
No formal qualification	9	0.7
Primary school education	7	0.6
Secondary school education	378	29.8
University degree	520	41.1
Postgraduate degree	352	27.8
Self-report economic status		
Low	13	1.0
Medium to low	238	18.8
Medium	529	41.8
Medium to high	387	30.6
High	98	7.7

to discuss the adaptation of the index to European standards.<sup>20</sup>

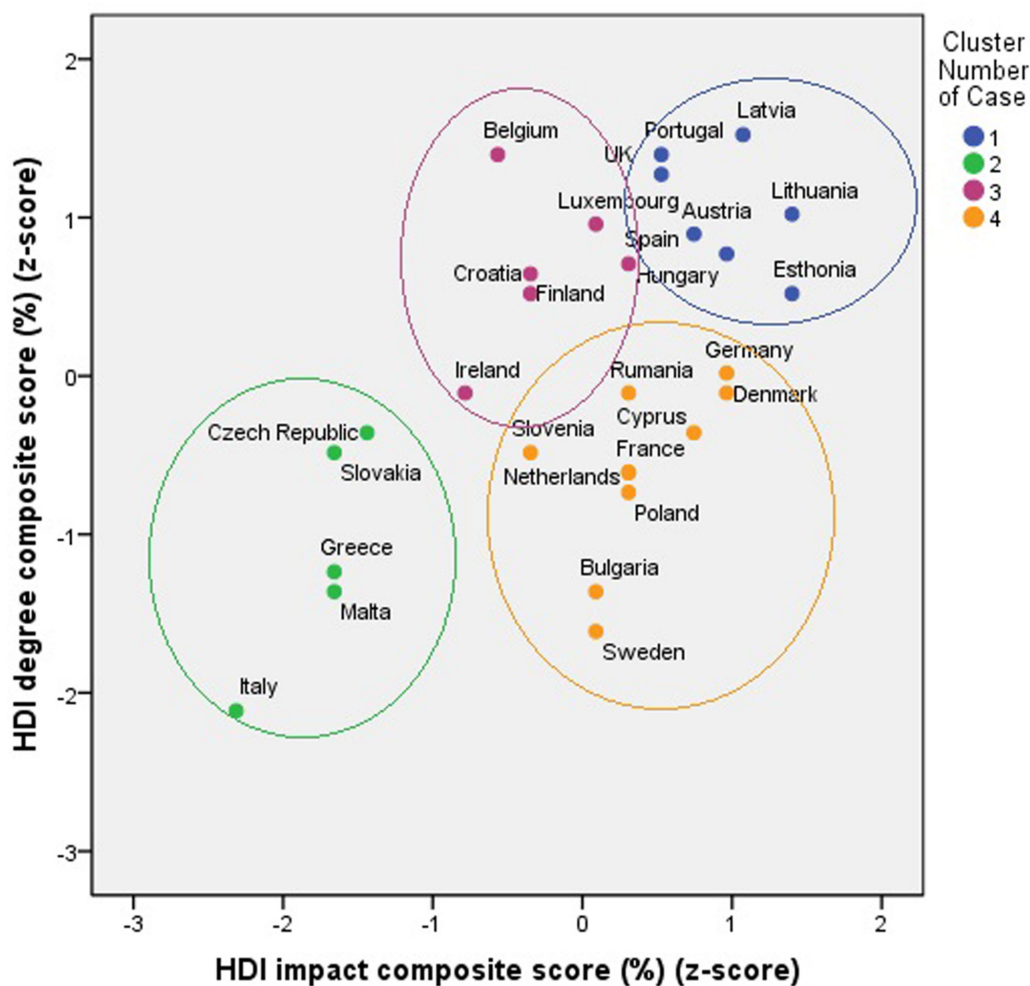
### Participants and procedures

Potential participants were identified through various channels (eg, internet search, on line databases of European cancer patients' associations, registries of the ministry of health, etc). CPO was considered any non-profit organisation with a legal entity. In addition, the CPO should have been cancer specific, be primarily composed of patients and their caregivers and representing and/or supporting their needs. To be recruited for the study, a CPO should have had an active representation of patients with cancer at a national level and a valid and accessible website. CPOs from EU-28 member states were included in the study. In order to be eligible for participation, an individual should have been a member of a CPO and older than 18.

An email was sent to CPO board members informing them about the study and inviting them to participate. Following their acceptance, the institutional review board of each organisation approved the study protocol and forwarded the invitation for participation to all of its members. All respondents filled a written informed consent form. Data were collected online (via web-link and email). The questionnaire was translated to each country's official language.

### Patient and public involvement

Patients play an integral role in this project, and thus, they have participated in various stages of the research process. The development of the HDI, which has been used to assess CPO participation in health policy decision-making, has involved both patients—members of patient organisations and patient representatives during



**Figure 1** Cluster analysis results. HDI, Health Democracy Index.

the phases of (1) reviewing the construct definition, (2) item drafting, (3) item review and (4) adaptation of the index to pan-European standards.<sup>20 21</sup> Moreover, patient representatives have participated in the formulation of research objectives, the design of the study and the interpretation of its findings, while members of patient organisations have constituted the study sample of this research work. It deserves mentioning that results will be disseminated to all identified CPOs, irrespectively of whether they participated or not.

### Statistical analysis

Descriptive statistics such as means, medians, SD, absolute and relative frequencies were computed, where appropriate.

Ward's method was used to compute distance patterns and determine the appropriate number of clusters for the K-means clustering procedure. K-means clustering was performed for the classification of cluster subgroups and was based on Euclidean distance. We changed all variables to z-scores to yield equal metrics and equal weighting. For the consistency and validity of the hypothesised groups of countries in the total sample; the total sample was divided into a split-half

random sample. K-means clustering was used then for the two subsamples to determine the presence of similar cluster subgroups from the previous analyses. Additionally, analysis of variance was used to compare degree of participation and impact of participation scores between the four groups defined by cluster analysis. Statistical analyses were performed using the SPSS for Windows V.19.0 statistical package.

## RESULTS

### Sample characteristics

The final sample consisted of 1266 members of CPOs from EU-28 countries and the mean number of respondents per country was 45 (table 1). Demographics of the sample are shown in table 2.

### Degree and impact of CPO participation

Composite scores of the HDI subscales (degree of participation and impact of participation) were used for clustering analysis (figure 1).

The findings revealed four groups of countries according to their score: (1) high degree–high impact, (2) high degree–low impact, (3) low degree–high

**Table 3** Median scores of degree of participation and impact of participation per country

	Median for degree of participation*	Median for impact of participation*
Austria	50.00	38.78
Belgium	58.33	26.53
Bulgaria	12.50	35.65
Croatia	43.75	28.57
Cyprus	29.17	38.78
Czech Republic	29.17	18.37
Denmark	33.33	40.82
Estonia	43.75	44.90
Finland	45.83	28.57
France	25.00	36.69
Germany	35.42	40.82
Greece	14.58	16.33
Hungary	47.92	40.82
Ireland	33.33	24.49
Italy	5.60	10.20
Latvia	60.42	41.84
Lithuania	52.08	44.90
Luxembourg	51.04	32.65
Malta	12.50	16.33
Netherlands	25.00	36.69
Poland	22.92	35.69
Portugal	58.33	36.73
Rumania	33.33	37.69
Slovakia	27.08	16.33
Slovenia	27.08	38.57
Spain	46.88	34.69
Sweden	8.33	35.40
UK	56.25	36.73

\*Median of the per cent score (ie, ((score-possible minimum score)/(maximum–minimum possible score))×100).

impact, (4) low degree–low impact. [Table 3](#) presents median scores of degree of participation and impact of participation per country. The median score for all countries was 33.3 for degree of participation and 34.69 for impact of participation.

The number of countries in each cluster can be seen in [table 4](#) and a snapshot of the European countries clustering can be found in [figure 2](#).

The total sample was afterwards divided into a split-half random sample and K-means clustering was repeated for the two subsamples. Clustering results indicated that the four-cluster solution recorded in the previous analyses was the most homogeneous solution in each subsample. Furthermore, the degree of participation and impact of participation scores were

**Table 4** Number of countries in each HDI cluster

Cluster	
1. High degree and high impact: health democratic environment	7 countries: Latvia, Portugal, UK, Lithuania, Austria, Hungary, Estonia.
2. High degree and low impact: ostensible participation	6 countries: Belgium, Luxembourg, Spain, Finland, Croatia, Ireland.
3. Low degree and high impact: limited but impactful participation	10 countries: Germany, Denmark, Romania, Cyprus, Slovenia, Netherlands, France, Poland, Bulgaria, Sweden.
4. Low degree and low impact: opportunities to develop	5 countries: Czech Republic, Slovakia, Greece, Malta, Italy.

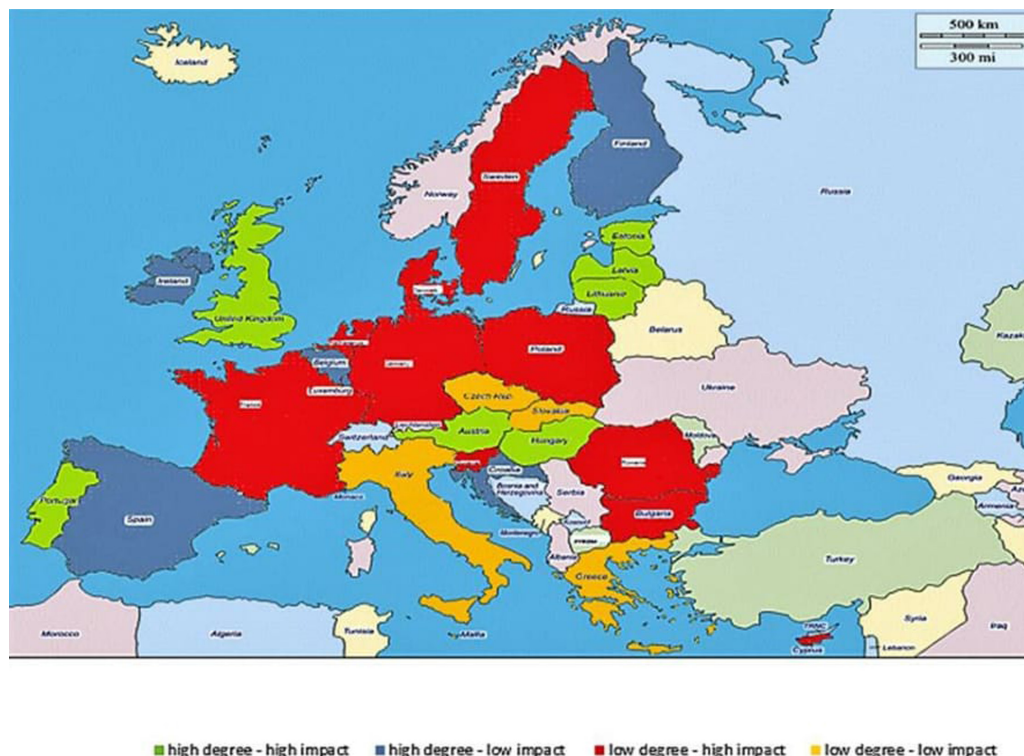
compared between the four country groups as defined by cluster analysis. All pair-wise comparisons were significant ( $p < 0.001$ ) providing additional evidence for the cluster solution.

## DISCUSSION

In contemporary healthcare systems, patients participate in decisions concerning their own health and healthcare (ie, the microlevel), and in decision-making processes on the mesolevel and macrolevel (ie, in local health authorities, organisations, health technology assessment procedures or at the parliament, to name few).<sup>22</sup> Their influence in these processes is greatly enhanced if they are grouped together. For this reason, patient organisations emerge as an indispensable vehicle for facilitating democracy, promoting patient interests and influencing health policy decision-making.<sup>22</sup>

Nonetheless, existing evidence suggests wide diversity in the EU with regard to patient organisation participation in health policy decision-making.<sup>16 18</sup> At the same time, converging evidence indicates that a greater degree of participation on the part of patient organisations does not guarantee the effectiveness of this participation.<sup>13–15 22</sup> In other words, patient organisations may be given opportunities to have a say in health policy decision-making, but are they being heard?

The findings from the present study revealed four groups of countries: (1) High degree–high impact: ‘health democratic environment’. The environment fosters patient organisation participation and patient groups contribute substantially to health policy decision-making (2) High degree–low Impact: ostensible participation. The system provides ample opportunity for patient organisation participation; however, this does not exert a significant impact. (3) Low degree–high impact: limited but impactful participation. The health policy shaping system does not give enough room for participation; however, it takes patient organisations into consideration. It seems that quality outweighs



**Figure 2** Patient organisation participation in EU-28 by country cluster. EU, European Union; HDI, Health Democracy Index.

quantity. One may suggest that either the health policy decision-making system takes highly into consideration the claims of CPOs or that the latter are very effective in advocating their interests. (4) Low degree–low impact: window of opportunity. The decision-making system does not facilitate participation and CPOs are not effective in advocating their claims.

### Interpretations

The findings of the present study corroborate the wide diversity among European countries with respect to the degree and impact of CPOs participation in health policy decision-making. These findings are to a large extent consonant with findings from the European Health Consumer Index.<sup>18</sup> Interestingly, both Bulgaria and Sweden rank very low in the degree subscale (median=12.5 and median=8.33, respectively); however, they rank high in the impact subscale (median=35.65 and median=35.40, respectively). At first glance, this appears in sharp contrast to the findings from the European Health Consumer Index, where Bulgaria was found to score good in the indicator ‘patient organisations involved in decision-making’ and Sweden intermediary. Nonetheless, the low scores documented in the degree subscale of the present study are probably explained by both countries’ low performance in the indicator ‘healthcare law based on patients rights’. As a result of this, these countries score very low in the degree subscale (enquiring about the opportunities of CPOs to participate in health decision-making); however, they do well in the impact subscale (enquiring about the impact of this participation). In other words, while the

healthcare system may not provide CPOs with ample opportunity to participate, CPOs appear to manage well into capitalising on the scarce opportunities given. This is perhaps the explanation why in this group of countries in spite of low degree of participation, there is high impact of participation. It is highly likely that CPOs in these countries have better advocacy and lobbying skills. Alternatively, it may be the case that CPOs form stronger coalitions in these countries. A study by Wood on patient groups in UK and USA has indicated that in both countries there is a proliferation of patient organisations; however, their political effectiveness is disproportionately low due to their autonomous activity and their reluctance to collaborate.<sup>23</sup> A similar concern was raised by the Vienna workshop, where heightened competition and tensions among patient organisations was suggested to hinder their political effectiveness.<sup>16</sup> Therefore, CPOs in countries with high impact may be more politicised and more united.

This may also explain why in certain countries there is high degree of participation but low impact. Members of CPOs in these countries may not be trained enough in lobbying and advocacy skills and may not engage into joint campaigning. Alternatively, the system may ostensibly involve patient organisations in health policy decision-making. This is congruent with the concern raised in UK<sup>13</sup> that the involvement of patient organisations in health policy decision-making may solely serve the purpose of adding legitimacy to governments, while the latter advance their own interests. Therefore, one should investigate further what happens in these

countries and endeavour to identify the determinants of impactful participation overall.<sup>24</sup>

It merits noting that the HDI entails items tapping perceived patient organisation participation in health policy decision-making on various realms: hospital boards, health technology assessment, ethics committees in clinical trials, national parliament, ministry of health, to name few. It is highly likely that an item-per-item analysis may reveal a different pattern of results with regard to country ranking. Our research team is currently working along this direction.

## GOOD EXAMPLES

### A good example of a country with high degree of participation

The decentralisation of the healthcare system in 2001 in Finland has led to an increased public participation in health policy decision-making. In 1999, the government set the foundations for the patients' participation in all levels and sectors pertaining to health policy. A network of agencies at local and national level was developed. Agencies were affiliated with the ministry of health, so as to facilitate, increase and sustain public involvement in each step of health policy decision-making processes by conducting local health needs assessments, priority setting surveys and informal evaluations.<sup>25</sup>

### A good example of a country with high impact of participation

Cyprus was found to be in the cluster of countries characterised by low degree of participation and high impact. In 2016, the Pancyprian Federation of Patient Associations and Friends conducted a national study in order to assess patients' organisations participation in health policy decision-making and identify unmet needs. The study results were disseminated to the community, local press and other key stakeholders. A few months later, the systematic advocating and lobbying activities ended successfully. New legislation providing for patients' participation in health policy decision-making at national level was established by the Cyprus Parliament based on the declaration for patients participation in health policy decision-making.<sup>26</sup>

## Limitations

The study was not without its limitations. As there is no sampling frame for CPOs in Europe, the representativeness of the sample is contested. In spite of systematic efforts to recruit participants through various pathways, one may not exclude the possibility that the most active and motivated CPO members agreed to participate. In this reasoning, sampling bias may have emerged if respondents differed systematically from non-respondents in terms of their views about their CPOs participation in health policy decision-making. Moreover, the HDI taps the patient perspective on the degree of and impact of patient organisation participation and thus findings deriving from its use should be considered complementary to other perspectives (eg,

policy-makers' perspective or more objective indices, such as data emanating from the parliament minutes). Finally, as the present study addressed CPOs, findings cannot extrapolated to other disease groups.

It is noteworthy that since the aim of the present report was to provide a snapshot of CPO participation in health policy decision-making in EU-28 from the patients' perspective, we could not have explored potential links between our data and other system performance indices, such as cancer survival rates and percentage of total health expenditures spent on cancer care across countries. Nonetheless, we are currently designing an ecological study that would enable us to go into greater depth on the topic.

## CONCLUSION

There is substantial diversity in EU-28 with regard to perceived CPO participation in health policy decision-making. Study findings indicate that a high degree of participation is not synonymous to high impact. As a result of this, there is still a long way to go in order to ensure that both the healthcare system will create many opportunities for CPOs to participate in health decision-making and that CPOs will be capable of capitalising on them.

### Author affiliations

<sup>1</sup>Faculty of Social Sciences, University of Peloponnese, Corinth, Greece

<sup>2</sup>Centre for Health Services Research, Department of Hygiene, Epidemiology and Medical Statistics, Medical School, University of Athens, Athens, Greece

<sup>3</sup>University Mental Health Research Institute, Athens, Greece

<sup>4</sup>Department of Surgery, University of Rome Tor Vergata, Rome, Italy

<sup>5</sup>Europa Donna, Paris, France

<sup>6</sup>Bulgarian National Patients' Organization, Sofia, Bulgaria

<sup>7</sup>FSNB Health & Care, Paris, France

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**Competing interests** None declared.

**Patient consent** Obtained.

**Ethics approval** The study was approved by the Research and Ethics Committee of the University of Peloponnese, Corinth, Greece in accordance with the ethical standards delineated in the 1964 Declaration of Helsinki. Furthermore, the institutional review board of the participating patients associations reviewed and approved the study.

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**Data sharing statement** The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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