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## The paradox of public participation in the healthcare in Poland – What citizens want, and what they think



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#### ABSTRACT

*Objective*: To assess the concept of public involvement in the decision-making process in the healthcare sector in Poland.

Methods: A poll was conducted in 2011 on a representative random sample of residents of Poland. Respondents were asked about their preferences concerning the selection of the groups most appropriately representing public interests in the process of decision-making in the healthcare: Patients' Advocacy Groups (PAGs), Carers' Advocacy Groups (CAGs) and Citizens' Councils (CCs). A systematic literature review was performed to study real life examples of patients' involvement in the decision making processes in the Polish healthcare sector as well.

Results: In total, 83% of respondents would wish the participation of PAGs in decision-making concerning healthcare resources. The attitude to the engagement of CAGs and CCs was still positive but significantly lower, by 6 and 7 percentage points respectively. Some socio-demographic differences were observed. In the literature review, five examples of the Polish patients' empowerment and three cases of PAGs' engagement in decision making process were identified.

*Conclusions:* Although its importance was met with a universal approval by the majority of responders, real life examples of public engagement in decision making process indicate there is still room for improvement in the Polish healthcare.

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#### 1. Introduction

Decisions concerning the allocation of public funds in healthcare may be based on an administrative, democratic or meritocratic approach. The latter is understood to b based on the rigorous criteria of clinical value and cost-effectiveness. Each approach to decision making can be subject to pressures from numerous stakeholder groups. As long as the availability of public funds for healthcare is limited, moral dilemmas will arise concerning the prioritization of various therapies.

In order to ensure the optimal allocation of scarce resources, healthcare policy makers have to engage the general public in strategic decision making processes. According to Kaplan, the following conditions have to be fulfilled: patient participation in decision making, public

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monitoring of the development of regulations, and strengthening the role of the state as an advocate for public interest [1].

There are many examples of citizens' engagement in the health policy making process in developed societies. It would be interesting to find out whether the role of the public is well established in young democracies such as the Central and Eastern European (CEE) region as well. Whether patients understand and execute their rights in this regard is particularly thought-provoking. These questions are justified in the light of the fact that patient satisfaction with the healthcare system in the CEE region falls behind that of those in developed countries. At the same time, the contribution of out-of-pocket payments to the total healthcare budget exceeds that of developed countries [2]. Poland was selected for this research, given that it has the biggest population in the CEE region.

The requirement to consult the public during the development of any new legal initiative was introduced in Poland in 2004 [3,4] in compliance with Recommendation No. R (2000) 5 of the Council of Europe. Since then, five different channels have been established which allow citizens to participate in ongoing decision making processes in the Polish healthcare sector. The first one is the public consultation process initiated by the respective Ministry for each new legal initiative [5]. The second one is the possibility of submitting a recommendation or feedback regarding any existing or future law regulation to the Health Commission at the Polish Parliament [6]. The third one is participation in regular meetings organized by the Federation of Polish Patients as part of the "Dialog for health" initiative established by the Ministry of Health at the beginning of 2012(5).

Finally, the public is involved in the process of health technology assessment. Since February 2012 two representatives of the Ombudsman of Patients' Rights are on the twenty member Consultative Council, which is the Appraisal body at the Polish HTA agency (AHTAPol) [7]. There is still too little experience to evaluate whether this form of participation has real influence on the processes of patient decision making, or whether it is simply a manifestation of expanding the decision making circle to involve civil servants from yet another public institution.

Given the numerous challenges encountered in the financing of healthcare services and the growing number of channels established to allow public participation in decision making processes in the Polish healthcare sector, it is entirely justifiable to seek insight into citizens' views on their rights and experiences. The objective of this research was twofold:

- 1. to explore the views of Polish citizens regarding their participation in decision making processes in the health-care sector (Questionnaire study)
- 2. to study real life examples of patient involvement in treatment choices, as well as public engagement in the pricing and reimbursement process in the healthcare sector (Literature review).

We hoped that a preformed study might initiate a public debate about the involvement of various stakeholders in the distribution of scarce healthcare resources, not only in Poland, but also in other CEE countries. Given that the transition to democracy occurred simultaneously across the CEE Region, it is believed that Polish experiences might be useful for its neighbouring countries as well [8].

#### 2. Methods

To achieve the first objective, a cross-sectional observational study was carried out in Poland between 23 March and 15 April 2011. The study was conducted by a professional research company, TNS PENTOR, as part of a multi-themed, quantitative omnibus, face-to-face study on a representative sample of 1000 residents in Poland aged over 15 years. The survey sample was representative of the Polish population regarding region and the size of urban centre of residence, as well as regarding gender, age, and education. The questionnaire consisted of several parts, each part having been tested in a pilot study. In the first part, respondents were asked to rate statements about the equity and efficiency of use of resources on a four-point Likert scale (1 = completely disagree, 4 = completely agree).

The second part of the questionnaire consisted of two experiments presenting hypothetical trade-offs that a decision maker might face. The findings of both the first and second parts have been presented elsewhere [9]. The third part comprised of a series of questions defining a subject's preferences concerning participation of three types of citizens' institutions (patients, carers and Citizens' Councils) in the healthcare decision making process.

Patient Advocacy Groups (PAGs) were defined as social organizations providing patients, their families and carers with psychological support and factual aid. Their aim is to propagate knowledge about a given disorder amongst patients, to inform them about available treatments and provide support, increasing their chances of recovery and return to normal life. They also cooperate with other organizations which support their activities.

Carer' Advocacy Groups (CAGs) were defined in a manner similar to that above. The difference is that their role is limited to situations where, due to a patient's general condition or disease progression, one is not able to manage all of his/her affairs by him/herself. In this situation, one of the patient's loved ones acts on his/her behalf.

By Citizens' Councils (CCs), the survey meant institutions made up of individuals representing ordinary citizens. The task of such councils includes investigating what the general public think about a variety of activities undertaken by the decision makers. Having appropriate insight into the beliefs of ordinary citizens, CCs engage in the decision making processes which are lead by the public payer. The health policy makers must become familiar with the opinions of ordinary citizens before making difficult ethical decisions regarding the allocation of scarce financial resources.

Respondents answered each question by choosing one of the options below on a four-point Likert scale:

- 1. Strongly disagree
- 2. Tend to disagree
- 3. Tend to agree
- Strongly agree

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