



How do we treat cancer in Poland?

Alivia Foundation's commentary on the report

Accessibility of innovative cancer drugs in Poland compared to selected European Union countries and Switzerland





Dear Sir or Madam,

We present you a report that we find both interesting and concerning. This document was commissioned by the Young People Oncology Foundation Alivia and prepared — in cooperation with the Polish-Swiss Chamber of Commerce — by the advisory agency EY Poland.

The report touched upon the important and at the same controversial topic of the access to modern pharmacological treatment of neoplasms.

Why did we decide to initiate and carry out a project leading to a report that attempted at analysing the access to modern cancer treatment? There are several reasons. Below are the most important ones.

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Personal experience

The Alivia Foundation (and hence the present report) would not have come into existence if not for the personal experiences of the current vice-president of the foundation – Agata Polińska. In 2007, at the age of 28, she was diagnosed with locally advanced, invasive breast cancer. Because of poor prognosis (stage IIIC, locoregional relapse after less than two years of the initial diagnosis) it was necessary to start aggressive treatment based on the latest advances in medical knowledge. Problems with obtaining such treatment was the source of our enormous frustration and unthinkable stress. Finally, as a result of our own work and private financial means (amounting to hundreds of thousands zlotys), the treatment was carried out in line with the global standards, but unfortunately it was largely thanks to the courtesy of foreign medical centres in the United Kingdom, Italy and United States. All our actions led to saving Agata's life, but we lost something irrevocably and for ever. It was our trust to the institutions of the Polish State and to the constitutional right to protection of health and life it guarantees.

The needs of Polish oncological patients and people under the care of Alivia Foundation

Our personal experiences from 2007–2009 (described above) led to the creation, in 2010, of the **Young People Oncology Foundation Alivia**. Since the very beginning, the foundation has tried to solve problems we have encountered ourselves — it has helped patients find their way in the "system" (the "Red Box" Programme [Czerwona Skrzynka]); provided them with knowledge and information about the newest global advances in oncology (the "Onco News" Programme); and engaged them in public auditing of oncological centres (the website www. onkomapa.pl) as well as monitoring of the length of queues to imaging diagnostics (the website www. kolejkoskop.pl). However, one of the most important activities of the foundation is the **Piggy Bank Programme** (Program Skarbonka), which allows collection of financial means for cancer patients.

The financial needs of patients largely stem out from limited access to reimbursed cancer treatments. The history of every person under the care of the foundation is dramatic and shocking - they are most often young persons, mothers and fathers of young children and people just entering adulthood. What they all have in common is that they have found themselves in a situation where they are forced to ask the society for help. What is heartening is that people answer those requests and are able to really help the patients. In 2014 alone, the Alivia Foundation handed over nearly 1,000,000 PLN to people under its care, which enabled the financing of e.g. non-reimbursed medications, diagnostics and rehabilitation. The cases of patients under the care of our foundation are not isolated - over the Internet imploring requests for help in fighting the disease have become a daily occurrence.

The situation of oncologists

While designing the report, we asked ourselves the following question: is the problem with access to innovative drugs felt only by the patients or is it also noticed by the medical community? We decided to find out. The Alivia Foundation commissioned TNS Polska in February 2015 to carry out a study which involved over 100 surveys completed by Polish on-cologists. We were surprised by the results:

- According to 90% of the surveyed oncologists, there is a problem of lack of access to certain modern cancer drugs in Poland; 95% claim there is a problem of limited access to drugs.
- 97% of the doctors claim that their patients could gain therapeutic benefit should they have more free access to cancer drugs (prolonged lifetime and progression-free survival as well as increased patients' quality of life were among the most frequently named benefits).
- As many as 85% of oncologists believe that elimination of restrictions in the access to modern drugs would improve the overall statistics of the efficacy of cancer treatment in Poland.

The full results of this study are presented in the remaining part of this publication. They unambiguously indicate that the subject of our analysis is not only problematic for the patients, but that it is also recognised by the medical community.



Systemic problems

Is cancer treated effectively in Poland?

It is not difficult to find the answer to this question – it can be achieved just by analysing the key factor which is the percentage of patients who survive 5 years following diagnosis (which often means permanent recovery). In Poland, out of every 100 patients, 46 will survive on average, which places our country among the lowest ranks in Europe.

The gap separating us form the leaders is vast – those countries reach figures exceeding 60%. The fact than in Poland over 150,000 persons are diagnosed with a new neoplastic disease each year means that, statistically, approx. 69,000 patients of this group will survive after five years, although the contemporary health care systems are able to save at least 100,000. The difference is approx. 30,000 persons annually – a population of one small town, which vanishes year after year.

Modern pharmacological treatment of neoplasms is one of the elements (besides prophylaxis, early and quick diagnosis, resources of the system and excellence of the processes) influencing the efficacy of cancer treatment.

How does the regulatory system in this field work?

The Supreme Audit Office (Najwyższa Izba Kontroli, NIK), as a result of the audit "Therapeutic and drug prescription programmes financed from public funds" (Programy terapeutyczne i lekowe finansowane ze środków publicznych), "...puts forward a motion to the Minister of Health to introduce clear rules of access to modern methods of treatment, since NIK finds the current rules of financing of these treatments lacking transparency. In the same report we can read: "The Supreme Audit Office also finds it appropriate for the Minister of Health to undertake actions aimed at increasing transparency of procedures in the process of drug reimbursement that would guarantee objectivity in decision-making". This is because we have learnt that the experts of the Agency for Health Technology Assessment and Tariff System (Agencja Oceny Technologii Medycznych i Taryfikacji, AOTMiT) on the assessment of new drugs were persons in a disclosed conflict of interest.

In 2015, the media were buzzing with the information which suggested that one of the Health Vice-Ministers addressed a letter to the Transparency Council by the Director of AOTMiT, stating that "it is with concern that I learn about the preference for clinical efficacy over cost-effectiveness" and suggesting that AOTMiT's recommendations for expensive drugs should be negative.

These few selected facts about the functioning of certain elements of the health care system in the field of oncology show only a small fragment of the complex system.

Social expectations

The society seems to understand cancer patients - it recognises the inadequate engagement of the state in solving problems of this social group and calls for effective treatment of the disease.

In a study performed by CBOS concerning the accepted norms and hierarchies of values appreciated by Poles, health invariably ranks among the highest (74% of respondents; family happiness — 82% of respondents).

As many as 68% of Poles believe that cancer treatment should have priority in our health care system, as indicated in an opinion poll conducted in 2012 by IPSOS and commissioned by the Polish Coalition of the Cancer Patient Organisations. Cardiac diseases were indicated by 32% of respondents, while diabetes by 26%. Only 1% of Poles stated that the efficacy of cancer treatment is "very good". Half of respondents with cancer patients in their families decided the efficacy of treatment to be bad or very bad, and 43% of all the respondents believe that the National Health Fund (Narodowy Fundusz Zdrowia, NFZ) does not guarantee good oncological care.

In a study conducted by MillwardBrown in 2014, as many as 54% of the respondents named cancer patients as the group who should have facilitated access to examinations and treatment (cardiovascular patients were the second most frequently named group, indicated by 25% of the participants). The above results no longer surprise when one learns the answer to the question "Among your family or close friends, have there been cases of neoplastic diseases?" - as many as 72% gave an affirmative response. Given the fact than over 150 thousand persons in Poland are diagnosed with a new neoplastic disease each year (and this disease affects not only the patient but also his or her family), it is easy to understand we are not talking about interests of a narrow social group, but rather about a nation-wide problem.

What are the most important conclusions of analyses performed in the report?

It turns out the Poland ranks among the worst European nations, not only when it comes to the efficacy of treatment. Among the 13 European countries studied, Poland spends the least on innovative cancer drugs (calculated per the number of deaths caused by neoplastic diseases). Polish patients have a very difficult access to drugs — out of 30 studied cancer treatments, only 2 are accessible

without limits in Poland, and 12 are not available at all (they are not reimbursed from the NFZ funds). Access to the remaining drugs is strongly limited at the level of the Ministry of Health's so-called "drug prescription programmes" (programy lekowe). The utilisation of the already few available drugs (standardised against the number of deaths) significantly deviates from the mean - only in the case of 2 drugs their utilisation level is above average, with a vast majority failing to reach even 50% of the mean for other countries. Another problem is a long interval between the time when a drug is granted marketing approval on the European level (approval to be sold in the EU) and the time it begins to be financed from public funds, amounting to more than 2 years – during this time patients are deprived of the possibility to receive treatment.

How can we then understand the emerging contradictions?

Why is it impossible in Poland to improve the efficacy of cancer treatment if it is clearly demanded by the patients, society and medical community alike? Why is the system defeated by the disease and why cannot the patients benefit from the advances of the modern science in the field of oncology? Why is Poland not joining the broad coalition of countries which declared war against this mysterious and terrifying disease? Why is it in our country that each year 30,000 persons die, although modern health care systems are able of saving them? Can wider access to modern drugs change the poor statistics for Poland regarding the efficacy of cancer treatment? An attempt to address these difficult questions requires thorough and unbiased analysis of the current state of access to innovative treatments. This is what the prepared report is for. We believe that there are solutions for the discussed problem. Solutions that would satisfy the patients and their families, the public administration and the medical community alike. Feel invited to read and discuss the report.



Patient's perspective

Study of the assessment of the method of cancer treatment

Notes on methodology

The study was carried out as part of the project "ONCOMAP – the guide to friendly oncological centres" (ONKOMAPA – przewodnik po przyjaznych ośrodkach onkologicznych). This question is one of many included in the oncological centre assessment questionnaire and belongs to the section "Treatment". Survey questionnaires, whose results are presented below, were completed by respondents from February 2014 to April 2015 (overall 5549 completed forms). Respondents provided answers during personal surveys carried out in medical facilities (the study was conducted by TNS Polska) and online at www.onkomapa.pl.

The website www.onkomapa.pl makes it possible to perform multifaceted assessment of oncological centres and medical personnel. Patients and their closed ones can complete an online survey, expressing their opinion about a given facility or a doctor, and learn about ratings given by other patients. Furthermore, the system visualises fluctuations of the ratings in time, making it possible to monitor changes.

Study conclusions

This question pertained to patient's assessment of the method of the treatment used. Respondents provided answers in a five-point scale: from "very bad" to "very good".

The study indicates that a vast majority of respondents believe that cancer treatments used in public centres are optimal (the best of possible treatments according to the current medical knowledge) — overall, nearly 90% of the participants rated the method of treatment as good or very good

Detailed study results

The method of treatment (do you feel that the patient is treated in the best possible way?) (N = 5549)

Fairly bad:	1.24%
Neither good, nor bad:	5.35%
Fairly good:	34.44%
Very good:	53.87%
l don't know/not applicable:	4.54%

Doctor's perspective

Study of limited access to modern cancer drugs

Notes on methodology

The study was carried out between 3 February and 2 March among 106 clinical oncologists using the following three techniques: CAPI – computer-assisted personal interviewing (68 interviews); CATI – computer-assisted telephone interviewing (31 interviews); and CAWI – computer-assisted web interviewing (7 interviews).

Before each interview the respondents were informed about:

- the name of the foundation commissioning the study;
- the non-commercial nature of the study;
- anonymity of the study.

Furthermore, they were informed about the following terms used in the survey:

Modern cancer drugs – anticancer cytostatic drugs (L01 code in the ATC classification) registered within the last 10 years by the European Medicines Agency (EMA).

Free access to modern cancer drugs – a situation where it is a doctor or a team of doctors who decide about using a drug, based on medical indications and the Summary of Product Characteristics (SmPC). The drug is reimbursed by NFZ.

Limited access to modern cancer drugs – a situation where the possibility of using an off-label drug depends on the fulfilment of certain regulatory criteria (e.g. so-called medication prescription programmes). The drug is reimbursed by NFZ only if the above criteria are met.

Lack of access to modern cancer drugs – a situation where there is no possibility of using an (EMA-)approved drug, irrespective of medical indications. The drug is not reimbursed by NFZ.

Study conclusions

The conducted study indicates that difficulties associated with lack of or limited access to modern cancer treatments are very clearly noticed by oncology clinicians — as many as 90% believe that in Poland there is a problem of lack of access to certain modern cancer drugs, and 95% indicate the problem of limited access to these drugs. The scale of the problem is significant — a vast majority of respondents indicate that it pertains to over 20% of clinical cases they know. Doctors are convinced about the efficacy of innovative treatments —



as many as 97% claim that some of the patients could gain therapeutic benefit (more than three fourths indicate the possibility of prolonging patients' life) if they could be properly treated. The study indicates that a significant group of patients may be denied information of the fact that there is a treatment which could be effective in their case, but is not reimbursed — only 14% doctors declare that they always inform their patients about the existence of such drugs, and 5% never do that. At the same time, almost all doctors (97%) demand greater freedom in making decisions concerning the choice of therapy; 95% believe that lack thereof causes difficulty or discomfort in performing the medical profession. In the Polish oncologists' opinion, there would be an improvement in the overall statistics of the efficacy of cancer treatment if it were possible to use modern drugs on a broader scale.

Detailed study results



1. What is your scientific degree? (N = 106)

2. Do you know modern cancer drugs, the access to which is limited or impossible? (N = 106)





3. What modern cancer drugs do you know, the access to which is limited or impossible? (N = 97)

4. Do you think that in Poland there is a problem of lack of access to certain modern cancer drugs? (N = 106)











6. What do you think – how many out of every 10 patients treated by you are faced with a problem of lack of access to modern cancer drugs? (N = 103)

7. What do you think – how many out of every 10 patients treated by you are faced with a problem of limited access to modern cancer drugs? (N = 103)



8. In a situation of free access to modern cancer drugs, could some of your patients gain therapeutic benefit? (N = 103)



9. What, in your opinion, therapeutic benefits could be gained by your patients if the access to modern cancer drugs were not limited? (N = 100)



10. In a situation where there are medical indications for using a certain drug in a patient and the drug is approved but not reimbursed in Poland, do you inform your patient that such a drug exists? (N = 103)





11. Does the limitation or lack of access to modern drugs causes difficulties or discomfort in performing your profession? (N = 103)



12. Do you believe that you should have greater freedom in using modern cancer drugs? (N = 103)



13. In your professional career, has there ever been a situation when you felt that using treatment with modern cancer drugs could bring therapeutic benefit, but the access to such drugs was limited or impossible? (N = 103)



14. Do you believe that elimination of restrictions in the access to modern cancer drugs would improve the overall statistics of the efficacy of neoplastic disease treatment in Poland? (N = 103)





The Polish-Swiss Forum for Dialogue 21st Century Healthcare creates an opportunity for discussion aimed at developing an optimum model of the health care system in Poland. The cycle of meetings is organised by the Polish-Swiss Chamber of Commerce under the auspices of the Embassy of Switzerland in Poland. Invitations to participate in the meetings are given to Polish and foreign experts, who share their knowledge and experiences concerning the functioning of the health care system and mechanisms of effective implementation of dialogue used in other countries.

Six meetings have taken place so far, dedicated to the most important problems of the health care system and the role of dialogue between its stakeholders:

How much of the market and how much of the state in health care? Competition between payers - the Swiss experience. (2011)

- Dr Eugen David, Member of the Social Security and Health Committee of the Council of Cantons, former Director of one of the largest health insurance funds in Switzerland;
- Dr Thomas Zeltner, long-standing Minister of Health in Switzerland;
- Marek Balicki, former Minister of Health;
- Dr Andrzej Sośnierz, former Director of the National Health Fund (Narodowy Fundusz Zdrowia, NFZ).

Prophylaxis and health promotion - new perspectives for the state and local governments. (2011)

- Dr Ignazio Cassis, MD, Member of the Health Committee of the Federal Assembly in Switzerland;
- Dr Thomas Mattig, Director of the Health Promotion Switzerland Foundation;
- Bolesław Samoliński, National Consultant for Public Health;
- Witold Tomaszewski, Chief Sanitary Inspectorate (Główny Inspektorat Sanitarny).

Dialogue as the best way to achieve optimum solutions in the health care system (2012)

- Dr Thomas Zeltner, long-standing Minister of Health in Switzerland;
- Thomas Cueni, General Secretary of the Swiss industrial association Interpharma;
- Prof. Witold Orłowski, Main Economic Consultant at PwC.

Senior citizen policy in Europe: the Swiss experience. Interministerial challenges in senior care in Poland. (2013) — in cooperation with the Sejm Health Committee under the supervision of MP Beata Małecka-Libera

- Hans Groth, Director of the World Demographic & Ageing Forum;
- Dr Ignazio Cassis, MD, Member of the Health Committee of the Federal Assembly in Switzerland.

How to implement a strategy for fighting cancer? Challenges faced by Poland. The Swiss experience - implementation of systemic reforms, the role of dialogue between stakeholders. (2014) — in cooperation with the Parliamentary Team for Oncology under the supervision of MP Alicja Dąbrowska and the Polish Society of Oncology (Polskie Towarzystwo Onkologiczne)

- Prof. Jakob Passweg, Director of the Swiss League for Cancer Control; head of the department at the Haematology Clinic, Medical University in Basel;
- Prof. Jacek Jassem, Head of the Executive Board of the Polish Society of Oncology (Polskie Towarzystwo Onkologiczne); Head of the Clinic of Oncology and Radiation Therapy at the Medical University in Gdańsk;
- Dr Beat Seiler, Medical Director at Helsana, the biggest health insurance fund in Switzerland.

How do we treat cancer in Poland? Accessibility of modern cancer treatment. (2015) - in cooperation with the Young People Oncology Foundation Alivia

- Prof. Francesco de Lorenzo, Director of the European Cancer Patient Coalition;
- Martina Weiss, Head of the Drug and Medical Service Purchasing Department of the biggest Swiss health insurance fund Helsana;
- Bartosz Poliński, Director of the Alivia Foundation.

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