**According to a recent survey conducted in Argentina**

**CANCER DIAGNOSIS IS DELAYED 6 MONTHS FROM THE ONSET OF SYMPTOMS**

* Data from the All.Can Argentina study on 400 patients residents in the Buenos Aires Metropolitan Area (AMBA).[[1]](#footnote-1) The research also had a qualitative component and further revealed inequities in access, delays in treatment from detection, and the disease’s emotional and financial impact.
* The survey methodology included 40-minute face-to-face or telephone interviews. It included patients from public health services, PAMI[[2]](#footnote-2), state, and prepaid health insurance. The objective was to understand and describe the cancer patients’ experience by focusing on the improvement opportunities for the process affecting them significantly.
* All.Can is a global initiative that brings together stakeholders from various healthcare sectors to carry out concrete actions that are effective and efficient in addressing cancer patients.

On average, the time from the onset of symptoms until the person is diagnosed with cancer in the Metropolitan Area of Buenos Aires (AMBA) is about six months. However, there is a two-month gap between those with prepaid health insurance and those without it. Only 12 out of 100 patients learn about their disease before the appearance of clinical signs, evidencing the need to enhance population-based screening programs for earlier detection of tumors associated with greater chances of survival.

These are just some conclusions of a quantitative and qualitative study conducted by IPSOS Healthcare South Cone for **[All.Can Argentina](https://www.all-can.org/national-initiatives/argentina/)**, the local chapter of a global initiative that brings together stakeholders from various healthcare sectors to carry out concrete actions that are effective and efficient in addressing cancer patients. The research also found that the time of diagnosis is when patients perceive failures in healthcare the most.

*“We need to pay more attention to the patients to identify all the opportunities for improving the process from the time before the detection of cancer to the time of treatment*,” emphasized Andrey Mendez Fandiño, director of IPSOS Healthcare South Cone, leader of the study in Argentina.

The objective of the quantitative study was to explore and measure patients’ experiences and to categorize the inefficiencies of the process. A total of 400 men and women over 18 years old, residents of the AMBA, with a diagnosis of lung, colorectal, hematological, prostate, breast or gynecological cancer, among other tumors, were interviewed. Fifty-four percent of patients were between 45 and 65 years old, with an average age of 55. Six out of 10 were undergoing therapy at the time of the survey. The results reveal various barriers and inequities for early detection and timely treatment with the least possible emotional and financial impact.

Of the total number of patients interviewed, 68% were diagnosed at an early stage of cancer (0I or II) and 29% at an advanced stage. However, the proportions vary according to the organ or system affected. For example, for breast and colon cancer, detection occurred before the tumor spread or when it had spread only locally in 7 and 6 out of 10 cases, respectively. At the same time, for hematological cancers (leukemias and lymphomas), almost half of the diagnoses occurred at more advanced stages. On the other hand, the average time from the onset of symptoms to the diagnosis was 6.2 months. However, the figure varies according to the health insurance: for those with prepaid health insurance, the lapse was 4.3 months, while it reached 6.4 months for those who are PAMI members, those with state health insurance or attended the public health services. There were also differences according to the cancer type: for breast cancer, the average time was 5.6 months; for colorectal cancer, 6.8 months; for lung cancer, 2.6 months; and for cervical cancer, 4.6 months. “*It is important that public health campaigns and programs address not only individuals but also physicians. Primary care professionals have to be aware of the screening strategies, know how to suspect a diagnosis, learn about the resources available (for diagnosis), and the referral circuit,”*  said Dr. Julia Ismael, medical oncologist of the Asociación Argentina de Oncología Clínica (Argentine Association of Clinical Oncology, AAOC), and member of the Executive Committee of All.Can in Argentina.

The research also reveals that screening or early detection programs identify only 12% of all diagnosed cancers. This figure rises to 30% for prostate cancer (even though the effectiveness of periodic controls after the age of 50 is controversial). Still, it is below 10% for colorectal cancer, with 9 out of 10 patients consulting the doctor after symptoms have already begun. “*The programs exist, but access needs to be facilitated. Besides, some myths should be eradicated. The recommended primary procedure for early detection of colorectal cancer is the fecal occult blood test, to be performed annually between the ages of 50 and 74, a test that causes no discomfort and is provided free of charge. Eighty-five out of 100 people will have negative test results. The video colonoscopy is reserved only for the 15 patients with positive testing. That is the most cost-effective strategy*,” explained Dr. Ismael.

Again, health insurance matters. According to the survey, among those with prepaid health insurance, almost 1 out of 4 tumors are detected early before the onset; for the rest of the patients, only 1 out of 10. The data is consistent with that recorded in other health systems, such as the United States, where there is a trend to a direct relationship between the benefits and income levels, said Dr. Ismael. In many cases, patients had to visit many doctors and undergo several tests until they knew the diagnosis. However, 20% of delays can also be attributed to diagnostic errors.

**Time to treatment**

Once patients are informed of their cancer diagnosis, they face delays in the approach or treatment of their disease. The impact of these deficiencies differed according to the cancer type.

On average, respondents had to wait two and a half months to begin treatment. There are no significant differences according to the cancer type. However, lung cancers tend to access some therapy earlier: 44% in less than a month. In contrast, 1 out of 10 patients diagnosed with colorectal cancer takes 6-12 months to begin treatment. Health insurance shows an increased influence when the most significant delays are analyzed: 4% of prepaid health insurance patients have to wait 6 to 12 months, versus 7% of those with state health insurance or attending public hospitals.

*“This is data to pay close attention to. For solid tumors, the recommended lapse is less than 45 days. For hematological tumors, if acute, treatment should start in the following days because the patient’s life is at risk. A lapse from 6 months to a year allows opportunities to be missed*,” lamented Dr. Ismael. “*Delays can result from both health system factors and social factors in the population, such as employment issues or the lack of a family support network to help them*,” she added. “*The research shows the importance of identifying the ideal time to provide additional psychosocial support to patients from the time of diagnosis*,” agreed Mendez Fandiño.

Other explored dimensions yield more satisfactory data. Seven out of ten patients report having had a great deal or enough involvement in treatment decisions, and a similar proportion considers the information received was adequate for that purpose. Meanwhile, 90% claim to have understood most or all of this information. “*Many times, the patient prefers not to make decisions or chooses not to know, but the health professional has to make sure that this is the patient’s choice. One should not be cruel in verbalizing a prognosis if the patient prefers to ignore it; the rights of patients to information and not to receive it at certain times of the disease must be respected*,” said Ismael.

However, the survey also showed a desire for more information, particularly about treatment (24%), the disease (22%), and the management of adverse effects and symptoms (15%). Likewise, one-third of patients stated the need for more in-depth talks with the doctor before diagnosis.

**Emotional, physical, and economic challenges**

Another section of the survey showed the main emotional and physical challenges in dealing with cancer. Forty-seven percent of respondents reported dealing with the lack of energy and fatigue, 39% with negative thoughts and feelings, and 38% with the physical effects of treatment. Half of the patients suffering from emotional effects felt that they had received little information on the subject and felt unprepared to deal with them. In contrast, factors such as non-delivery of medication, bureaucracy or the amount of paperwork and authorizations were much less mentioned. However, it does not necessarily mean that they do not exist or impact the patient experience.

The study results also reflect the financial burden of cancer, and its impact on work capacity, a challenge identified by approximately three out of ten respondents. Before treatment, 80% of patients had a work activity (full-time, part-time, or household activity). However, after treatment, this proportion decreased by half. And people with disabilities increased from 3% to 35%.

Respondents also identified resources that would have helped them get through the process better. In their opinion, resources that should be encouraged are transportation to and from medical appointments, financial counseling or administrative support with medical documentation and insurance issues, and household care help. “*It’s important to make an effort for distributing resources so that they reach the person who needs and uses them*,” said Mendez Fandiño, because interviews also revealed that many resources were offered but little were used by these patients.

However, these challenges, deficiencies, or difficulties in cancer care seem not to be reflected in the overall experience of respondents: 71% said that their expectations had been met and that “*nothing could have been done better during the process*.” “*Sometimes patients describe situations in one way or another out of humility or gratitude, or because they have no previous similar situations to compare with*,” explained Mendez Fandiño. *“The opportunities for improvement only appear when the processes are analyzed further, when we explore the reasons behind the figures and learn about the patient’s history.”*

**Qualitative study: the story behind the data**

Once the quantitative analysis was completed, the study’s second stage began focusing on the qualitative aspects. Fifteen patients participated with the same approach of face-to-face or telephone interviews: 3 with breast cancer, 3 with colorectal cancer, 3 with lung cancer, 3 with prostate cancer, and 3 with multiple myeloma. The opinion and experiences of three oncologists and two onco-hematologists were also gathered. “*Through this approach, we corroborated the inefficiency in the quality of the service provided at different times through the lifetime of the cancer patient, which makes it a difficult path to follow for all stakeholders: patients and doctors,*” warned Mendez Fandiño.

From the patients’ perspective, the most critical moment turns out to be learning about the diagnosis: it is “a bucket of cold water,” they agreed with different terms. They remember that instant as a bad dream in which they are not entirely aware and awake. From diagnosis, the first concerns revolve around an uncertain future at the economic level, particularly having enough income to cover the expenses arising out of the disease. In the case of retirees, this means reducing personal and family costs. Regarding family relationships, the patient strengthens them and requires assistance (for example, to attend treatment sessions), but, at the same time, they do not want to be a burden or depend on others in their daily routines. Death often turns into an unspoken reality, but which hovers around, like clouds on the horizon.

As shown by the quantitative survey, difficulties are more significant for those with state health insurance. “*They pose a lot of difficulties for patients to authorize studies, medicines*,” said a consulted onco-hematologist. She lamented, “*You know the patient is doing worse, but we don’t have the tools to fix it.*” The view of other specialists was similar. “*Doctors have the knowledge and expertise in new treatments, but many times they feel abandoned by the system: they feel they do not have all the tools to care for their patients*,” summarized Mendez Fandiño. Consequently, they change their clinical and therapeutic decisions. In the first case, they consider tests that can be accessed easily, even if they are not the most precise ones they would indicate. In the second case, they prescribe the drugs that the health insurance authorizes and even overlook quality preferences to avoid delays and interruptions in treatment. They even contact families or patients who may have unused doses and give them to those who cannot get them.

All this implies an additional emotional burden for doctors, added to the frustration and fatigue of not having stable and motivating conditions to practice their profession.

**Reasons for the delays**

Regarding the delay in diagnosis, the qualitative evaluation confirmed the average times and also was able to identify some variables that extend the time of detection beyond six months: cancer types without associated symptoms, such as myeloma, colon or prostate cancer; direct request for consultation with specialists not related to the pathology; difficult access to testing; and misdiagnosis: One respondent said, “I was treated for hemorrhoids for a year and a half.”

Regarding the delays in treatment initiation, some triggers identified were: difficulty in obtaining authorizations from the health insurance, changes in treatment due to transition from health insurance as an employee to retired or permanently disabled category, and the patient’s decision not to start treatment due to personal issues.

According to the report prepared by IPSOS Healthcare, deficiencies in the health system and its response capacity, as well as administrative bureaucracy, are “the main weak points of disease management” for patients.

**Conclusions and suggestions**

Although the great effort of support entities, doctors, clinics, and hospitals in the care of cancer patients in Argentina is acknowledged, these are some conclusions and suggestions to improve the process derived from both studies of All.Can:

* Understand the aspects with more impact on the access to options for detection and treatment of the different cancers, considering, in decreasing order, colorectal cancer, prostate cancer, cervical cancer, hematological cancer, and breast cancer, including the psychosocial profile of the patients.
* Increase the coverage of cancer screening programs to reduce the number of patients detecting cancer from the onset of the symptom, especially colorectal.
* Approach the disease care process from the diagnosis, centered on patient’s needs so that they have certainty about what their disease entails and what they will undergo during the course of the disease.
* Address the management of negative thoughts and feelings of patients. For prostate cancer patients, for example, implement specific oncology and sexuality programs.
* Alleviate the out-of-pocket expenses of the most affected population, for example, through subsidies on the SUBE card (transport system) to attend their medical appointments.
* Create working groups with different stakeholders to generate policies and good practices that minimize delays in access to treatment for different cancer types.
* Taking into account the existing programs, groups, and associations for patients’ support, improve their promotion and awareness of all their scopes and activities, and make these spaces relevant allies as a mechanism of different types of support for patients and their families.

“*To improve the scenario, there should be a better integration of stakeholders: doctors, industry, patient associations, authorities...*,” suggests Mendez Fandiño. *“Programs must be articulated to increase the efficiency of the system. All.Can’s value is that it can bring all the stakeholders together and build trust among them*,” she concluded.

**FURTHER STATEMENTS FROM OTHER MEMBERS OF ALL.CAN ARGENTINA**

*“The opportunity to measure the experience of having a disease brings us closer to more humanized and person-centered care and, on the other hand, it drives us to improve the quality and safety of the cancer patient care. This is possible only if we have data such as the survey conducted by All.Can which drives decision making to address the real problems of patients and their families.”*

**Dr. Emilia Arrighi. Director of Patient Advocacy, Fundación Hospital Universitario [University Hospital Foundation]**

“*At present, the main challenge for oncology in these times is undoubtedly early detection. That is a commitment of the entire healthcare system. The contribution of oncologists in this area should focus on improving the use of screening tools. If a little more than 10% of diagnoses derive from the population taking part in such tests, that is the way to go. It will not only save many lives but also make health costs more efficient.*”

**Ignacio Zervino. Coordinator of Fundación Pacientes con Cáncer de Pulmón (FPCP) [Foundation Patients with Lung Cancer].**

*“The All.Can survey shows us the difficulties and obstacles that cancer patients have been going through for a long time in our country. In addition to the political decision, the approach has to be multi-sectoral and patient-centered. Patient organizations work tirelessly to provide support, containment, and assistance in accessing treatment. We believe that it is time to think about better processes, organization, and budget for the health system.”*

**Alejandra Iglesias. President of Asociación Civil Sostén [*Sostén* Civil Association]**

*“Diagnosis is the stage of the greatest emotional impact. In contrast, treatment is assumed as a paradox: side effects of the treatments added to the fear and previous ideas about them are difficult to symbolize: ‘how can something that makes me feel so bad be healing me?’. Negative thoughts and feelings are very common, and it becomes necessary to stick to rational thoughts to reach valid conclusions about what is going on. It is a process that takes time but is essential to better cope with the disease. Therefore, emotional support becomes a fundamental pillar to get through oncological disease. Cancer is a critical and stressful event. It is estimated that the individual and their family and friends will be in the throes of it for at least a year. The patient feels he is losing his health, as well as his self-image, his life projects, his possibility of procreation (not always), and his ‘sense of control.’ Everything becomes emotional, and the situation implies not only cognitive restructuring but also family and social restructuring. There is also the phenomenon known as the ‘conspiracy of silence,’ in which the patient and the family do not talk about the disease: the patient does not want to worry (even more) the family, because the family cannot provide an effective response, and the family does not want to overburden the patient. It has been proven that being able to talk about cancer improves coping with it; therefore, we encourage talking about it openly in all areas. Fear and uncertainty prevail at all stages of the disease, and the important thing is to be able to identify these feelings, recognize them, observe their nuances, and be able to talk about them, of course.”*

**Haydee González. President of Asociación Civil Linfomas Argentina (ACLA) [*Linfomas Argentina* Civil Association]**

1. *The sample was weighted to represent the proportions of each cancer type according to Globocan 2018 estimates.* [↑](#footnote-ref-1)
2. PAMI: National Institute of Social Services for Retirees and Pensioners [↑](#footnote-ref-2)