



# The tip of the iceberg? Budget restrictions and patient perspectives on cancer drug costs: An international survey in 29 hospitals and 56 patient organizations



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## ABSTRACT

**Background:** The rising cost of cancer drugs are a challenge for health systems, providers, and sometimes patients' individual financial capacities. We conducted a survey in European countries on negotiation options for providers and effects of high costs on providers and patients.

**Patients and methods:** We asked health care providers (members of the Organisation of European Cancer Institutes (OECI) hospitals) viewpoints on discount mechanisms, budget restrictions and patient related issues. Secondly, representatives from the member organisations of the European Cancer Patients Coalition (ECPC) were approached concerning consequences for patients, such as access and receiving appropriate treatment.

**Results:** Response rates were 38% for OECI and 11% for ECPC. Among 29 participating OECI members, a wide range of discount mechanisms and payments methods are being used in cancer drug purchasing processes. 90% (26/29) of institutions allow joint drug price negotiations; however, only 69% (18/26) use this strategy. Two-thirds of institutional responders are of the opinion that treatment choices are being affected by cost issues. 79% (n = 56) patient representatives of ECPC member organizations responded that patients may be missing out on best possible treatments due to high drug costs and 43% thought that patients may not be aware of that.

**Conclusion:** Our findings revealed a lack of systematic approach towards purchasing agreements, and a limited use of potentially powerful mechanisms such as joint negotiations. Furthermore, a large majority of patient representatives (79%) and providers (66%) indicated that the drug cost issue is likely to influence treatments decisions. Access issues and coverage delays seem to be present in all countries regardless of level of GDP.

## 1. Introduction

During the past few years large variations in cancer drugs list prices, and even more in actual prices, have been observed between European countries [1,2]. The rising cost of cancer drugs is a challenge for health systems, providers, and sometimes patients' individual financial capacities. Beyond questions related to underlying pricing mechanisms, variations in prices may lead to inequalities in patient access as the significant impact on societal/hospital budget has been reported to lead to significant delays and barriers to receiving treatment [3]. This phenomenon has thus far been investigated using market data on diffusion and access of new drugs, and through analyses on in-country drug utilisation variations, as was done in the extensive analysis of Jonsson et.al. [4]. What remains to be investigated are the mechanisms behind

negotiations and price discounting, and the resulting impact on care provision and drug access.

The issue of cancer drugs cost as a threat to system sustainability is becoming increasingly important, especially in view of the pipeline of promising new (expensive) drugs, including targeted cancer therapies and immunotherapy regimens, indications widening over tumour types, and the growing need to treat in combinations, [1,5,6].

The aim of this research was to explore the dynamics of negotiation mechanisms in relation to high cancer drug costs, and the consequences for providers and patients. By means of a survey amongst providers throughout Europe, we assessed how costs influence care provision and access. We also sought to understand the structure of purchasing agreements, discount mechanisms and the utilisation of joint negotiations between institutions/hospitals. By means of a separate survey

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amongst patient representatives via member organisations of the European Cancer Patient Coalition, we assessed the consequences of cancer drugs cost and its impact on patients throughout Europe.

## 2. Methods

### 2.1. Providers perspective

We approached 76 members of the Organisation of European Cancer Institutes (OECI), a network of 76 (Dec. 2016) cancer centres. We used a Microsoft Word-based semi-structured survey (full set of questions is presented in supplementary appendix 1) containing questions concerning the discount mechanisms, budget restrictions and patient related issues from the providers' perspective (out-of-pocket costs, additional financial support). The surveys were distributed via email in December 2016, followed by one reminder and responses were collected in the first quarter of 2017. Ethical review was not necessary. Respondents were informed that the results would be handled anonymously, and that the results would be published.

### 2.2. Patient perspective

For a more in-depth understanding of the patient perspective on consequences of- and issues related to cancer drugs cost, we established collaboration with European Cancer Patients Coalition (ECPC), the largest umbrella organisation for cancer patients in Europe. Boards of the (member) patients organizations or - coalitions were approached by the board of the European Cancer Patient Coalition. After they agreed on participation, they received an online survey concerning the patient perspective on access, coverage of cancer treatments and related issues was distributed in the first quarter of 2017 (full set of questions is presented in supplementary appendix 2). Initial request was sent to 527 recipients of 408 member organisations and the survey was closed in June 2017.

### 2.3. Analysis

Results were analysed using descriptive analysis in Microsoft Excel and IBM-SPSS Version 24.

## 3. Results

### 3.1. Providers survey

Out of 76 OECI member institutions 29 professionals responded, involving 17 European countries in the analysis (response rate 38%). (The full list of responders is presented in supplementary appendix 3).

A wide range of discount mechanisms (15) (Fig. 1) and payment methods (14) that hospitals use was reported. The most common mentioned were (traditional) "agreed discounts" (made prior to purchase) and price/volume agreements (rebate by the drug manufacturer, when sales exceed the agreed threshold), mentioned respectively by 24 and 14 centres. When prompted to shed more light on the drugs cost and price information availability, the most common obstacles are confidentiality clauses or disclosure restrictions reported by the survey participants. Additionally, it was frequently reported that price information is not available due to drugs being used for trial use ("compassionate use") only or due to the fact that the drugs are not currently used in specific country. (Fig. 2).

Joint negotiations are not allowed within the purchase process of cancer drugs by the local legislation between institutions/hospitals in three institutes (two from Italy, one from Russia). Even though joint negotiations are allowed in the majority of countries, actual use of this mechanism is not applied as widely as possible, as only 18 out of 29 use them.

13 providers from 9 countries (45% of total) reported their budgets

to be insufficient to cover all drug costs and 19 providers from 13 countries (65%) stated that treatment choices are affected by financial limitations. In addition, according to 52% of responders, cancer drugs high cost has been a reason for not obtaining coverage. Furthermore, only around half (52%) of the responders consider the current pricing system in their country transparent.

Providers in 6 countries stated that patients need to pay out of pocket costs for cancer drugs, while additional financial support for cancer patients is provided in 15 centres in 9 countries. See Fig. 3 and supplementary appendix 4 for a more comprehensive overview.

### 3.2. Patient perspectives

Out of the 527 recipients of 408 ECPC member states, we received 56 responses from 24 countries. A list of responding organisations and countries they are located in is presented in supplementary appendix 5.

Fig. 4 gives an overview of the most relevant responses given by patient representatives. 79% believed patients may be missing out on best possible treatment due to high drug costs and 43% thought that patients may not even be aware that they are missing out on (the most optimal) treatment options. 62% of the responders thought that the issue of affordability was not given enough attention.

Despite 48% of responders stating that additional financial support is provided to patients (often noting it can be just minimal or insufficient concerning patients' actual expenditure), only 23% stated that financial counselling (providing information, support and advocacy to assist people in financial difficulty) is provided to cancer patients. The main limitation (Fig. 4) behind patients' difficulties are perceived to be lack of funds (64%) and legislation (31%) according to patient representatives. For a more detailed overview see supplementary appendix 6.

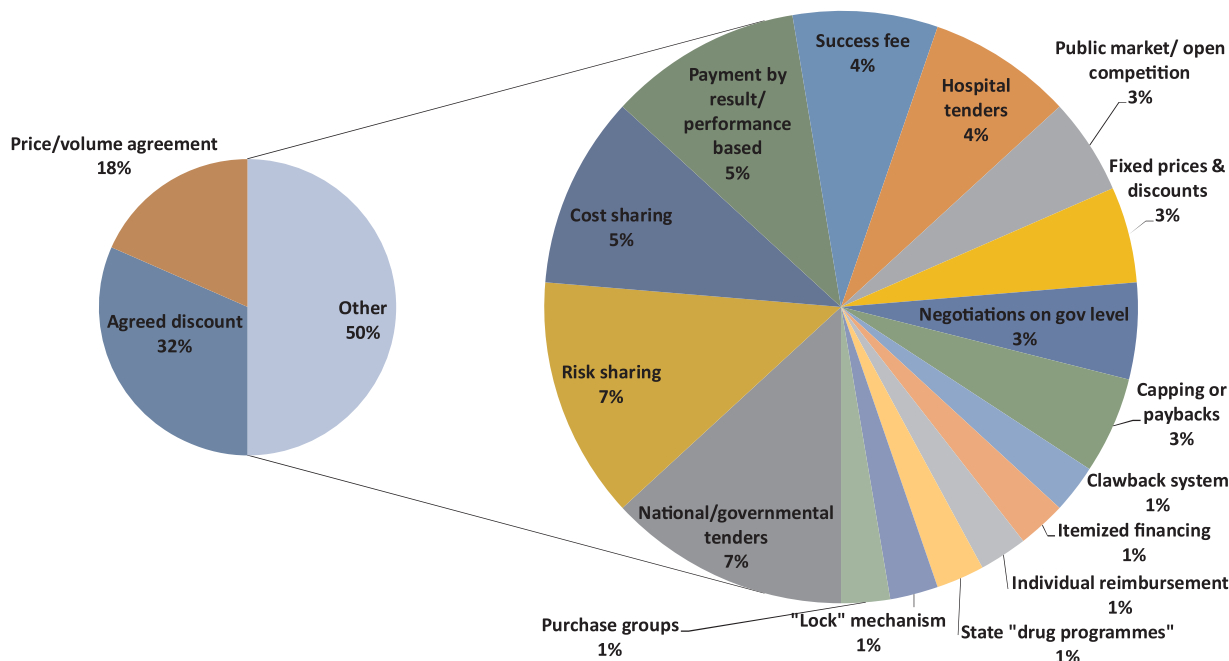
## 4. Discussion

To the best of our knowledge, this is the first large scale survey on perceptions of the relation between cancer drugs cost and accessibility, provision of care and related issues. Over half of the providers, as well as a large majority of patient representatives, stated that it is their impression that treatment decisions are influenced by the drug cost issue. Moreover, it is estimated that nearly half of the patients are not aware of the possibilities or that they are possibly missing out on optimal treatment. Access issues seem to be present in all countries regardless of the level of their GDPs.

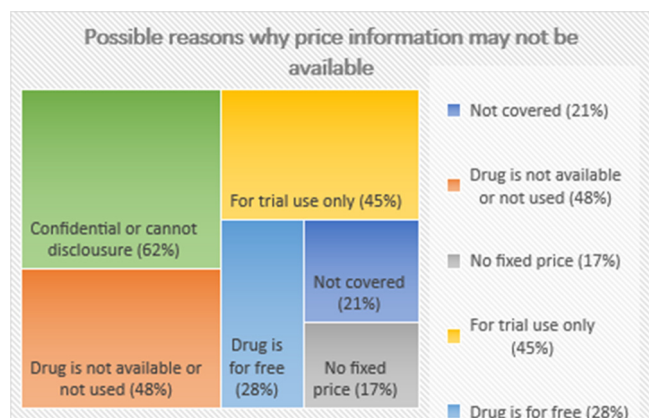
A wide range of discount mechanisms and payment agreements was found to be currently in use. However, we could not observe a pattern in the responses regarding purchasing mechanisms in use, nor in joint negotiations between hospitals. It seems to be rather random which mechanisms are used, thus providing pharmaceutical industry with the opportunity to "divide and rule" between countries and providers (groups). Despite the legal possibilities for joint negotiations, this option is not commonly used. This may be restricted by the related administrative workload or lack of purchasing expertise, but the reasons were not studied and should be followed up for further research. As smaller countries with smaller markets may have a disadvantage in their negotiation position [7], joint international negotiations could improve their situation, firstly as a country and later possibly as a European-wide initiative. This calls for an urgent program to develop mature drug purchasing schemes both on national and preferably also on international levels. This is especially relevant as it is completely unclear whether schemes that are promoted by pharmaceutical industry, such as pay for performance, actually contribute to cost control on national levels.

A comparable approach such as types of performance-based purchasing agreements might improve the countries relative positions and contribute to reducing inequalities of drug prices over Europe. All countries would benefit from having a consensus on what is a

### Main mechanisms used to obtain discounts for cancer drugs



**Fig. 1.** Organisation of European Cancer Institutes (OECI) responses from 29 centres in 17 countries, collected between December 2016 and January 2017. Full question: „What are the main mechanisms in your country used to obtain discounts for cancer drugs? “Besides agreed discounts and price/volume agreements several „other “mechanisms were mentioned by responders.



**Fig. 2.** Organisation of European Cancer Institutes (OECI) responses from 29 centres in 17 countries, collected between December 2016 and January 2017. Full question: „What are the possible reasons why price information may not be available?“.

The most common obstacles are confidentiality clauses or disclosure restrictions reported by the survey participants. Additionally, it was frequently reported that price information is not available due to drugs being used for trial use (“compassionate use”) only or due to the fact that the drugs are not currently used in specific country.

transparent pricing system and more uniform mechanisms for drugs purchasing. Stimulating transparency to be able to compare prices, even in a retrospective manner, is important and can assist both national agencies and hospitals in purchasing arrangements. It is also likely to force more societal responsible behaviour in pricing [1].

A very disturbing finding was the high percentage of providers and patient representatives under the opinion that patients’ access to best possible treatment is likely to be restricted. In addition, many indicated that patients may not be aware of the fact that they are missing out treatment as a result of their high prices. The challenges related to medicine affordability at the national and international level

disproportionately affect patients with lower socioeconomic backgrounds, deepening the inequalities that high drug prices create. In previously published studies [1,2], a huge variation in price levels (both list and actual) were shown and this adds to an uncomfortable feeling of patients having unequal access to appropriate cancer medication. In western Europe, the public has been largely protected from the high cost of medicines because the financing of their healthcare does not fall on individuals [8]. Still, a delay in coverage decisions and regional variations do exist despite a country’s affluence. Adequate research into actual effects on patients’ treatment access and financial consequences in different countries is urgently needed.

Cost levels are already considered by many to be increasing to levels that are not sustainable. Therefore, it is crucial to acknowledge the dual responsibility of pharmaceutical industry in the process of developing and launching life-prolonging and life-saving innovations, while simultaneously considering a more responsible course towards affordable medicines. This calls for a paradigm change in providing more transparency, considering different R&D development schemes, spending less on marketing and sales and accepting lower profit levels. This is not likely to be directly appreciated by the actual stakeholders. In view of the huge commercial interests this will be a difficult process and will take time.

This study has limitations which should be considered when interpreting the results. Different numbers of hospitals and patient representatives responded per country, and we did not have control over possible response bias in these populations. We were not able to verify whether the responses were shared or single person based; contacts in OECI member organisations usually relate to executive-, director- or head of department positions. Although not as strong as with surveying actual prices, some respondents might have been restricted by signed confidentiality clauses. Representatives from cancer centres and especially patients are usually not educated in health economics, so responses may be affected by individual perceptions. However, despite these limitations, we do have the impression that in general valid answers were provided. Furthermore, the literature on drug costs and access to expensive medicines is rather opinionated and seemingly lead

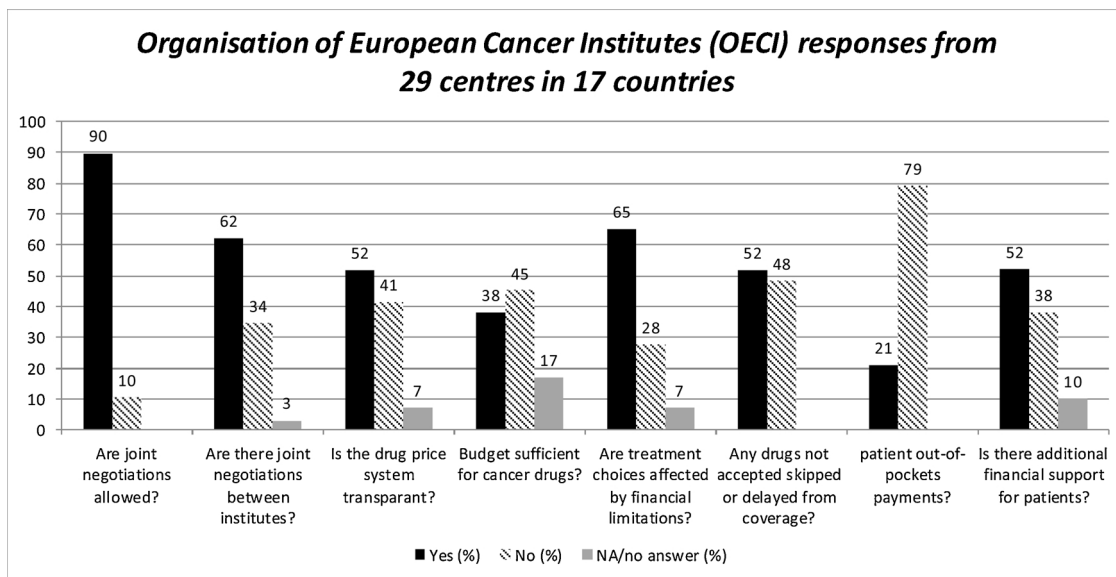


Fig. 3. Organisation of European Cancer Institutes (OEI) responses from 29 centres in 17 countries, collected between December 2016 and January 2017. Viewpoints as health care providers on discount mechanisms, budget restrictions and patient related issues.

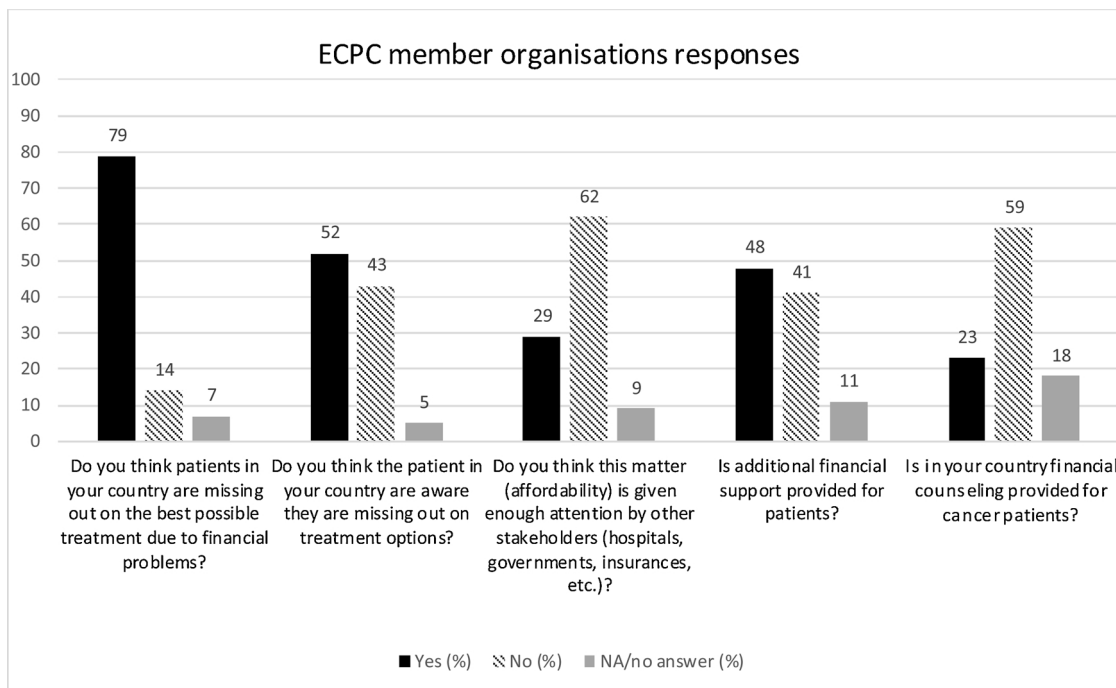


Fig. 4. European Cancer Patient Coalition (ECPC) responses form 56 member organisations in 23 countries, collected between January 2017 and June 2017 via online questionnaire form.

by incidents like new, ever more expensive drugs entering the market and seeking for coverage. In further research and literature reviews one should preferably try to establish a consensus on frameworks containing the relevant aspects that can be used to structure evaluations and discussions in this field.

To conclude, this study contributes to the agenda for further research into mechanisms behind price negotiations and highlights the need for systematic and collaborative approaches to lower cancer drug prices in Europe. Research into actual and detailed access to innovative cancer drugs is urgently needed.

**Authors contribution**

RO carried out the collection of the data, performed the analyses, and drafted the manuscript. VR have made substantial contributions to the collection, critical revision of the analyses, interpretation and writing of the manuscript. WvH designed the study, critically revised the analyses, interpretation and writing of the manuscript. All authors read and approved the final manuscript.

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## Declaration of Competing Interest

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## Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.jcpc.2019.100195>.

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