Stakeholders' Perception on the Social Burden of Cancer: Evidence from Romania

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Abstract

This paper aims to identify the perspective of multiple stakeholders on the socio-economic burden of cancer in Romania. The Romanian health system is among the poorest in the European Union and cancer patients are among the most vulnerable. They do not only face difficulties in accessing diagnosis and treatment, but they encounter obstacles on the labour market due to the lack of support from the authorities and business environment. Using a qualitative approach (focus group) different categories of stakeholders have been investigated: patient associations, practitioners (physicians), academics and labour market representatives. Six recurrent themes occurred from the analysis of these stakeholders' perspectives: lack of data, financial toxicity of cancer caused by the burden of the "out of the pocket money", healthcare insufficient resources (material and human), lack of interest in the patient needs, inconsistent and inefficient legal framework, and systemic deficiencies of the Romanian society. The results are important for policy makers in order to design a proper Cancer Policy in Romania.

Keywords: stakeholders; social burden of cancer; cancer policy; Romania;

JEL Classification: I13; I18;

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1. Introduction

The social burden of cancer is an increasing concern for all countries, as the number of cancer patients is expected to grow worldwide. The complexity of this concern is influenced by many factors: from medical, to economic, social, or political ones, and shapes both the consequences of and the solutions towards this disease. Cancer needs a wider approach, as many stakeholders are involved in managing the complex dimensions of the disease.

A unitary approach about stakeholders' involvement in managing cancer does not exist in the literature. The wider or narrow approach depends on a multitude of factors, like the characteristics of the health system and health insurances (and the type of state involvement

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in managing diseases like cancer), the performances of the health system (Mulligan, Appleby and Harrison, 2000; Ham *et al.*, 2015), new discoveries in treatments, prevention policies and their implementation, health education among general public, mentalities and social attitudes towards diseases, mostly toward cancer, and many other aspects. All these factors influence the categories of stakeholders, their implications, and their influence.

Stakeholders approach in cancer disease is a complex analysis. Not only the multitude of the stakeholders features this analysis, but differentiation in the needs stakeholders have complete the investigation of the burden of cancer (Muller, Hahlweg, Scholl, 2016). Over the last few years, numerous academic studies have analyzed stakeholder views on various aspects of cancer prevention and treatment, using the focus group and in-depth interviews as the main method of gathering information (Pastrana *et al.*, 2010; Gupta *et al.*, 2015; Liles *et al.*, 2015; Johnston *et al.*, 2019; Thomas *et al.*, 2021).

Pastrana *et al.* (2010, p. 859) used the focus group (with German experts) to assess and evaluate palliative care methods and strategies. An abundance of topics was identified, pointing at the complexity of the disease: quality of life, needs assessments of patients and relatives, resource assessment, surveillance of decision-making processes, as well as spiritual well-being.

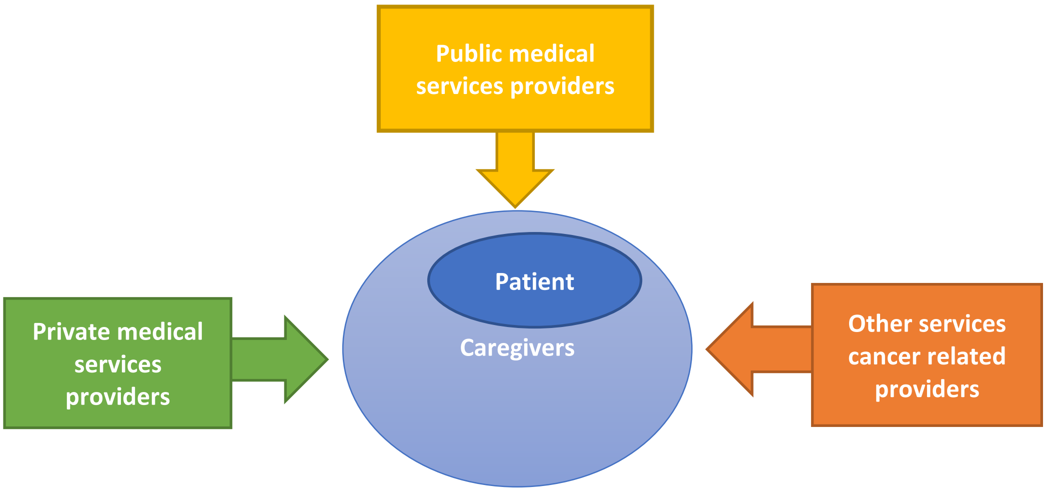
Gupta *et al.* (2015) used both in-depth interviews and focus groups to study the views of three categories of stakeholders (persons who attended cancer-screening camps, health care providers, and cancer survivors) on cancer stigma, as a barrier for patients in India to benefit from an early detection of the disease, which increases the chances of survival.

The importance in studying stakeholders' need in cancer was, also, demonstrated by the study of Thomas *et al.* (2021). The study looked at caregivers, a stakeholders' category that represent a large, overburdened, and underrecognized part of the cancer care workforce, which contribute a lot to healthcare delivery. Using a focus group with 15 cancer caregivers, conducted during a cancer caregiving workshop at the University of Pittsburgh in February 2020, a content analysis of the discussions summarizes caregivers' priorities: training and information about cancer and treatment, integration into the patient's healthcare delivery, assistance with navigating the healthcare system, focus on caregiver health and well-being, and policy reform to address caregiver needs.

Liles *et al.* (2015, p. 1) studied the views of several categories of stakeholders (health plan leaders, primary care providers, program managers, and endoscopy specialists) in the North-western United States (Washington and Oregon) to "explore external and internal barriers to CRC screening".

Based on these, the present paper considers the cancer stakeholders' system as having in center the **patient**, together with **his/her family and other caregivers,** and being served by public medical services providers, private medical services providers and other services cancer related providers (Figure 1).

Figure 1. Cancer patient stakeholders' system



Source: Authors own compilation

This study is an investigation that adds to the literature focused on stakeholder's perspective on cancer. This paper aims to analyze the stakeholders' perspective on the social burden of cancer in Romania, as it results from discussions with relevant categories of stakeholders, and to identify the most important concerns these stakeholders encounter in their fight against the disease. Two objectives with several subobjectives are followed: (1) to present a general description of the stakeholders in cancer disease; (2) to investigate the perception of different categories of stakeholders in Romania, for: *(i) identifying the major obstacles patient with cancer encounter in investigating and treating the illness;(ii) detecting associate burdens (social, emotional, etc.) that patient and their close care givers face when access services for investigating and treating the illness; and (iii) exploring the involvement of stakeholders in investigating, treating and supporting the life of a cancer patient.*

After the introduction, the methodology of the study is presented. Findings and discussions' part is following, where the analysis and the interpretation of the qualitative data obtained from focus group discussions are provided.

2. Methodology and Limits of the Study

The methodology followed by this paper is a qualitative one and was based on focus groups. The rationale behind this lays on the exploratory nature of this study, which aimed to identify answers on "how", and "why" questions (Zaharia and Zaharia, 2018). There is a scarcity of studies to date that focus on Romania, aiming to investigate the social burden of cancer, from a multiple stakeholder perspective. Also, in cancer studies concerning stakeholder perspectives, qualitative research, based on focus groups or in-depth interviews, are widely used: Pastrana *et al.*, 2010; Gupta *et al.*, 2015; Liles *et al.*, 2015; Mazor *et al.*, 2015; Zafar *et al.*, 2013, Zafar, 2016; Johnston *et al.*, 2019; Srinivasan *et al.* 2020; Bergerød, Braut and Wiig, 2020. For example, in the study of Johnston *et al.* (2019) semi-structured in-depth interviews (five) and stakeholder focus groups (four) were conducted with cancer patients, caregivers, health care administrators, oncologists, and community health workers (CHWs), members being recruited through snowball sampling.

For this paper, the research based on four focus groups. Focus groups have been organized as following: one focus group with academics, one with patient representatives, one focus group with practitioners (physicians), and one focus group with labour market representatives. An invitation to participate in the focus group, that described the objective of the study, was sent twice, to numerous academics, physicians, cancer patient association, trade union leaders, business, or governmental representatives, at the beginning of January 2021 and at the end of January 2021 (a reminder). The first focus group was conducted in February 2021 (with academics), the second one, in March 2021 (with patient associations), the third (with physicians) and the fourth (with trade union leaders, business representatives) in April 2021. The focus groups discussions have been moderated by three members of the research team, the discussions were recorded with the participant agreement, and notes have been taken by the moderators. The group meetings were online. For each focus group a specific semi-structured interview guide was prepared; however, all interview guides have been corelated and harmonized in order to respond to the research objectives. At the beginning of the discussions all the participants have been informed that their privacy will be respected and that they may withdraw from the discussion whenever they want.

30 academics, from Romania and from abroad, have been invited to participate in a focus group representing the academic perspective. The sample was constructed based on convenience and snowball sampling (academics known to have publications and research studies in the field and academics that have investigated related aspects to cancer in Romania). Five of them responded positively to the invitation (three from abroad: USA, Ireland and Sweden, and two from Romania). The participants in the first focus group were aware about the cancer situation in Romania and were differently professional related to cancer: economic perspective, anthropological perspective, communication perspective, public policies perspective. The interview guide is attached in the *Annex 1*.

For the second focus group, the invitation was sent to 38 patient associations, as they are listed on the website https://www.ghid-cancer.ro/asociatii/. Eight Associations (some of the associations' representatives being cancer survivors themselves) responded and participated to the discussions, including the leader of the largest Cancer Patients Associations. The interview guide is presented in *Annex 2*.

The third focus group was formed by practitioners, medical specialists (physicians). The invitation was sent to 12 specialists (all of them specialized in treating cancer). The selection was convenience and snowball based. Five of them have responded positively: two oncologists, one oncology surgeon, one public oncologic hospital manager, one private clinic oncologist. The interview guide is presented in *Annex 3*.

Finally, the fourth focus group was composed of 4 labour market representatives (a trade union leader, an analyst in labour market processes, a governmental representative for labour issues and a business representative). The invitation was sent to 15 trade union leaders, business association and business people from companies. Only four responded and agreed to participate to the discussion. *The interview guide is presented in the Annex 4*.

Transcripts of the focus groups were coded using the "paper and pencil" approach (Björk and Kauppinen-Räisänen, 2012). As with the study of Björk and Kauppinen-Räisänen (2012), this research did not determine a broad structuring of the data. Two teams of two researchers each compared, independently, their codes, decided on a common list of codes, and themes were generated. Based on these themes, the findings and discussions section were elaborated.

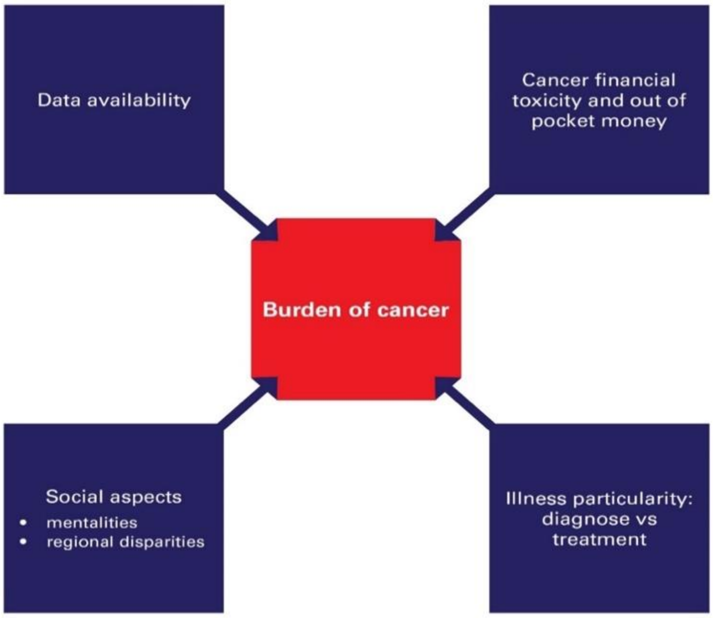
There are some limits of this study. Qualitative research does not allow generalizing the conclusions. The findings of this research are explorative in their nature. However, the insights offered by the multiple categories of stakeholders investigated through this research offer valuable information for policy decision makers in substantiating public policies and in orienting further quantitative and qualitative studies.

3. Findings and Discussion

3.1. Academics Perspective: the social burden of cancer is a deep, complex, and far more difficult issue to investigate

Looking at the discussion with academics, codes as: "difficult", "worth to investigate", "lack of data", "social aspects", "cancer financial toxicity", "out of the pocket money", "mentalities", "education", "difficult to diagnose", "difficult to access treatment", have been selected. Based on these codes, four themes were considered, as presented in Figure 2.

Figure 2: Academic perspective: The social burden of cancer is a deep, complex and far more difficult issue to investigate



Source: Authors' compilation based on findings from the focus group

The discussion with academics started from the *importance of researching other aspects than medical features in cancer* (as economic and social consequences of cancer, costs of cancer, stakeholders' perspectives on cancer, cultural influences on cancer, etc.). One of the participants, a world expert in economic research on cancer, underlined that cancer disease "is a very difficult topic to analyze from economic, social, or other nonmedical perspectives" (BJ). "Research on the social costs of cancer offers the possibility to forecast more efficient the financial resources in the health system, to balance the loss and the gains of implementing different policies or to design public health policies" (JD). "For example, studies showed that ambulatory treatment in cancer reduced the economic burden of the disease” (BJ).

The discussion continued with sharing the experiences academics had in investigating different aspects of cancer. The difficulty in investigating and measuring the burden of cancer, mostly from economic and social point of view, is given by *the complexity of data necessary to run an accurate analysis.* The impact of cancer is quite difficult to describe, and mostly to measure. “Mostly in economics, where people love numbers and quantitative approaches, those that decide how the public money is spent, want to rely on figures. The impact of any disease, cancer in particular, is very hard to measure even in countries with a more rigorous registration on health issues. It is even more difficult in countries like Romania, where „data related to the health system, mostly for cancer, are missing” (JD). “Without data, you cannot substantiate any serious investigation” (BJ).

The economic burden of cancer needs to be approached, also, on two levels: *diagnosis and treatment*, and this aspect emerged as an important theme necessary to follow in a comprehensive analysis on the burden of cancer. For each level there are specific costs, and it is important to be individualize them. “Maybe in the treatment stage you cannot do too much in order to reduce the costs, but you might do a lot in order to diagnose it earlier. An early diagnosis might lead to less treatment and less loss in productivity, a better quality of life. And all of these means less costs!” (JD).

Difficulties in measuring the burden of cancer are also driven by the differentiated impact of the disease on different groups of people. “In general, it is advisable to look at three major groups: children (less than 18 years), adults (19-65) and elderly (over 65). Each group has specific burdens: „for elderly, we have to take into account the comorbidities, with the costs generated by these comorbidities. For children, we look to the compulsory assistance provided, in almost all cases, by one of the parents, that induces additional cost, like loss in parents’ labour productivity “(BJ).

Literature discusses about the *financial toxicity of cancer* (Zafar, 2016). *Out of the pocket money* spent because of the illness causes distress, and some studies consider that this distress is associate with higher mortality and lower quality of life (Zafar *et al.*, 2013; Zafar 2016). “In any research that investigate the burden of cancer in terms of costs, it has to be taken into consideration that there are direct costs (related to cancer illness), costs related to pain therapy or costs generated by the other illnesses that are associated with cancer. It is a complex approach” (VM). To estimate out of the pocket money is difficult. There are differences in the amount of money spent by a patient that lives in big cities, with large hospitals and diversity of medical services (as radiology) comparing to a patient that lives in a small city or in a rural area. The last one has to support costs related to transportation, meals, housing and additional treatment if he/she is not hospitalized. Also, some patients treat the illness outside Romania, entirely or partially from their own pocket. As one of the focus group participants mentioned: “it may be useful to know, for example, how much is paid by the patient who goes for diagnose/treatment outside Romania, how much is paid by CNAS (National House of Health Insurance – Casa Nationala de Asigurari de Sanatate) through EU compensation mechanism, how many patients with cancer are going for diagnosis and/or treatment outside Romania – and where, outside Romania” (SS). For methodological reasons, an average amount of” out of the pocket money” is advisable to take into consideration, but to do this, a lot of information are necessary and, for Romania, this information is missing. “There are no clear data about how many cancer patients are treated, what is the age structure of these patients, where they reside and many other information that would offer a higher accuracy for any research that intent to measure any type of burden of cancer in Romania" (JD). Lack of data is another finding that influence the difficulty of assessing the financial toxicity of cancer.

The focus group discussions revealed another important theme. The economic dimension of the burden of cancer is highly influenced by *social aspects*, as (i) informal employment in agriculture and, as a consequence, the limited financial resources of those living in rural areas, (ii) social class differences in terms of health care access, income disposition, family doctor existence or access to primary healthcare. The evaluation of the President of the Medical College in Romania is that 700 localities in Romania do not have family doctors (primary healthcare) (Digi24, 2021). Other social aspects may influence the burden of cancer: cultural mentalities that influence or determine the patient and family approach to cancer, or the negative coping mechanism. "People respond to cancer in very different ways. Some of them develop chronic alcoholism, for example: it can be because of shame; it can be because of desperation. Others ignore the signs, refuse to go to the doctor or refuse to follow the treatment and approach the illness with plants, prayers and lighted candles" (TR).

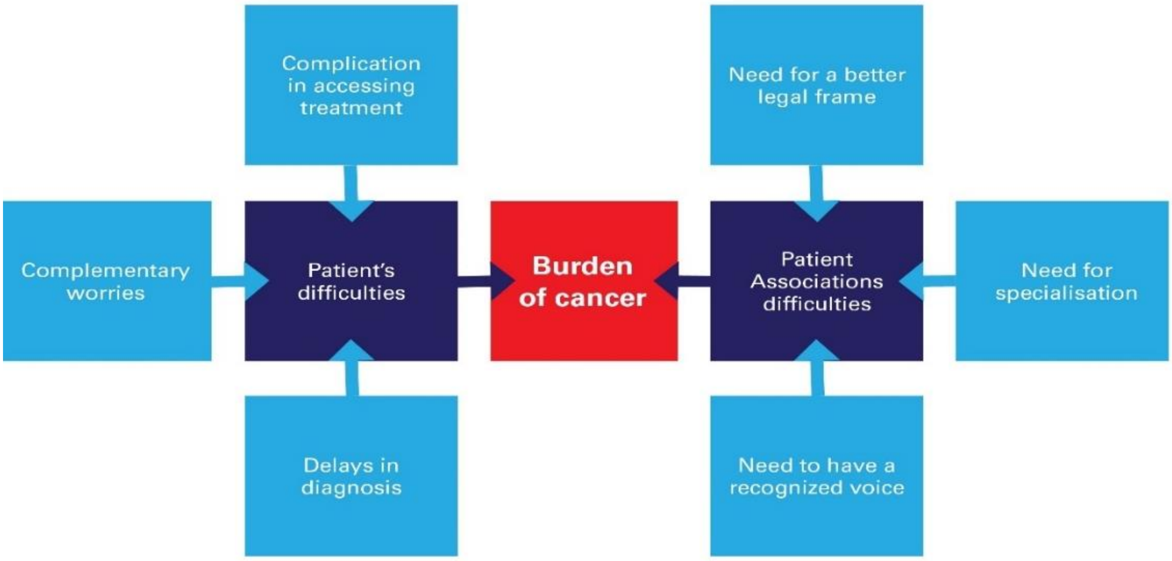
Therefore, an inquiry to determine the burden of cancer is influenced by data availability, has to look to the financial toxicity of cancer, needs to pay attention of social aspects and request to separate the cost on diagnosis and treatment, as some improvements in one phase (early diagnosis) may reduce the costs of the second one (softer and less expensive treatment).

3.2. Patient perspective on social burden of cancer: between frustrations and hopes

Patients, their next of kin and other caregivers (usually member of the extended family or close friends) are essential stakeholders in cancer disease (Bergerød, Braut and Wiig, 2020). In fact, they are in the center of the stakeholders' system (Figure 1).

The focus group with cancer patient associations revealed two major themes, related to the (A) *difficulties cancer patients in Romania face* and (B) *difficulties cancer patient associations encounter*. An illustration of the discussions themes is presented in Figure 3.

Figure 3. Cancer patients between frustrations and hopes



Source: Authors' compilation based on findings from the focus group

The first topic of the discussions was related to the difficulties a cancer patient encounter when he or she face the illness. Codes as “delay”, “high costs, lack of accessibility”, “lack of infrastructure”, “quality of treatment”, “lack of access to the second opinion” or “lack of regulations” were mentioned by all the participants in the focus groups. Under the first theme, ***difficulties cancer patients in Romania face***, several sub-themes emerged.

The first sub-theme was related to *delays in diagnosing cancer*. An early and a correct diagnose is the first key step in having a positive prognosis in terms of surviving or curing the illness. Why is so difficult to diagnose cancer in Romania? Several causes were identified during the discussion:

A1. Delays in diagnosis due to hampered access to the healthcare system:

o **Wait a long time until you can have an appointment for CT, MRI, or other investigations covered by CNAS**. “Imaging investigations, supported by CNAS, is always problematic. There is never enough money to investigate with celerity, let’s say, within a month. A patient that has a recommendation for MRI or CT, has to call again and again, to different hospitals, to check if there is any available place. Many times, you are on a long waiting list” (CI, AB, AM).

- **Weak territorial network of health services causes difficult access to the doctor and fuels late diagnosis** (there are large territorial discrepancies, in terms of the existence of family doctors or in terms of the proximity of hospitals with oncology specializations, which are usually in large cities). As it was mentioned earlier, 700 localities in Romania do not have family doctor. For a specialized investigation, patients have to go into a larger city (as imaging investigation). According to some opinions, the distance between the citizen and a medical center has increased from 70 km to 115 km in the last 10 years.

- **High costs of investigations** (some costs, although they should be reimbursed by CNAS, are supported by patients, like tumour board). “You can choose, if you have money and you know where to go, to support, from your own pocket, a complex investigation. But this is a serious financial effort and not too many patients have the possibility to support all these investigations. Cancer is not about one set of tests that you have to perform. Cancer means many tests, and periodical tests. Unfortunately, cancer patients discover very soon that not to wait means to spend a lot” (CI, AM).

- **Poor medical education of the population.** Very often people ignore the sign of a serious illness as cancer is. Some people trust more in the power of plants, others delay the doctor appointment because of ignorance or fear. There is a large discrepancy in medical education not only between rural and urban areas, but between different age groups and different level of education. “Just look at the school drop rate for Romania. Just look at the pass rate for the baccalaureate. These are indicators for a low level of awareness about the importance of the health issues and that you have to go to the doctor when a problem occurs. Combine with poor health service network, high costs and inconsistent public health policies, mostly towards cancer, and you will have the image of a disaster!” (NN). Internet access, coupled with a lack of trust in the medical system (due to poor organization of healthcare, due to difficulties in accessing investigations, high costs, etc.), fuels self-diagnosis at the first signs of the disease and self-treatment in the first stage of the illness. “The health system in Romania, as it is built and organized, throws you, the patient, in despair and in looking for more obscure and less costly alternative ways”.

A2. Complications in accessing treatment

The second sub-theme emerged from the discussion was related to *complications in accessing treatment.* Treating cancer encounter similar difficulties as diagnosing cancer. Causes that determined these complications may be summarize as following:

• **Insufficient medical infrastructure to meet the treatment needed for cancer determines a very difficult access to treatment, especially for vulnerable persons.** "If the medical infrastructure is a barrier to diagnose cancer, imagine how is it to treat this disease, that required long and systematic treatment!" (CI, AM). "As in the case of diagnosis, the differences between rural and urban areas (especially between rural and large urban centers) are huge and affect the access to treatment and its continuation. Some patients give up when the doctor tell them that there are 8 or 10 sessions of chemotherapy or when they find out that they need over 20 radiotherapy sessions in a city which is more than 150 km away from their place of residence". The treatment is exhaustive, patient do not feel well after the treatment, they cannot just to pick up a car and go home" (AC, CG).

• **Treatments can be very expensive, especially for financially vulnerable patients, and the lack of clear regulation of what is deductible and what is not deductible increase the cost of treatments.** "If you do not live near the center where it is performed (radiotherapy) and the hospital cannot provide hospitalization, you need to pay for accommodation, transportation, meals, etc." (CG, CI, AC). Even for some patient not at financially risk, the "financial toxicity" occurs. "Some patients start the investigations in private clinics, but they realize that the treatment is very expensive and come back to the public hospitals. In the private clinics, some investigations may cost them over 2,000 lei, and these investigations have to be performed several times during the treatment" (CI, AM, AC).

• **The quality of access to the treatment and, sometimes, the treatment itself is low, the lack of "navigators" worsens the situation and the communication with doctors**: there is a lack of guidelines for patient orientation, from the diagnose to the final treatment, there are queues, there is congestion at any stage of the treatment (as well as at diagnosis). "It's depressing, the conditions are totally unfavourable for a patient who is confused anyway, with a low morale. He/she doesn't know what to do, where to go, what to start with, how long he/she may expect to take the 'cancer journey'…nothing!" (CI, AM, AC). "The approach to treat cancer is not patient-specific. It should be a personalized medicine, to perform deeper investigations (immunohistochemical analyzes, for example) in order to have a targeted treatment, which is much more effective (in France, for example, personalized medicine led to savings of 30%). The Romanian state does not encourage and doesn't support immunohistochemical analyzes" (AM, AC, CI, NN). **Cancer is a disease that must be treated in a holistic way**, because it has many implications and the treatment has many side effects. There are no clear protocols regarding treatment, some doctors are less open to new treatments and investigations recommended abroad and validated by international studies. A **Cancer Board or Tumour Board** is a must in investigating such a complex disease. "There are no integrated cancer centers in Romania, doctors are limited in their recommendations by the existence or inexistence of regulations, by the lack of healthcare facilities, by the lack of financial resources and by the lack of medical personnel. There are not enough doctors, we do not have a Tumour Board protocol to increase the accuracy of the diagnosis and the efficiency of the treatment, we do not have a National Cancer Registry to be able to perform analyses about the efficiency, side effects, alternative treatments and many other aspects; there is chaos in the management of cancer patients!" (CI, NN, AC, AM). We do not have aggregate data about cancer patient in Romania, nor about the number of patients treating the illness abroad." Cancer Patient Associations in Brasov estimates that 10% of the patients from Brasov are treated abroad" (CI). In the same line with low access to treatment, there is a lack of information and guidance for patients regarding alternative treatments - some patients cannot afford too many alternative treatments, others do not know which would be the most appropriate.

• Treatment is blocked, in some situations, by the **patients' mentalities**. Some people deny the diagnosis and the treatment, trusting more in nonmedical solutions. "The precarities of the health system, which does not give you confidence that you will receive the proper treatment, on time, are those that takes you away from the doctor or pushes you into the arms of charlatans".

A3. Complementary worries

The third sub-theme was related to other aspects that affect the quality of life of cancer patients and their next of kin. These aspects are almost impossible to measure. Studies conclude that a significant proportion of cancer survivors experience physical, emotional, and social problems such as fatigue, pain, cognitive deficits, anxiety, and depression, all of which may become chronic (De Boer *et al.*, 2009, p. 753). The discussions in the focus group lead to the following additional difficulties cancer patients and their family members face:

• **Emotional distress** induced by cancer is almost impossible to estimate. The quality of life of a cancer patient is deeply affected, as well as that of its family members: low work performance (in the case of those who work), low ability to concentrate, low enthusiasm to accept professional challenges, depression. Many patients developed anxiety, depression and become much more psychically vulnerable. Family members are also affected. Some of them lose their quality of life when one of their close family is diagnosed and similar anxiety and depression conditions are developed. In other cases, families broke. Mostly in the case of women diagnosed with cancer, there is a high risk of being abandoned by their husbands; as well as if a child is diagnosed with cancer: there is a high risk that mothers, especially, will be abandoned by their husbands.

• Furthermore, there is a **low level of security,** caused by material deprivation as a consequence of the lack of support (sick leave) offered by the state to some categories of workers. Those who have their own business or free licenser, those involved in gig economy usually do not benefit sick leave. "According to patient associations, 60% of employers diagnosed with cancer no longer want to continue their business" (AM). For others, the risk of being fired by the employer is high, because the professional performance is not the same or is not perceived to be the same in the future. "Data from patient associations show that 36% of those diagnosed with cancer are fired in the first 6 months after returning to work". (CI, AAM).

The second theme display the difficulties Cancer Patient Association encounter (CPAs). Some of the CPAs, in Romania, emerged as a result of many difficulties and frustration cancer patient had in their way through the illness and from the desire to help others to limit these difficulties. Also, the life experience some of the founder members had in their fight with the disease and with the incapacity of the Romanian health system to offer decent services for cancer patient are reasons for the appearance of these organizations. These are also the reasons that motivates these association to act in order to reform the system, to enlarge the access of all patients to decent treatments, to press the public authorities to reform health policies. The discussions in the focus group reveal a lot of unhappiness and disappointments CPAs have regarding the public authorities' receptivity towards cancer, in terms of necessary regulations for improving the situation of cancer patient. These association are the only hope and the only support some cancer patients have. Maybe the highest disappointment is that, despite the work and diligences CPAs putted in pushing authorities to install a National Cancer Patient Registry, starting with 2001, even after 20 years this initiative is not in place. Therefore, the focus group with CPAs displayed codes like "resources for cancer association", "improved legislation for cancer associations'', "cannibalization", or "voice for cancer associations". These codes lead to the second theme, (B) *difficulties cancer patient associations encounter*. Several sub-themes composed this theme, as following:

B1. Lack of recognition of CPAs specialization

There is a sort of "cannibalization" between CPAs, as a result of the **lack of recognition of their specialization**. As financial resources for these associations are rather limited, recognizing the specializations of these NGOs dealing with cancer patients, can lead to a better and more efficient distribution of funds. CPAs should not replace the health system, they should not be involved in treating the patient. Rather these associations should focus on improving the quality of life of cancer patients. There are activities that are left on the shoulders of the associations, even if they are under the public health system responsibilities (how to navigate between specialties and treatments, how to deal with side effects, access to second opinion, including appointments to the doctors or access to investigations). "Too much is expected from us. We should not do the job of the healthcare system!" (CI, AM, AC, NN). By recognizing the specialization of CAPs, these may be more efficient in fundraising and may be more helpful for their patients.

B2. Need for a better legislative framework for CPAs

A better legislative frame for CPAs, in order to improve their functionality is necessary. There are series of expenses absolutely necessary for the proper functioning of any CPA (headquarters, utilities) for which the sponsors (pharmaceutical companies, especially) cannot pay. Also, it will be useful to allow CPAs to access European Funds: "if you do not have a research CAEN code, European funds cannot be accessed" (CI). In a similar spirit, the Ministry of Health should have a functional structure dedicated to the management of patient problems.

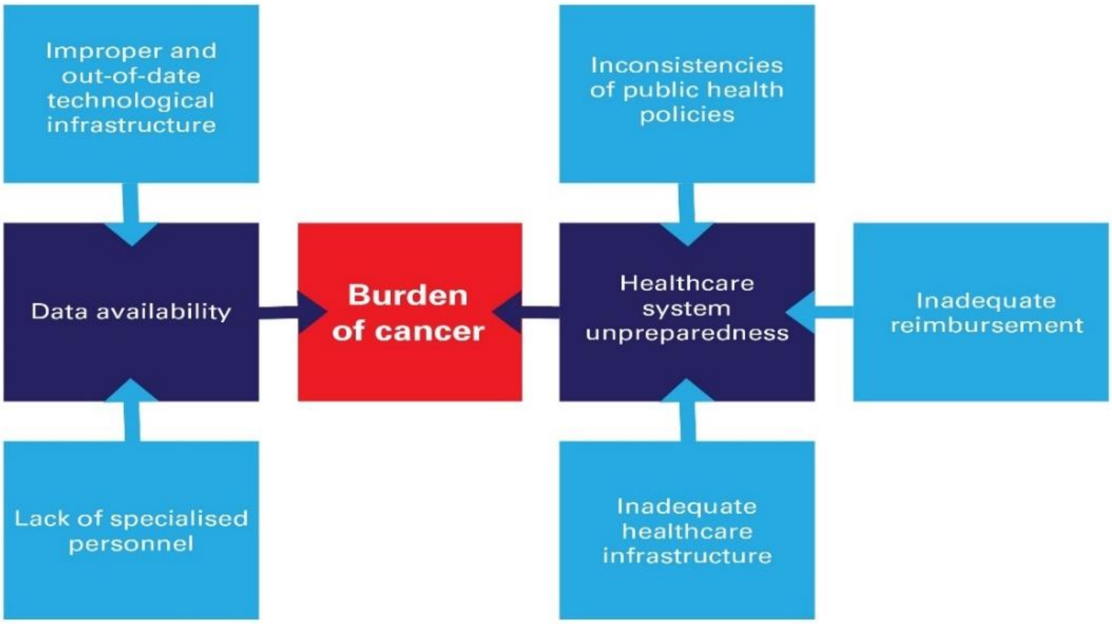
B3. Necessity to have a recognized voice

To have a recognized voice is an acknowledgement of the fact that CPAs are a valuable and important partner that help the health system to face the burden of cancer and have positive effects on the entire society. Unfortunately**,** the opinion of CPAs matter too little for the authorities, both when discussing the legislative framework and when implementing specific actions. "We (CPAs) come up with concrete proposals to streamline patients' access to diagnosis and treatment. We came with the proposal of a Registry of Cancer Patients, since 2001, we came back with a clear structure of a such registry in 2008, but nobody listen to us. As a result, now, in 2021, there is no such registry, there are no clear statistics of cancer patients in Romania. We do not matter for the authorities! Patients do not have any power in front of the authorities!").

3.3. Practitioners' perspective on social burden of cancer in Romania: depends on what you want: healthier people or happier doctors

The focus group organized with practitioners (oncologists and hospitals managers) was centered on the most important obstacles practitioners encountered in dealing with this illness. Several ideas have been followed during the discussions: (i) the availability of data on cancer patient, (ii) health care infrastructure specific to cancer and patient access to these facilities, for diagnose and treatment. The codes generated after the discussion transcript were: “no data systematization”, “limited information”, “no cancer registrars”, “limited health care infrastructure”, “lack of informatization”, lack of digital skills”, “insufficient reimbursement”, “National Plan for Cancer”, “National Registry of Cancer Patients”, Cancer/Tumour Board”. Based on these codes, two themes emerged: *data unavailability* and *healthcare system preparedness for the burden of cancer* (Figure 4).

Figure 4. Practitioners’ perspective on cancer: lack of information and inadequate infrastructure



Source: Authors’ compilation based on findings from the focus group

Data unavailability

For the first themes, the subthemes occurred in the discussion were related to “lack of specialized personnel” (digital skilled to work with different data), and an “improper, outdate technological infrastructure in the healthcare system”. No aggregate data about cancer patients are available in Romania for investigating in a holistic manner the cancer disease: from economic point of view (costs, economic status of patients, regional distribution of cancer patient, employment status etc.) or from social or medical point of view (number of patients, age structure, level of education, type of cancers, tumour stages, treatments, periodical medical evaluations, etc.). Practitioners underlined the shortages the entire medical system have related to cancer patients. As the National Cancer Registry is not in place, despite the fact that all the investigations supported by the CNAS are stocked, it is very difficult to access them in order to have a comprehensive picture of the illness.

Lack of specialized personnel. There is important to have specialized personnel not only for medical reasons but also to register information concerning cancer patient. These data are important for multiple purposes: medical, economic, administrative, etc. In other countries there is a specific category of personnel, **cancer registrar**. A cancer registrar, as it is defined by the US National Cancer Registrars Association (NCRA), “is a data information specialist who collect and report cancer statistics. Cancer registrars capture a complete history, diagnosis, treatment, and health status for every cancer patient” (NCRA, 2021). This is an important specialization, with an important responsibility. In Romania, such a specialization doesn’t exist. One of the group participants commented: “in Romania, cancer registrars are some middle age aunties, who struggle with a simple registration in an old software, and their digital skills rest on navigating on Facebook” (MM).

Improper and outdate technological infrastructure in the healthcare system. Close related to the lack of cancer registrars, the outdate technological infrastructure create a real disaster for data availability. The registration process, in the Romanian healthcare system, is a low performant one, with outdated hardware and software. It takes a lot of time to introduce simple information in the system. Nobody knows how access the information exited in the system or how to obtain an aggregate data, and the soft do not permit to categorize information. Data security is a real challenge for the Romanian medical system: frequent crashes in the informatic system, cyber-attacks on hospitals, problems with the maintenance and so on.

Healthcare system preparedness for the burden of cancer.

The lack of healthcare preparedness is a hot debated theme. The discussions were grouped under the following subthemes: “inadequate health care infrastructure”, “insufficient reimbursement”, “inconsistences in the public health measures”.

Inadequate health care infrastructure. As it was mentioned, there are 700 localities in Romania without family doctors. There is a lack of medical facilities and infrastructure: from technical and material aspects, to human resources. Specific to cancer, some are more acute than others. Critical is the radiotherapy infrastructure that limit patient access to treatment (in those few private clinics, where radiotherapy is available for a fee, the price is high and very high). There are 10-12 radiotherapy centers all over the country, patients cannot be hospitalized for radiotherapy, and all the expenses with accommodation, transport, meals for patients coming from other areas have to be sustained from their own pocket (*out of the pocket money issue*). “Some hospitals (with the help of CPAs and other NGOs) provide accommodation for some patients during radiotherapy, other hospitals manage some arrangements that allow reimbursement from CNAS, but for a small number of patients” (MM).

Inadequate reimbursement. Money creates additional difficulties in treating the patients. Some interventions are reimbursed at a too low price by the CNAS, (from the perspective of the hospital). The maximum amount paid for a cancer patient is 12,000 Lei (around 2,500 euro), which is insufficient for someone who does a complete therapy (a person usually need investigations complex investigations, apart from oncology, surgery, or radiotherapy). The reimbursement is not the same. Radiotherapy is satisfactorily reimbursed, surgery is a section that “eats” the hospital's money (CNAS compensates less than 30% of the cost of a surgery - if the reference cost of the surgery is considered that in the private system), IC (Intensive Care) ward consumes money in a hospital, an oncology ward brings money to the hospital. Many times, other specialist are necessary, but to hire an cardiologist, or an endocrinologist, is quite difficult (very few oncological hospitals have these specialization, but not all).

Inconsistences in the public health measures. There was a consensus among all the participants that decision in the field of public health policies can be characterized by “inconsistencies”, just to use a nice word. The fact that today we do not have a “National Plan for Cancer”, a “National Registry of Cancer Patients”, or a “Cancer/Tumour Board” is a consequence of an inefficient public health policy and “a result of personal arrogance of different specialists (doctors) involved in designing health policies” (MM). These inconsistences in the field of public health policies (incompetent people that managed different subsectors in the health system, nepotism, corruption) coupled with insufficient resources, map the present situation in cancer in Romania. For example, Cancer Commissions (Cancer Board /Tumour Board) are very useful. They have been implemented in some places (like Timisoara and in the private health system), even if the format is rather informal. Meetings take place virtually, so there are not problems to delay the treatment. Where Tumour Boards work, the results are spectacular: in 2013, out of 1800 cases, in 40% of the cases the initial solution offered to the patient was modified, and in 90% of the cases, the change was for the benefit of the patient.

3.4. Labour market representative's perspective: social burden of cancer in Romania is a reflection of systemic deficiencies of the Romanian economy

The last focus group was organized with labour market representatives. Discussions intended to find out if there is a specific attention to cancer patients that are active on the labour market. The literature reports that cancer patients are more likely to be discriminated against healthy people. In a meta – analysis (De Boer *et al.*, 2009), describing 36 studies that covered 20,366 cancer survivors and 157,603 healthy control participants, from the United States (16 studies), Europe (15 studies) and 5 studies from other countries, cancer survivors were more likely to be unemployed than healthy control participants (33.8% versus 15.2%). Long-term medical and psychological effects of cancer or its treatment may cause impairments that diminish social functioning including the obtainment or retention of employment. Job discrimination, difficulty to combine treatment with full-time work, and physical or mental limitations may be major causes of unemployment. Additional factors such as age, sex, and the prevailing unemployment rate in a specific country or region could further increase the risk of unemployment for cancer survivors. Many cancer survivors want and are able to return to work after diagnosis and treatment, employment being associated with a higher quality of life (De Boer *et al.*, 2009, p.753).

As a consequence, the discussion was centered on aspects related to: (i) the help that labour market offers to cancer patient, (ii) forms of monitorization the social costs of cancer (from the labour market perspective) and (iii) the illegal and unethical practices against cancer patients employed.

Codes emerged from the focus groups with labour market representatives were: "lack of targeted projects to cancer patient", "different approaches determined by the size and power of the organizations", "no monitorization towards the costs generated by cancer", "no specific monitorization of illegal and unethical practices against cancer patients", "necessity for a more responsible employers", "need for a more responsible state". A particularity of this focus group was a sort of polarization of opinions between trade unions and employers/patronage representatives. Trade unions were more offensive, bringing into discussion many problems the employees face because of low wages, little protection in some industries or companies, inefficient and sometimes irresponsible authorities regarding health issues. On the other hand, employers/patronage representatives were more defensive, opting in underlying the constant concern they have to improve labour conditions for employers.

Codes emerged from the discussions directed to one theme (see Figure 5): *No specific attention is paid by the labour market for cancer patients.*

Figure 5. Social burden of cancer in Romania is a reflection of systemic deficiencies of the Romanian economy

Source: Authors' compilation based on findings from the focus group

Trade union representatives mentioned that there are **no specific projects targeting members with cancer**. Cancer patients have the same benefits as any other person with health issues. Trade unions and employer/patronage recognized that cancer patient may have different needs, but no projects oriented towards this category of employees were developed.

However, the benefits offered by trade unions or, in some cases, by the companies, depend on the **size of the trade unions and companies**. Large trade unions and large companies have more projects and better and more sophisticated means of intervention; small trade unions and small companies are less active (or not active) in helping those patients facing health problems.

Similar, **a lack of particular actions** is **in the case of illegal or unethical practices against cancer employees**. Trade unions monitor partially the illegal and unethical practices against employees, in general. "The Territorial Inspection of Labour is responsible for this, but its responsibilities are limited. Our monitorization (trade unions) shows a tendency the patronage and the state have, to transfer the costs of assisting employees from companies and state to the employees" (BH). Trade unions take legal action against enterprises where employees were discriminated, but there is no specific attention for those with cancer. Employer/patronage representatives mentioned that they are constantly preoccupied by a correct approach towards all employees facing illness problems and, according to the resources, "all companies are, at least, empathic and try to do the best to keep their employees healthy and to support them according to the law".

The aspect the trade unions and employer/patronage representatives agreed on is that the health system in Romania is inefficient, lacking empathy, "patients are humiliated" (BH), and the burden of cancer, as the burden of any disease is a reflection of "the failure of the health system to offer dignity to the patient" (BH). "In all areas we have too little: too little money for health, too few doctors (even though we have a lot of medical school graduates), too few hospitals, too few tomographs, too many patients…the health system cannot be better than those that manage it. We need more responsible leaders, capable to design a health system to serve the citizen, a system that people trust, a system that educate people and cure people” (CG).

4. Conclusion

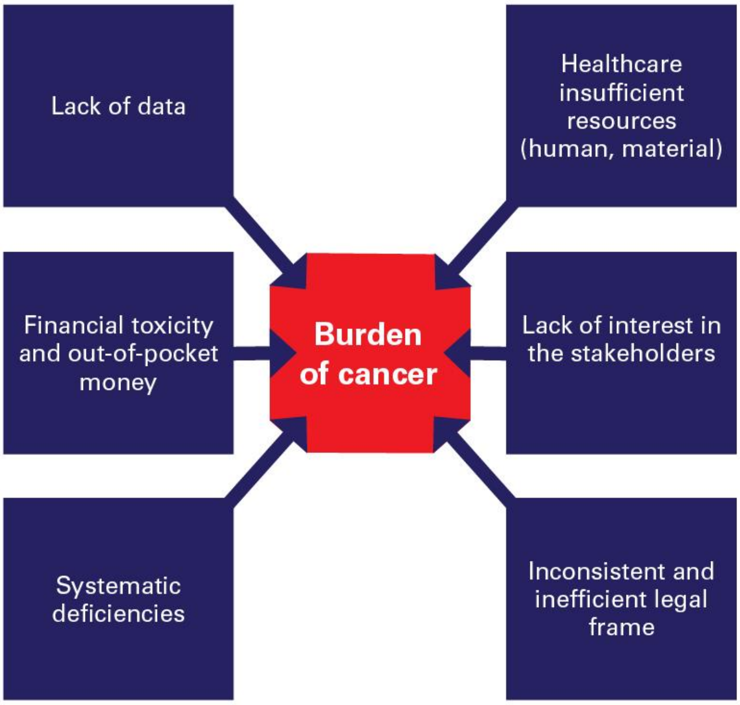
This study aimed to search the stakeholders’ perspective on the social burden of cancer in Romania. Using focus groups, four categories of stakeholders have been investigated: academics, patients’ representatives, practitioners, and labour market representatives. These stakeholders are the most important in studying cancer from multiple perspectives and there is a rich literature sustaining this. However, very few research projects showcasing primary data analysis are available on the Romanian case study. As such, the present study adds to the literature empirical evidence for the Romanian context by putting together the perspective of different categories of stakeholders as an alternative way to gather empirical evidence in a data-scarce environment. We argue that this is not a compromise, but rather a richer investigative path, as it provides a complex perspective on the socio-economic burden of cancer in Romania is attained.

Investigating the stakeholders’ opinions on social burden of cancer in Romania, several conclusions emerge.

(i) Researching cancer outside medical aspects is a more complex and difficult process. The reliability of any scientific endeavour depends on the quality of available information. Mostly for economic and social aspects, on which public policies usually rely on, data regarding the number of patients, their characteristics, costs for diagnoses, treatment and other related investigations are essentials (just to mention few of them). Without this information any research is incomplete. Even with all these data in place, the complexity of cancer illness will be never capture completely in a scientific study. Emotional and phycological consequences of cancer, for example, are almost impossible to be measured.

(ii) Each category of the stakeholders expressed specific opinions, according to their relation to cancer disease. Integrating the perspectives of the four researched categories of stakeholders, six recurrent themes occurred about the social burden of cancer in Romania (Figure 6): lack of data, financial toxicity of cancer caused by the burden of the out of the pocket money, healthcare insufficient resources for cancer (material and human), lack of interest in the patient needs, inconsistent and inefficient legal frame and systemic deficiencies of the Romanian society, in general, that aggravate the burden of cancer.

Figure 6. Integrative stakeholders' perspective on social burden of cancer in Romania



Source: Authors' compilation based on findings from the focus group

In the **absence of accurate data** and in the impossibility to generate aggregate data about different aspects of cancer, the instruments of intervention in the benefit of the patient do not produce the estimated effects: patients do not have better access to diagnose and treatment, hospitals are not better equipped for the patients, physicians have not better solution for treating patients, the state cannot project efficient health policy. The **financial toxicity of cancer**, caused in large part by the out of the pocket money that patients have to spend in order to access the diagnose and the treatment of the illness lead, in the end, to a higher mortality, because many patients cannot sustain the cost of investigations and treatments or cannot access the best treatments for them**. Inconsistencies and inefficiency of the legal frame** were mentioned by all categories of stakeholders as a barrier that loads additionally the burden of cancer and contribute to the inefficiency of the health policy. The **lack of interest in listen to the stakeholders needs** reflects in inconsistent and inefficient policies towards cancer in Romania. From doctors to patients, from academics to trade unions, all stakeholders mentioned that a real, constructive dialog between authorities and stakeholders must be in place. A better and a more constructive dialog may help in sharing the burden of cancer and solutions can be identified. **Insufficient resources of the cancer healthcare system** (from human resources, as cancer registrars or doctors to material resources as radiotherapy facilities, technological infrastructure etc.) determine a late and outdated public response to cancer disease. More resources are needed, but, more importantly, better managed resources are the response. Money can be spent wisely, and more efficient. Finally, the **systemic deficiencies** existed in the Romanian society amplify the social burden of cancer. The lack of sanitary education as a consequence of the deterioration of the educational system in general, is an example of the systemic deficiency that increase the social burden of cancer.

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ANNEX 1

Interview guide with academics

1. Why is important to study the burden of cancer outside the medical aspects of the illness?
2. Which are the major challenges in studying the social burden of cancer?

ANNEX 2

Interview guide for cancer patient associations (CPAs)

1. What are the difficulties faced by the patients that your association represents?

- difficulties in diagnosis? Which? (Including financial aspects)
- difficulties in accessing treatment? Which?
- lack of information about cancer, in general
- difficulties in communicating with doctors and medical staff?
- financial difficulties following the prescribed treatment?
- mentalities of patients (contesting the diagnosis, distrust in treatment, etc.)
- other difficulties, please detail ……

2. What are the difficulties you face as an association? Please identify as many difficulties as possible that your association has faced

ANNEX 3

Interview guide for physicians

1. What are the difficulties faced by the cancer patients? Please present as many difficulties as you can from your expertise as a practitioner.
2. What are the difficulties you face as physician/hospital medical manager? Please identify as many difficulties as possible. Please refer to the problems related to data availability on cancer, also.
3. Refer to the health policy towards cancer in Romania. How would you describe it? What is missing? Please present as many aspects as you can from your experience

ANNEX 4

Interview guide for labour market representatives

1. From the discussions with cancer patients, we found out that some trade unions provide to cancer patients, who are members, a series of financial facilities (reimbursement of tests, procedures, treatments performed in private clinics, products associated with this disease, such as prostheses or wigs, etc.). Are there targeted, coordinated projects of trade unions or employer/patronal organizations for these patients?

2. Are there any concerns or initiatives on the part of trade unions, employer/patronal organizations to monitor the social costs of cancer for employees?

3. How do trade unions get involved in identifying illegal, unethical practices of some employers against employees facing health issues, especially cancer samples? (if there are concerns in identifying, monitoring and stopping / sanctioning these practices)

4. What policies are developed by employer/patronal organizations to fight against discrimination against cancer patient?

5. Are there specific policies developed by employer/patronal organizations to support a better working environment for cancer patient?

6. How do trade unions, employer/patronal organizations get involved in establishing the health policy in Romania, in general, and the policy on fighting cancer, in particular?

7. To what extent have the governmental authorities involved the trade unions, employer/patronal organizations in substantiating the health policies in Romania?