

ONCOPEDIATRIC HEALTH SERVICE'S NETWORK IN ARGENTINA: BACKGROUND, CAPABILITIES, AND CHALLENGES

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Health, Nutrition, and Population (HNP) Discussion Paper

Oncopediatric Health Service's Network in Argentina: *Background, Capabilities, and Challenges*

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Abstract: The development of integrated health services networks is one of the main priorities set by the National Health Ministry of the Argentine Republic (Ministerio de Salud, MINSAL), considering that these networks are an effective strategy to overcome the inefficiencies and inequities that affect the health system. As a result, MINSAL requested the World Bank's financial support to design and implement a National Fund for High Complexity Diseases (NFHCD) by means of a new loan provided under a Program for Results scheme (PforR). As a first step toward the design of a National Fund for High Complexity Diseases, this paper, based on the study of childhood cancer in Argentina, seeks to investigate the key aspects that should be considered when planning an effective service network for such diseases. The selection of case studies was based on the characteristics of a high-complexity and low-incidence specialty, with a marked specificity in approach strategies. In addition, it is a high-cost network, taking into account the price of treatments—which may involve days, months, or years of hospitalization—and the cost of the drugs required to treat such cases. The evidence collected has allowed us to shed light on the critical pathways patients navigate in the current oncopediatric care structure. First, the family is the one that identifies the child's first symptoms and therefore approaches the health care system. Second, there is a poor understanding that both health care service providers and users have of the health network organized by levels of resolution. Another structural challenge is the fragmentation between subsystems—public, social security, and private health insurance companies—resulting in different approaches and qualities of care beyond the health need identified. A strong interplay between national public referral hospitals with patients with different health care coverage schemes could contribute to reducing access gaps.

Keywords: Health network, oncopediatrics, incentives, Argentina

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PREFACE

The development of integrated health services networks (Redes integradas de servicios de salud, RISS) is one of the main priorities set by the National Health Ministry of the Argentine Republic (Ministerio de Salud, MINSAL), considering that these networks are an effective strategy to overcome the inefficiencies and inequities that affect the health system. As a result, MINSAL requested the World Bank's financial support to design and implement a National Fund for High Complexity Diseases (NFHCD) by means of a new loan provided under a Program for Results (PforR) scheme.

This new initiative arises in the context of the success already achieved by the federal health service network for congenital diseases of the population with solely public coverage, first implemented in 2010 under the Sumar Program. The creation of a common risk fund at a national level, the so-called Solidarity Insurance Fund (Fondo de Aseguramiento Solidario), supported by a capitation payment based on the total eligible population registered in the program, ensures funding of more complex surgery procedures. With time, the service coverage grew and the scheme evolved and became the Fund for High Complexity Diseases (Fondo de Enfermedades de Alta Complejidad, FONAC), changing its name to National Fund for Health Equity (Fondo Nacional de Equidad en Salud, FONES) in 2020.

As a first step toward the design of a National Fund for High Complexity Diseases, this paper, based on the study of childhood cancer in Argentina, seeks to investigate key aspects that should be considered when planning an effective service network for such diseases. The selection of case studies was based on the characteristics of a high-complexity and low-incidence specialty, with a marked specificity in approach strategies. In addition, it is a high-cost network, taking into account the price of treatments—which may involve days, months, or years of hospitalization—and the cost of the drugs required to treat such cases.

Although childhood cancer represents a small portion of the global cancer burden, its significance in terms of the number of years of life to be saved is socially sensitive and economically abatable. In Argentina, childhood cancer is the fourth cause of death among children between one and four years old. There are 1,400 children and adolescents under 15 diagnosed with cancer every year, and although the oncological disease prevalence in pediatrics varies according to age groups, in the population under 15 years of age, leukemia is the most frequent type, followed by central nervous system tumors and lymphomas. The higher incidence of advanced stages and the high percentage of diagnoses based on death certificates (9 percent of diagnosed cases are postmortem) suggest the need to optimize timely diagnosis, since the initial symptoms are generally nonspecific, requiring a heightened awareness of oncological signs at the primary levels of care. Equal access to accurate diagnosis and treatment plays a key role in this regard.

With the purpose of creating an oncopediatric network aimed at sharing integral care services, the elaboration of this document began in late July 2021, with contributions from the National Directorate for Provincial System Strengthening (Dirección Nacional de Fortalecimiento a los Sistemas Provinciales), the National Directorate for Quality Health Services and Health Regulation (Dirección Nacional de Calidad en Servicios de Salud y Regulación Sanitaria), the Garrahan Hospital (Hospital Professor Dr. Juan P. Garrahan), and the National Cancer Institute (Instituto Nacional del Cáncer, INC). The ultimate goal of this paper is to contribute to the development of a road map aimed at establishing an oncopediatric network in Argentina.

During the development of this study, Act 27674 was enacted for the protection of the rights of children and adolescents with cancer. The act provides for the creation of a national program that, among other functions and responsibilities, will manage a service provision network aimed at improving outcomes in childhood cancer care (early diagnosis and access to treatment, to reduce mortality and morbidity).

The purpose of this study is to identify and analyze the operation of the formal and informal networks that provide oncopediatric services in Argentina, to identify the challenges that hinder their consolidation and the opportunities to enhance their performance. The scope of the study is essentially national, but two provinces have been selected as case studies to gain an in-depth view of the network's operation. The selection of those territories was derived, on the one hand, from the recommendations of specialists from the National Health Ministry, the National Cancer Institute, and the Garrahan Hospital, which have extensive experience in providing diagnosis, treatment, and support to childhood cancer patients. And, on the other hand, the two provinces selected—located in northeast Argentina—have critical social and economic conditions and account for 60 percent of all childhood cancer cases in the region. This makes them especially relevant to the investigation of subnational approach mechanisms in challenging economic contexts and in a decentralized health context. Additionally, the geographic setting of both capital cities, Resistencia and Corrientes City, located on opposite shores of the Paraná River, makes it possible to investigate the presence or absence of cooperation, coordination, and articulation mechanisms linked to the territorial context.

The study considered three complementary approaches. The first one consisted in a review of the literature, geared toward the search for evidence in four dimensions: childhood cancer, the health system's care levels and how they work, health care systems integration, and networking experiences. The study included articles submitted to peer review processes published in national, regional, and global reviews, as well as grey literature. At the same time, a search for regulatory and normative guidelines on the abovementioned subjects was carried out, including protocols and good practice guidelines by care level. The second approach involved the search for information on the background of the Argentine oncopediatric network and other associated initiatives. The third approach covered a stakeholder mapping both at national level—within the public, private, and social security sectors—and at subnational level for the provinces under study (Corrientes and Chaco). This process was enhanced by contributions describing the experiences of other countries across the region. The analysis was enriched by data submitted by the National Cancer Institute, the Garrahan Hospital, and the Sumar and Redes Programs, both directly reporting to the National Health Ministry, as well as by the Single Central National Institute for the Coordination of Ablations and Implants (Instituto Nacional Central Único Coordinador de Ablación e Implante, INCUCAI).

The evidence collected has allowed us to shed light on the critical pathways in which patients navigate in the current oncopediatric care structure. The survey reflects each instance of the journey, enabling an identification of the challenges and opportunities for strengthening the system. As reflected in the regional and international literature review, at the outset, the family is the one that identifies the child's first symptoms and therefore approaches the health care system. Some parents have more information on the symptoms leading to the suspicion of cancer than others. This is why the future oncopediatric network should consider a **communication strategy** targeted in this direction.

Hence, a second element should be addressed: the poor understanding that both health care service providers and users have on the **health network organized by levels of resolution**, leading to limited attendance to health care centers and more direct visits to hospital emergency

rooms or specialists, without consulting the general practitioner first. This element, also reported in local and global literature, goes beyond the construction of an oncopediatric network, but it limits its performance in terms of the delay between detection and diagnosis. This interaction with the health system also reveals another structural challenge: **the fragmentation between subsystems**—public, social security, and private health insurance companies—resulting in different approaches and qualities of care beyond the health need identified. A strong interplay between national public referral hospitals with patients with different health care coverage schemes could contribute to reducing access gaps.

Once the patient accesses a hospital or clinic—whether local, regional, or in the Greater Buenos Aires area (Área Metropolitana de Buenos Aires, AMBA), the practitioner will perform the clinical diagnosis, confirming or ruling out the pathology. Due to disparities in terms of human resources, technologies, and infrastructure, there are health care centers capable of performing both the **relevant tests and diagnosis**; others that can carry out the tests but lack specialists to make a diagnosis; and others that cannot perform either task. The latter cases require inter-consultation with a specialist and referral for the performance of the pertinent tests, respectively. Therefore, the time involved in the diagnostic stage is not the same for all health care providers.

Once the pathology is confirmed, the practitioner decides where to treat the patient, whether in the hospital of origin or in a facility with higher complexity capabilities, thus requiring a referral. **No consistent mechanisms for patient referral** and counter-referral were identified. The **informal relations that usually prevail** between health care practitioners determine the patients' referral to one center or another. The return (counter-referral) of the patients to the hospital of origin—and therefore, to their town or city of residence—is also not standardized.

Given that many patients are of school age, access to education is a key element in the critical pathway. Should the patient require hospitalization and/or rest at home, the treating medical center will take the appropriate actions to **ensure the continuity of the child's schooling**. Based on the elements gathered during the stakeholder mapping, classroom spaces within hospitals—for hospitalized patients—as well as home teachers—for patients at home—are reported to be present.

Each hospital is responsible for coordinating actions with the Education Ministry on a case-by-case basis. Also, if a patient is referred to a health care center located in another province, there are family-support mechanisms in place. Both private sector and social security funders, as well as high-complexity hospitals, provincial governments, and civil society foundations, **provide financial assistance to families to cover their transportation and accommodation costs** in the destination city.

Once both the treatment and the health care center have been defined, there arises the **need for treatment drugs**. The medication for patients who do not have any social security/private health insurance coverage is provided by the state through the provincial or national drug banks. In the case of patients who have social security coverage or another health insurance coverage, these pay for health care costs. Medication is delivered at the hospital or treatment center in every case.

It is important to note that the private and social security health care subsector has formally established circuits for requesting medication, which generally provide for maximum response times. In the public drug supply system, there is no formal mechanism guiding requests; each province chooses where to make the request: at the **Provincial Drug Bank, the National Drug Bank, or the Directorate for Direct Assistance in Special Situations** (Dirección de Asistencia Directa por Situaciones Especiales, DADSE). Each agency and/or funder (public, private, and social security sectors) has its own procurement mechanism and, therefore, it usually pays

differential prices. Although prescription guidelines may vary according to the decision of each practitioner, there are protocol utilization records in the drug banks and, based on this, the medication may be accepted or rejected. If the patient has private health insurance or social security coverage, an auditor must accept or reject the request. In the event of a refusal, there is a procedure of the **appeals for legal protection of constitutional rights (“writs of amparo”)** filed by the families, which results in the judiciary decision on the treatment to be provided to the patient. In this respect, as noted, in most cases the funding institution is compelled to provide the medication.

The main recommendations arising from this research can be summarized as follows:

- (i) To design and implement a set of regulations for the network’s activities, involving each of its stakeholders, both in the public and social security domains and in the private health care service provider and insurance sectors, and to enhance the categorization and certification processes carried out by the INC to date, strengthening their performance.
- (ii) To create two twin structures to enable the coordination of the network’s clinical and administrative management. The first one should be provided with an inclusive and collegiate governance structure to carry out analyses, diagnosis, and treatment guidance, while the second one should enable administrative management, the creation of national-provincial-regional management agreements, indicator monitoring, and incentive management.
- (iii) To develop indicators to track the key processes involved in the journey of oncopediatric patients, paying special attention to the management of delay times between different network management areas—treatment, referral, and cross-referral— protocolization and certification of coverage and institutions, etc.
- (iv) To create a National Fund for Pediatric Oncology Financing supplemented by the extension of health services rendered under the Sumar Program framework.
- (v) To promote health care training to encourage more effective health-related practices of all those involved in each level of care, including systematized information to families and systematic training to health care staff and human resources at the primary and secondary levels of care.
- (vi) To generate improvement mechanisms in the drug supply process based on the development of drug tenders by price vector.
- (vii) To develop monetary and nonmonetary incentive schemes to guide the behavior of stakeholders according to the goals set by the network, through investment funds for the creation of regional intermediate centers, scholarship and internship programs, etc.

PART I

Introduction

In Argentina, the health system is highly fragmented and segmented according to employment condition, income levels, and place of residence. The country has three health subsystems: the decentralized public health system, the social security system, and the private health insurance system, with low levels of coordination among them (Maceira 2021a). The lack of coordination has an impact on health service quality, particularly as regards prevention and control of noncommunicable diseases (NCDs), which are the main causes of death and disability in the country.

To address both the efficiency and equity problems and enhance service quality, the National Health Ministry (Ministerio de Salud, MINSAL) intends to work toward the development of integrated health services networks (Redes integradas de servicios de salud, RISS) as one of its priorities. In particular, the primary focus is placed on the design and implementation of a network for chronic childhood diseases.

To this end, MINSAL has appealed to the World Bank for financial support to design and implement a National Fund for High Complexity Diseases (HCD) through a new loan provided under a Program for Results scheme (PforR). This new initiative follows up on the successful experience of the federal network of health services for congenital diseases aimed at the population with exclusively public coverage, implemented in 2010 in the context of the Sumar Program. The creation of a common risk fund at national level, the Solidarity Insurance Fund (Fondo de Aseguramiento Solidario), supported by a capitation payment based on the total population registered that is eligible for the Program, ensures the funding of more complex surgery procedures. Service coverage increased with time, first by including a High Complexity Perinatal Scheme for congenital heart diseases, and later through the incorporation of services related to acute myocardial infarction. The scheme evolved to become the Fund for High Complexity Diseases (Fondo de Enfermedades de Alta Complejidad, FONAC). In 2020, the Fund changed its name to National Fund for Health Equity (Fondo Nacional de Equidad en Salud (FONES)).

As a first step toward the design of a National Fund for High Complexity Diseases, this work, based on the study of childhood cancer in Argentina, explores the key aspects required for a successful service network for high complexity diseases, with special focus on the lessons learned through the articulation with the Sumar Program. Possible mechanisms to include the social security subsystem in the network are also examined. This case study is justified by the fact that it focuses on a high-complexity and low-incidence specialty, with markedly specific clinical approach strategies. It is also a high-cost network, both due to the price of the treatment—which can involve days, months, or years of hospitalization—and of the drugs required to deal with these cases.

Although childhood cancer represents a small portion of the global cancer burden, its significance in terms of the years of life to be saved is socially sensitive and economically abatable (Pritchard-Jones et al. 2013).

At world level, more than 1,000 children are diagnosed with cancer every day¹ (WHO, 2021). The Lancet Oncology Commission estimates that from 2020 to 2050 there will be 13.7 million new cases of childhood cancer in the world, 44.9 percent of which will go undiagnosed. According to the same source, if no additional investments are made to improve access to care and treatment, 11.1 million children will die of cancer, 84.1 percent of whom reside in low- and medium-low-income countries (Atun R. et al., 2020).

At the same time, significant differences in mortality and survival rates are observed between high-income countries and low- and medium-income countries. According to the World Health Organization (WHO), the possibilities of survival for this patient group are 80–90 percent in high-income countries and less than 30

¹ Based on WHO's criterion for 2021, the "children" category includes the age interval 0–19.

percent in low-income countries. The main reasons for these differences are delays in diagnosis, inability to reach accurate diagnoses, difficulties in accessing effective treatments, treatment dropout, death by toxicity (side effects), and avoidable relapses (WHO 2021).

In Argentina, childhood cancer is the fourth cause of death among children between one and four years of age. There are 1,400 children and adolescents under the age of 15 diagnosed with cancer every year, and although its occurrence in children varies according to age group, in the population under 15, leukemia is the most frequent type, followed by central nervous system tumors and lymphoma (SAP and UNICEF 2013).

In general, from a comparative viewpoint, Argentina² shows better outcomes than its Latin America peers as regards the five-year survival rate (ICCI-LA 2020). Some examples are Hodgkin-type lymphomas (90.2 percent in Argentina compared to 79.6 percent in Chile, 76.7 percent in Colombia, and 71.4 percent in Brazil), and low-grade astrocytoma (79.1 percent in Argentina compared to 49.0 percent in Chile and Colombia). Instead, when comparing these values with high-income countries, the percentage for Argentina is 67.6 percent,³ that is, lower than the 80–90 percent average (INC 2021; Pritchard-Jones et al. 2013). According to the National Cancer Institute (Instituto Nacional de Cáncer, INC), this difference can be partly explained by untimely diagnoses and by the lack of adequate follow-up mechanisms allowing the proper administration of the treatment, as childhood cancer includes pathologies that are not so frequent but are characterized by their high morbidity and mortality rates and require highly specific diagnostic and therapeutic strategies (INC 2021).

The higher incidence of advanced stages and the high percentage of diagnoses based on death certificates (9 percent of diagnoses are postmortem) suggest the need to optimize timely diagnoses, since the initial symptoms are generally nonspecific, which requires a heightened awareness of oncological signs at the first levels of care. Equal access to accurate diagnoses and treatments plays a key role in this regard.

When devising a national strategy to improve timely access and enhance quality and equality in childhood cancer management, it is essential to develop specific actions aimed at promoting timely access to diagnosis, adequate treatment, and integral after-treatment care, ensuring the availability of and access to affordable essential drugs and technologies, guaranteeing high-quality health training and education and supporting local-level research and dissemination campaigns (Pritchard-Jones et al. 2013).

The aim of this study is to identify and analyze the operation of formal and informal networks providing health care services to children and adolescents with cancer in Argentina, to identify the challenges to their strengthening and the opportunities to enhance their performance. The scope of the study is mainly national, but two provinces—Chaco and Corrientes—will be considered as case studies for an in-depth examination of the network's activities. The selection of these two territories is based, on the one hand, on recommendations made by specialists from the National Health Ministry, the National Cancer Institute (INC), and the Garrahan Hospital, which have extensive experience in providing diagnosis, treatment, and assistance services for childhood cancer patients.

These two provinces located in northeast Argentina experience critical social and economic conditions and account for 60 percent of childhood cancer cases in that region. Thus, they are especially relevant to the investigation of subnational approach mechanisms in challenging economic contexts and in a decentralized health structure. Additionally, the geographic setting of the two capital cities, Resistencia and Corrientes City, located on opposite shores of the Paraná River, allows investigating the existence or absence of cooperation, coordination, and articulation mechanisms linked to the territorial context.

² The World Bank has classified Argentina as a medium-high-income country.

³ According to ROHA (2021), the five-year survival rate estimated for the period 2005–2014 was 67.6 percent.

The paper is organized into three chapters: background and methodology, results, and discussion.

The first section of the Part I outlines the conceptual framework and briefly describes the Argentine health system, which will be further analyzed in the section discussing the results. Then, the methodology used for the work is explained and the primary and secondary sources consulted to develop this document are mentioned. The background of the network and the actions undertaken up to now for its construction are described, including approval by Congress of the oncopediatrics act 27.764, which was enacted while this project was being developed. The Part I ends by examining the findings resulting from the literature review, establishing the key lines of analysis for the study and posing a series of specific questions for research.

The Part II has two sections. The first analyzes and summarizes the main conclusions drawn from an extensive stakeholder mapping. The mapping includes focal points from the three subsectors of the Argentine health system, the specific viewpoints of the two provinces mentioned above, and some thoughts on the operation of this kind of network in four countries of the region: Chile, Colombia, Costa Rica, and Uruguay. The second section presents an analysis of the available databases used to characterize the operation of the network. The databases used were those of the National Cancer Institute, Garrahan Hospital, the Sumar and Redes Programs—both run directly by the National Health Ministry—and the Single Central National Institute for the Coordination of Ablations and Implants (Instituto Nacional Central Único Coordinador de Ablación e Implante, INCUCAI), the institution in charge of transplant management in the country. The thematic lines addressed in the following section benefited from and built on the lessons learned from this material.

Finally, the Part III opens a debate on the main findings of the research process, underlining the potentials and limitations identified, with a view to strengthen the networks that provide health services to the oncopediatric sector. Lastly, the main conclusions, which include a road map intended as a contribution to a national agenda on this subject, are presented.

1.1 Conceptual and sectoral framework

The health care systems in Latin American countries face major challenges when responding to the needs of the population, in particular the availability of infrastructure, human resources, technologies, materials and supplies, drugs, and funding (PAHO 2014b). Their fragmentation is one of the main barriers to the provision of equitable and integral health services (Lopez Puig et al. 2009). Some of the main causes of this phenomenon are institutional segmentation of the health systems, service decentralization, predominance of targeted programs, lack of resources, and weak steering capacities on the part of health authorities (PAHO 2010).

In this scenario, several countries are envisaging the development of systems based on primary health care and supported by networks. The Pan American Health Organization (PAHO) has long been promoting the integrated health services networks (RISS) model as a way to address fragmentation problems. The RISS are among the main operational tools of the Primary Health Care Strategy (Atención Primaria de la Salud, APS) and contribute to the realization of several of its essential elements: universal coverage and access; first contact with the health system; integral, integrated, and ongoing care; appropriate care; optimal service organization and management; and guidance for intersectoral action (PAHO 2010).

The microeconomics of the systems and services shed light on some key components of network operation. When analyzing the oncopediatric network in Argentina, the following factors should be taken into account: the context where it operates; the degree of formalization of the mechanisms supporting the network; and the incentives offered to the stakeholders involved in the operations.

As regards the context, the Argentine health care system is characterized by its high level of fragmentation and segmentation. The public system—providing coverage to the poorest third of the population—operates on a decentralized basis, and the provinces are the institutions in charge of health service funding, management, and provision. In turn, the health aspect of the social security system accounts for more than 50 percent of the coverage and comprises over 350 social security health organizations (so-called obras sociales) with different levels of average income and memberships, most of which are regulated by the Superintendency of Health Services (Superintendencia de Servicios de Salud), which provides a single package of access rights. These institutions include the Integral Medical Assistance Program (Programa de Atención Médica Integral, PAMI), a social security agency covering the elderly by means of a solidarity system. In most cases, these institutions do not have their own providers and subcontract services in the private sector. Lastly, 10 percent of the population—residing mostly in Buenos Aires and its suburbs and in large provincial capitals—channel their contributions to private health insurance companies. Although all inhabitants have access to effective health coverage, the system is hampered by serious problems in relation to equity and access (Maceira 2014).

The system is divided into three subsystems based on their funding source: public noncontributory funding (national, provincial, and municipal); contributory social security (national and provincial social security health organizations, and social security health organizations for pensioners and retirees); and contributory (prepaid) private health insurance companies. Financial protection is established in different ways.

The public subsystem consists of the three levels of government: national, provincial, and municipal. The provinces set their own rules autonomously and retain health service management and provision functions, resulting in the coexistence of 24 different health systems in the same national territory.

Funding is based on provinces' own general revenues derived from national program-related transfers and offers universal coverage, providing health care to all inhabitants requesting it. The coordination mechanisms allowing for equity among the provinces are scarce (Maceira 2021b). With the public subsystem, financial decentralization is critical: the provinces and municipalities generate and administer 8

out of every 10 pesos used in the public system, and the National Health Ministry represents only 20.54 percent of public health expenditure—approximately 6 percent of the total expenditure (Maceira 2021b).

The social security health subsector is largely dependent on the formal job market, resulting in overexposure to job market and macroeconomic fluctuations. This sector is divided into approximately 350 national and provincial social security health organizations (Health maintenance organizations, HMOs), organized by activity sector. The subsystem displays significant differences in terms of coverage and service quality, mainly characterized by financial and epidemiological risk differentials.

This group includes PAMI, which operates as an autarchic agency of the Health Ministry and provides coverage mainly to the retired population. This group of institutions provides coverage through their own suppliers and mainly through private hospitals, clinics, and health professionals (Figure 1).

Lastly, private health insurance companies (prepaid medical services) offer health care services through direct contracts with voluntary medium-high income members as well as through supplementary payments from contributors covered by social security who opt for a higher-quality health scheme.

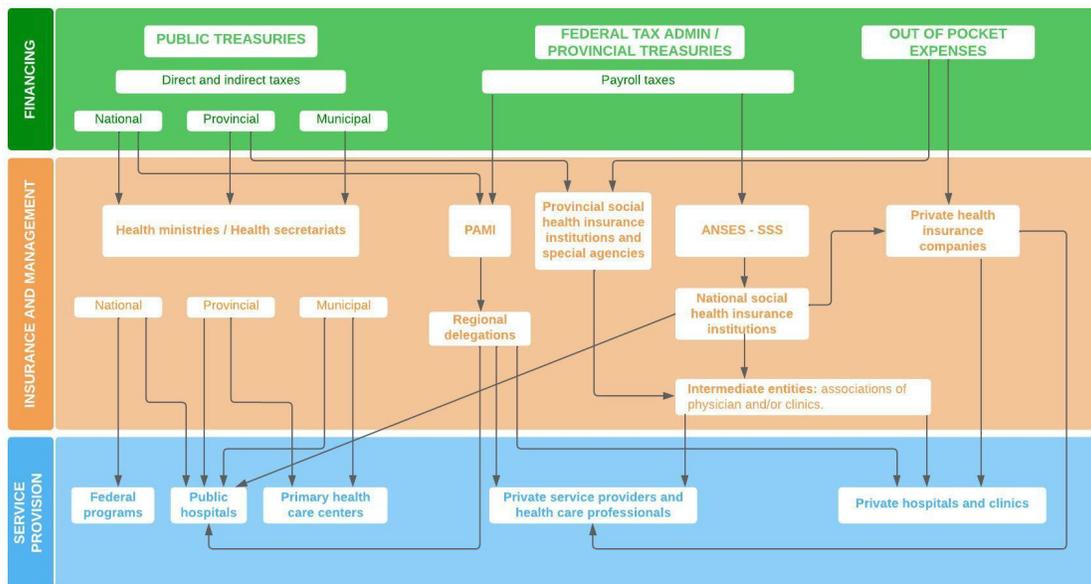
As regards the distribution of health expenditure among subsectors, 49.34 percent of the total expenditure is covered by social security, 30.35 percent by the public subsystem, and 20.31 percent by the private sector. Almost 80 percent of every 100 pesos allotted to the health sector is paid by the public sector or by the social security sector, while 20.3 percent corresponds to out-of-pocket expenses, one of the lowest in Latin America (Maceira 2021a).

As a whole, the coexistence of subsystems and public decentralization poses challenges to the operation of the health care network, as it multiplies the number of funding institutions, which are not necessarily aligned with the institutions providing the services. This leads to undesired cross-subsidies, theoretical double coverages, and inconsistencies among the packages offered to different populations with similar needs, thus affecting the system's outcomes in terms of efficiency and equality (Maceira 2014).

Another challenge posed by the health care network is the degree of formalization of mechanisms that support its activities. The existence and use of patient referral protocols and of regulations defining their sequence, as well as the necessary information tools (health cards, medical histories, digitalization of the information shared among the levels, etc.) are essential elements to achieve any network's optimum performance (Maceira 2014).

Figure 1

Funding Sources, by Subsector: Funding, Insurance, and Service Provision, 2021



Source: Authors, based on Maceira (2014) and Maceira (2021a).

Note: PAMI = Social Insurance Institute for the Elderly; ANSES = National Social Security Administration; SSS = Superintendency of Health Services.

The oncopediatric network in particular involves interaction spaces among players that extend from the first level of care to the intervention of particularly specific centers with resolution capabilities. From an organizational perspective, this joint production space requires coordination, clearly divided responsibilities, and the development of diverse abilities, both related to early detection, timely diagnosis, treatment, and referral, all consistent with the patient's needs. A context such as the one described above has negative effects on all these aspects.

The purpose of the present document is to identify from an organizational point of view the capabilities and operational needs of the oncopediatric care scheme in Argentina, to propose actions aimed at consolidating achievements, facilitating the resolution of its limitations, shedding light on the opportunities for strengthening, and considering possible coordination strategies for collective action. From this perspective, a systemic thinking approach is particularly useful to understand and explain the functioning of complex spaces such as health systems. This approach offers an integral perspective, as it considers both the subsystems operating within the health system and the interests of the stakeholders involved (Peters 2014).

1.2 Methodology

The study was based on three complementary approaches. The first was a literature review geared to the search for evidence in five dimensions: childhood cancer, performance of the health system's care levels, health system integration, health cost-effectiveness analysis, and network-related expertise. The review covered articles subjected to peer review processes published in national, regional, and global peer-referred journals, as well as grey literature. At the same time, a search for regulatory and normative

guidelines on the subjects mentioned in the previous section was carried out and included protocols and good practice guidelines by level of care.

The second approach built on the search for information on the background of the Argentine oncopediatric network and other related initiatives. This was supplemented by an analysis of the data provided by the National Health Ministry, the National Cancer Institute, and other sources.

The third approach involved a stakeholder mapping both at national level—within the public, private, and social security sectors—and at subnational level for the provinces under study (Corrientes and Chaco). This process was combined with reports describing the experiences of other countries in the region.

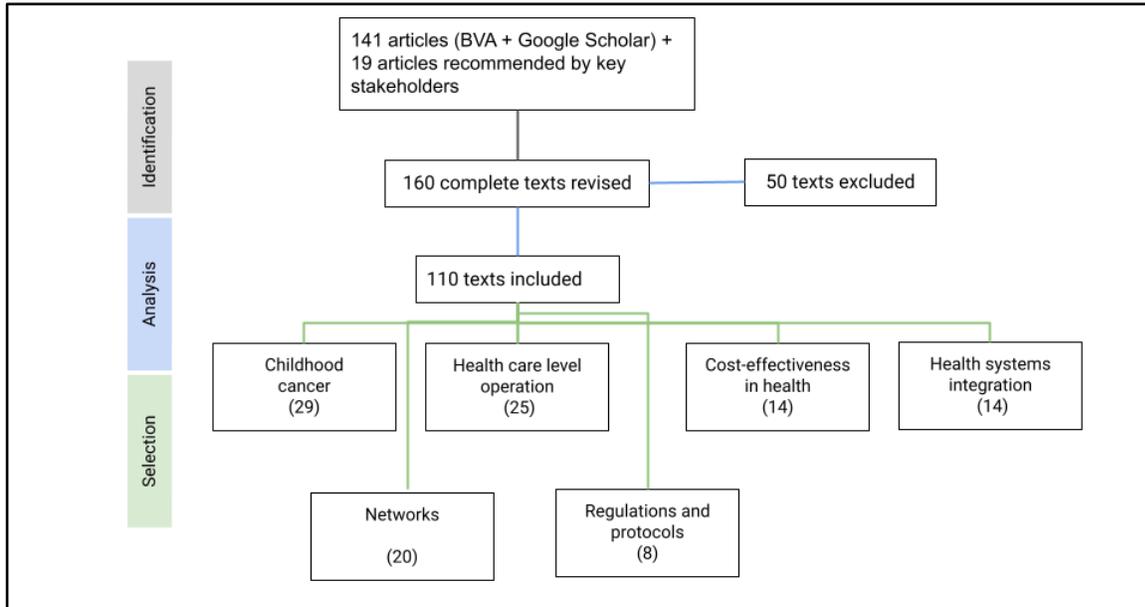
At the outset, the search for literature references, undertaken as a scope review, was geared toward articles subjected to referee processes published in national, regional, and international journals, through traditional platforms. This first round of review yielded 160 articles. Considering the dimensions ruling the present study, 50 articles were excluded because they failed to fulfill the eligibility requirements. The articles included ($n = 110$) were systematized in an analysis matrix according to the criteria shown in Figure 2.

Out of the 110 studies included ($n = 110$), 66 were performed in low- and medium-income countries; of these, 62 were developed in Latin America. Of the total studies, 29 deal with childhood cancer, 25 refer to health care–level performance, 14 are studies on health system integration (centralized management), 14 are cost-effectiveness studies on related themes, 20 are about networks, and 8 focus on oncopediatric regulations and protocols.

Based on the literature review, it is observed that childhood cancer is a high-complexity, low-incidence specialty, with a marked specificity in clinical approach strategies. Early diagnosis and quick referral have a direct impact on patient survival, increase the chances of recovery, and entail lower costs for the system and families. In general, childhood cancer symptoms are nonspecific and usually resemble those of other benign conditions. For this reason, stress is laid on the role played by families, as they are *responsible for identifying the first symptoms and later approaching the health system*, and by primary health care centers (centros de atención primaria, CAP) and health agents, which are *responsible for referring the patients to higher-complexity facilities in case they suspect or identify the presence of oncological pathologies*. Awareness campaigns and action guidelines on the subject provide resources that help families and first-care levels to suspect the presence of the disease.

Figure 2

Flowchart of the Studies under Analysis



Source: Authors, based on studies analyzed.

Some necessary guidelines for the design of a federal oncopediatric network in a fragmented and segmented health system are also provided. In this sense, it is necessary to consider mechanisms capable of addressing equity issues, such as differences in survival possibilities among jurisdictions; the shortage of qualified professionals; logistic difficulties related to delays; and distances to health care centers, treatment interruptions, and health care costs. The creation of RISS can help to overcome the existing fragmentation, especially if it is accompanied by both formal and informal referral and counter-referral mechanism⁴. Additionally, monetary and nonmonetary incentives improve care level operation, since they are an additional source of motivation that encourages health practitioners to change their clinical behavior as regards prevention, diagnosis, and treatment decisions.

As to health system integration, the dominant paradigm identified in the literature has been the concentration of resources and expertise in some specialized centers, which usually resort to other institutions that provide less complex treatments. One way to strengthen the integral care provided in these centers is through strategies aimed at facilitating collaboration between specialists. Some examples are the professional grand rounds, where practitioners examine the cases from a multidisciplinary perspective, and the use of telemedicine.

The search for information on the particular background of the Argentine oncopediatric network included a review of official documents and databases reflecting the development and performance of various initiatives directly affecting network operations. The information sources were the different areas of the Health Ministry, INCUCAI, and the National Cancer Institute. For this purpose, requests for access to public information were submitted.

⁴ It has been shown that, at times, the presence of discretionary mechanisms supplements the operation of the network (Crojethovic, M. and Maceira, D., 2009; Maceira, D. and Kremer, P., 2012).

As regards the national stakeholder mapping, 43 interviews were carried out in the public, private, and social security sectors. Additionally, several focal points furnished information on related subjects from two Argentine provinces and four countries in the region (Chile, Colombia, Costa Rica, and Uruguay). This helped to characterize the childhood cancer issue in each of those countries and gather information on similar initiatives. Multilateral regional organizations were also taken into consideration. The mapping exercise was replicated at provincial level for each case study. Given the characteristics of the study, it was not possible to include in the mapping the voices of the patients' families or the perspective of the associations directly linked to the users of the system addressing these pathologies. Some interviews with civil society institutions helped to capture such perspectives indirectly. An in-depth analysis of such interviews could become the subject matter for a future initiative.

The interviews took place both virtually and personally, taking into account the interviewees' preferences, and lasted approximately 45 minutes to one hour. A semi-structured questionnaire comprising 20 questions was prepared. The questions were adapted to each particular stakeholder interviewed. The questionnaire followed the criteria for a semi-structured interview with additional questions.

The meetings were arranged in five thematic blocks: oncopediatric service operation, characteristics of the subnational level, protocols, public-private interface, and processes. In the first case, the questions addressed issues related to the patients' entry points and their journey through the health system, the identification of the pathology and the mechanisms applied to reach a diagnosis.

Then, the questions addressed the following subjects: the criteria used to define referrals, referral and counter-referral mechanisms, bottlenecks, articulation between care levels, and communications among stakeholders. The questions in the second block addressed the existence of regional health corridors, human resource specialization levels, and the existence of health networks.

The third block of questions focused on the formality and informality levels existing in the health system, specifically in the oncopediatric area. The fourth block addressed aspects related to procurement processes, treatment and drugs costs, recovery processes, and contracts and agreements in force between the public and private sectors. Finally, the questions in the last block investigated average times and delays in relation to patient care, critical situations, and emergencies.

With the interviewee's consent, the working team recorded or took notes of each interview, and that information was then used as input for the results section. The fact of considering these stakeholders as part of actual or potential national networks, together with the thematic lines selected to develop the structure of the interviews, made it possible to build a network characterization, shed light on the main barriers hindering network efficiency, and identify opportunities for enhancement.

The following table details the stakeholders interviewed, by sector and organization.

Table 1
National Stakeholders Mapping

Sector	Area
National public sector	Sumar Program - Health Ministry
National public sector	Redes Program - Health Ministry
National public sector	Drug Bank - Health Ministry
National public sector	PROCUINCA / ROHA - National Cancer Institute
National public sector	Program for Cancer Research Promotion - National Cancer Institute (INC)
Social security	Superintendency of Health Services
Social security	Single Reimbursement System (SUR)
National public sector	Directorate for Direct Assistance in Special Situations (DADSE) - Ministry of Social Development
National public sector	Single Central National Institute for the Coordination of Ablations and Implants (INCUCAI)
National public sector	Garrahan Hospital
Subnational public sector	Gutiérrez Hospital
National public sector	Posadas Hospital
Subnational public sector	Elizalde Hospital
Private sector	Federation of Private Health Service Providers of the Argentine Republic
Private sector	Private Health Insurance Companies
Social security	Health Organization for Railway Personnel
Social security	Health Organization for Construction Personnel (OSPECON)
Social security	Health Maintenance Organization for Business Workers and Civil-Activity Personnel (OSECAC)
Private sector	Henry Moore Oncological Institute
Private sector	Sanatorio Güemes
Private sector	Italian Hospital
Private sector	Specialist
Private sector	Consultant
Private sector	Argentine Society of Pediatric Hemato-Oncology (SAHOP)
Private sector	Argentine Group for Acute Leukemia Treatment (GATLA)

Source: Authors.

Note: PROCUINCA = National Program for the Integral Care of Children and Adolescents with Cancer.

The following table details the international actors interviewed, by country, sector, and area.

Table 2
International Stakeholder Mapping

Country	Sector	Area
Chile	Public sector	Explicit Health Guarantees Program (GES)
Colombia	Public sector	Health Ministry - Health Promotion Entity (EPS)
Costa Rica	Public sector	Costa Rica Social Insurance Fund (CCSS)
Uruguay	Public sector	National Resource Fund
Regional	Multilateral organization	Inter-American Development Bank (IDB)

Source: Authors.

The following table details the provincial actors interviewed, by province, sector, and area.

Table 3
Case Study Stakeholder Mapping: Chaco and Corrientes

Province	Sector	Area
Chaco	Public sector	Dr. A. L. Castelán Pediatric Hospital, Resistencia
Chaco	Public sector	National Institute for Social Security, Insurance and Loans (INSSSEP)
Corrientes	Public sector	Provincial Health Ministry
Corrientes	Public sector	Juan Pablo II Pediatric Hospital
Corrientes	Public sector	Vidal Hospital
Corrientes	Public sector	Anna Rocca de Bonatti Oncological Center
Corrientes	Public sector	Social Security Institute of Corrientes
Corrientes	Social security	OSECAC Medical Directorate - Corrientes

Source: Authors.

1.3 Background of the oncopediatric network in Argentina

Based on the precedent of the Maternal and Child Health and Nutrition Program (Programa Materno Infantil y de Nutrición, PROMIN), implemented with international funding in the 1990s, the “Plan Nacer” initiative was developed in early 2000 with World Bank funding. This plan was targeted at the maternal and child population not covered by formal insurance in nine provinces in the northern part of Argentina. In 2007, a second phase of the program extended its benefits to the rest of the country⁵. The main feature of this initiative is that it combined the traditional supply-side subsidy established by provincial public subsystems, with performance-related incentives in prioritized health services (performance trackers). The Plan Nacer scheme based its strategy on the nominalization of users in primary health care centers with performance rewards established through management agreements between the National Health Ministry and its peers in the provinces. Each subnational jurisdiction has its own resource allotment system. The ministry advanced toward the coverage of the population accessing the public subsystem until it encompassed the whole group, extended the coverage to the Plan Nacer scheme in 2020, and gradually developed care-line based initiatives (Health Ministry and Sumar 2016)⁶.

Starting in 2009, the National Health Ministry began to implement the current Redes Program, adopting the strategy of the RISS (PAHO, 2010) and strengthening the Primary Health Care strategy (Atención Primaria de la Salud, APS). The aim of this program was to promote equal access to health care services for population segments lacking health coverage, thus boosting the Sumar Program. Based on this perspective, it has pursued the development of strategies and investments for provincial projects with the aim of enhancing the networks, prioritizing the first level of care (Primer Nivel de Atención, PNA), including the definition of referral and counter-referral circuits, the management of scheduled medical visits, and the implementation of information systems (Health Ministry 2013b).

As to existing policies promoting the expansion of service provision coverage in the social security and private subsystems, the Superintendency of Health Services (Superintendencia de Servicios de Salud, SSS) plays a crucial role in the regulation and control of national social security health organizations and private health insurance companies, including the management of two tools: the Mandatory Medical Program (Programa Médico Obligatorio, PMO) and the Single Reimbursement System (Sistema Único de Reintegro, SUR).

The first tool guarantees the rights of beneficiaries of the subsystem and can be seen not only as a list of services for social security institutions to plan their expenditures and negotiate service provision, but also as an instrument that may reveal behavioral trends related to prescription, consumption, and health investment (Maceira 2018). The SSS also manages the Solidarity Fund for Redistribution (Fondo Solidario de Redistribución, FSR), a solidary mechanism that provides financial support to National Insurance Agents through transfers from each national health organization.

The FSR transfers resources to social security health organizations through different redistributive mechanisms, foremost among which is the Single Reimbursement System (Sistema Único de Reintegro, SUR), which is geared toward high-cost services and low-incidence and chronic diseases. The pathologies covered include transplants, prostheses, and cancer medication (Maceira 2018).

Despite these efforts, the initiatives have not managed to break down the barriers among the institutions in each subsystem or those existing between subsystems. Both the fragmentation among social security

⁵ The implementation of both phases was financed under IBRD Loan Agreements Nos. 7225-AR and 7409-AR.

⁶ As this program provides exclusive public coverage, health service provision is limited to 30 percent of the population.

institutions and the decentralization of the public administration create significant challenges to the construction of a network.

With respect to previous experiences in health network development, the Federal Network for Congenital Heart Defects (Red Federal de Cardiopatías Congénitas, RFCC), created in 2010, set a precedent by introducing maximum complexity, low prevalence, high-cost pathologies into a system where the supply of health services is highly concentrated in a few facilities, especially as regards surgical procedures. Hence, a formal national network was implemented to articulate province-level networks and organize the procedures for detection, treatment, and patient follow-up. These modifications resulted in the creation of the RFCC,⁷ which is formed by Provincial Referral Hospitals (Hospitales de Referencia Provinciales, HRP), a Referral Coordination Center (Centro Coordinador de Derivaciones, CCD) based in the Dr. Juan P. Garrahan Pediatric Hospital, and Treating Cardiovascular Centers (Centros Cardiovasculares Tratantes, CCTs) (INC, no data; Health Ministry 2016).

As regards its operation, the CCD is responsible for assigning patients to the CCTs. The existence of rules, circuits, and procedures explicitly defined by a national organization generally entails a loss of autonomy for the provinces. In this context, the inclusion of provincial participation in the RFCC as a condition for participating in the Plan Nacer program (and obtaining its funding for every line of care) was a crucial incentive to promote its sustainability. The incentives geared toward funding and investment in equipment and training for human resources working in hospital facilities also proved useful (Zanetta 2020). A Solidarity Insurance Fund aimed at funding higher complexity surgeries was created through the Plan Nacer program. Low and medium complexity surgeries are included in the Basic Services Plan, with 15 percent co-funding by the provinces (Health Ministry 2009).

The references consulted report a significant reduction in waiting lists, a large increase both in the number of surgeries performed and in timely patient diagnoses, and a high degree of satisfaction and appreciation on the part of the population with respect to the care provided in the health care facilities. In addition, the creation and implementation of an agency charged with the supervision and management of the relations between the parties encouraged a shift from a high case concentration model to a scheme of node-based network, and thus eliminated the waiting list in the Garrahan Hospital (Health Ministry 2013b and 2016).

In particular, the oncopediatric network builds on the actions of already existing public organizations. The Argentine Hospital Oncopediatric Registry (Registro Oncopediátrico Hospitalario Argentino, ROHA) was created by the Kaleidos Foundation with the aim of developing a single model for childhood cancer registration, in accordance with international guidelines (WHO/ International Agency for Research on Cancer, IARC). When the ROHA was institutionalized within the National Cancer Institute, it started to gather information on patients under 19 years of age⁸ with oncological diagnoses.

This registry, mainly based on public and private hospitals, is organized as a network of reporting centers. It contains information on incidence rates, prevailing cancer pathologies by sex and age group, indicators on patient survival 5 and 10 years after diagnosis, and the different migratory situations of children aged up to 19 (INC, 2021).

Later, the National Program for the Integral Care of Children and Adolescents with Cancer (Programa Nacional de Cuidado Integral del Niño y Adolescente con Cáncer, PROCUINCA)⁹ was launched as a

⁷ The RFCC was established when the health services for congenital heart defects (CHD) were included in Plan Nacer in 2010, with the endorsement of the 23 provinces and the Autonomous City of Buenos Aires, formalized through the Plan Nacer Framework Agreement (Resolution No. 327/2011).

⁸ Starting in 2010, patients aged 15 to 19 were incorporated into this system.

⁹ Resolution 1565 - E/2016: <https://www.argentina.gob.ar/normativa/nacional/resoluci%C3%B3n-1565-2016-265889/texto>.

continuation of the working guidelines of the National Cancer Institute. Among its functions, the program must comply with the ROHA register,¹⁰ provide training in timely diagnosis, organize workshops, manage a scholarship program, and develop program guidelines as well as guidance documents on diagnosis and treatment practices. This program must coordinate actions with the Sumar Program and manage the oncological centers' network and assist them in the provision of quality care (INC; Health Ministry, no data).

To formalize a health care service network providing shared integral care to cancer patients, in late July 2021 the National Directorate for Provincial System Strengthening, the National Directorate for Quality Health Services and Health Regulation, the Garrahan Hospital, and the INC started to coordinate their actions to advance toward the consolidation of the Argentine oncopediatric network.

As part of this initiative, a process involving the stratification and certification of the Hematology and/or Oncopediatric Units was undertaken throughout the country based on their resolution capability. This process was based on a self-administered online questionnaire answered by each center, which covered human resources, infrastructure and equipment, and integral care. Although the results are being systematized, the input provided by this process helps to classify the country's oncological centers into three complexity levels.¹¹ In parallel, the INC has two lines of funding for cancer research in general, which involve the oncopediatric sector.¹²

At present, due to the absence of formal regulations, care centers that treat childhood cancer are articulated in an informal network through mechanisms based on intersectoral contacts and on academic, institutional, professional, and personal relations among the stakeholders of the pediatric oncology field (Health Ministry and National Cancer Institute 2019). While attempting to define the composition of the network, we found disparities in terms of the number of centers comprised in it. On the one hand, it was observed that the Network for Pediatric Oncology and Palliative Care consists of 42 health care centers, 29 of which are Units within Public Hospitals (Unidades en Hospitales Públicos, UHOP), 6 are Diagnosis, Referral, and Follow-up Units (Unidades de Diagnóstico, Referencia y Seguimiento, UDRS), and 7 are units operating in private health facilities. This estimation is based on documents provided by INC¹³ and on information from the Garrahan Hospital. It is important to mention that according to ROHA's 2021 official report, the reporting of cases and the active follow-up of children were the responsibility of 30 UHOP, 20 units in private centers, and 6 UDRS (ROHA 2021).

As to the interaction with the prevention programs run by the National Health Ministry, the Sumar Program, jointly with INC, has developed a series of services geared toward the visibility and early detection of cancer in children and adolescents through the care line, based on suspected oncological pathology, with special attention to the diagnosis, treatment, and follow-up of patients suffering from leukemia or lymphoma.¹⁴ Consultation and notification services include consultations for diagnosis, posttreatment clinical follow-up, referral report for diagnosis, and notification of treatment commencement, respectively. The oncological

¹⁰ In this sense, the ROHA was included in the action lines of the PROCUINCA Program as of 2016.

¹¹ Although the ROHA is applied in public and private centers, up to now the information for stratification purposes was gathered only in public hospitals.

¹² Unfortunately, the research team of this project was not able to access this repository, as it is not freely accessible.

¹³ INC, Network for Pediatric Oncology and Palliative Care (2019), ROHA report (2021), and the list of Pediatric Oncology Units (Unidades de Oncología Pediátrica [UHOP and UDRS]) provided by INC and the Health Ministry.

¹⁴ Starting in 2012, health services aimed at strengthening the pediatric oncology sector were included in the Sumar Program through the incorporation of leukemia and lymphoma lines for patients aged 0 to 19. In 2015, the scheme was reinforced by introducing the oncological pathology suspicion line for patients aged 0 to 19.

pathology care line includes consultation due to oncological signs and the report for counter-referral to the first level for patients referred because of suspected cancer (diagnosis notification) (INC internal document, no data).

With the aim of improving the integral protection of oncopediatric patients, Act 27674 on the establishment of a regime for the integral protection of children and adolescents with cancer was enacted, its application authority being the INC (the act is currently in process of implementation). This act may be considered as an extension of the National Program for the Integral Care of Children and Adolescents with Cancer (Programa Nacional de Cuidado Integral del Niño y Adolescente con Cáncer), INC line of action (a program based on ministerial resolution 1565-E/2016). The main elements incorporated in the act are the program's responsibility to manage and assist the oncological center network to provide quality treatments, train health personnel particularly as regards early detection and diagnosis, and ensure compliance with ROHA. In addition, the coverage provided by social security health organizations and private health insurance companies for services directly or indirectly associated with oncological diagnoses increased to 100 percent; a financial aid allowance equivalent to the subsidy provided for Children with Disability was established; and actions promoting access to adequate housing were proposed for families in social vulnerability situations. This benefit is provided through a housing subsidy in cases of patient health care migration or when the home requires refurbishment.

The initiatives and public policies described in this section have contributed to the strengthening of child health care services as well as to the promotion of equal access to health services for population segments lacking coverage. In particular, ROHA stands out as a valuable instrument to shed light on the oncopediatric context in Argentina, and thus requires strengthening. Additionally, the initiatives promoted by INC may be used as a baseline when structuring a formalized network. Special attention should be paid to the experience of RFCC, which has proved that the existence of a well-designed incentive scheme promotes cooperation among provinces, and that one way to achieve improved collective performance is to establish performance-based incentives. Finally, the existence of current legislation regulating the health care of children and adolescents with cancer (Act 27672) facilitates the construction of formal networks, which make it possible to properly address this patient segment.

PART II

2.1 Stakeholder Mapping

Thirty interviews were arranged with stakeholders in the areas of oncopediatric service funding, management, and provision. These players belonged both to the public sector and to social security health organizations, the private sector and civil society organizations. Specialists were also included. Five stakeholders from the international sphere were also interviewed, and eight meetings were held with province-level stakeholders in the framework of the case studies selected for this project. The interviews took place from May to July this year. From the responses given by the interviewees, the following significant topics were identified:

- Aspects related to oncopediatric patient's access to the system
- Rules on referrals and use of treatment protocols
- Particular features of local health systems
- Required and available human resources, equipment, and infrastructure
- Funding of drugs, supplies, and treatments
- Dialogue between public and private sector actors on patient reception and network needs

2.1.1. Access: The Critical path followed by patients

Consistent with the literature review, there is a consensus to characterize oncopediatrics as a high-complexity and low-incidence specialty, with a marked specificity as to approach strategies owing to the diversity and particularities of the tumors treated. It is important to note that the stages of these diseases in pediatric patients generally tend to develop rapidly. Therefore, the time required to reach a diagnosis and start the treatment has a direct impact on the patient's survival.

Detection is carried out both in the first level of health care and in the higher complexity levels. The first step required to diagnose a patient is the suspicion of oncological disease. Some interviewees stated that screening mechanisms are not used in oncopediatrics because of the low incidence and heterogeneity of the pathologies. Some public sector interviewees praised the interventions promoting early detection, since, as one interviewee said, *“that helps the child to start treatment in better shape.”*

According to the register developed by INC, there are approximately 27 public hospitals distributed across the national territory with the capacity to treat oncopediatric patients, although the case resolution level is particularly heterogeneous.

All interviewees agreed that 80 percent of the patients attend public hospitals. The managing directors of two trade union-based social security health organizations pointed out that they do not have their own professionals to treat oncopediatric patients, so they hire private centers offering such services. However, other persons from the same subsector mentioned the presence of clinics like Sagrado Corazón that is operated by the Health Maintenance Organization for Business Workers and Civil-Activity Personnel (Obra Social de Empleados de Comercio y Actividades Civiles, AC), which provide services for such pathologies, but said that in specific high-complexity cases, they usually refer the patients to the Italian Hospital or to the Austral Hospital, both privately owned.

It is observed that a small group of public and private institutions treat the largest number of patients. Within the former group, the main institutions are the Garrahan Hospital (shared management between the National Health Ministry and its counterpart in Buenos Aires city), Gutiérrez and Elizalde Hospitals (which belong to the Autonomous City of Buenos Aires), and Posadas National Hospital and Sor María Ludovica Hospital, both in the province of Buenos Aires, managed at national and provincial level, respectively.

Within the Buenos Aires Metropolitan Area (AMBA), some private health facilities such as the Italian Hospital, the British Hospital, Hospital Universitario Austral, and Sanatorio Güemes are also among the major treatment providers. Public sector hospitals treat cases from the whole country regardless of their coverage type,¹⁵ while those in the private sector receive patients with private coverage according to the agreements concluded between the funders. Most cases are admitted by referral; spontaneous demand is exceptional.

As to the rest of the service providers with resolution capacity, the interviewees stated that the provinces of Córdoba, Mendoza, Santa Fe, Neuquén, and Tucumán assist the largest number of patients. However, they differentiated between the institutions that treat and/or refer cases properly and those whose performance is poor. The former are characterized by their timely diagnoses and treat or refer the patients according to their capacity in terms of service, medical expertise, and infrastructure. As for the latter, it was mentioned that they exhibit serious delays in the diagnosis process, thus delaying the patients' treatment.

¹⁵ It should be noted that the interviewees mentioned that they receive mostly public coverage cases. Cases with formal coverage are covered by social security health organizations, and only private health insurance companies cover a minority.

Also, there are two recurring scenarios: centers that refer the patients even though they are able to treat them, and centers that decide to treat patients although they lack the necessary expertise. One of the interviewees stated the following: *“As there are no regulations, each center does whatever it wants.... And in the end, they refer the patients when it’s too late.”* From the private sector, this problem was described as a characteristic of the public sector, where *“no one controls anything.”* In this sense, the National Cancer Institute said that a stratification process is currently being implemented and that this process will allow the service capacity of each provider to be gauged.

Due to the shortage of human resources, these diseases are not always diagnosed by pediatricians, and many cases are treated by general practitioners. It was mentioned that not all professionals are able to identify malignancy, which leads to many patients being referred on the basis of clinical severity conditions, thus delaying treatment initiation. Also, interviewees from the Garrahan, Gutiérrez, and Elizalde Hospitals reported having received terminal patients who had been referred to them *“even when the hospital of origin was aware of their condition.”* In this respect, one of the interviewees said that this situation is due to the fact that families *“want to find an optimistic response even when there is nothing to be done.”*

As regards transplants, the Single Central National Institute for the Coordination of Ablations and Implants (INCUCAI) stated that, although many patients with leukemia or lymphoma receive chemotherapy, some require bone marrow transplants. In this sense, INCUCAI is responsible for this process, which includes both the bone marrow donor register management and the certification of the centers where donation and transplant procedures are performed. Patient identification is carried out by the professional (hematologist or immunologist), who makes a preliminary search for donors among the patient’s relatives. Once the patient arrives at the transplant center, he/she is registered and if no compatible donors are found, INCUCAI starts a second search through the mentioned register. It was stressed that when no compatible donors are found at national level, international registers are used. There is a permanent exchange of information, which helps to identify those donors that best suit the needs of each patient. In terms of service supply, the person interviewed at INCUCAI mentioned that most transplant centers, both public and private, are in the province of Buenos Aires.

In this respect, the Argentine Group for Acute Leukemia Treatment (Grupo Argentino de Tratamiento de la Leucemia Aguda, GATLA) stated that there are constant interactions among the public, private, and social security sectors because patients are treated in the public sector, but their transplant procedures are generally performed in private institutions. GATLA also reported that about 40 percent of the persons requiring transplants access the procedure, while 60 percent *“do not reach the transplant stage.”* This is because most patients have public coverage, and the waiting list for transplants exhibits significant delays. Another obstacle identified is patient-donor compatibility. On the one hand, many treating institutions lack the technology required to perform histocompatibility studies, resulting in delays to the transplant process, and on the other, compatible donors cannot always be found.

Lastly, all interviewees indicated that, although survival indicators have improved in the last few years, fluid communication among care levels to achieve early identification and define the proper approach to each case remains a challenge. Along these lines, it was mentioned that there is an informal network involving public service providers (Garrahan, Gutiérrez, Posadas, and Sor Ludovica Hospitals) that organizes the reception of referred patients, which was strengthened thanks to the emergence of technological resources and the virtual working modality produced by the COVID-19 pandemic. However, it was also mentioned that this is a *“very precarious”* tool sustained only by the professionals’ efforts.

2.1.2. Rules on referral, counter-referral, and protocol usage

With regard to patient referral, the responses received indicate that although a referral pattern exists, there are no formal rules regulating and ordering the process: *“From La Rioja or Catamarca, patients are referred to Córdoba and sometimes to Buenos Aires, but there is no rationale behind these decisions.”*

Behaviors vary hugely from one province to the other, as some jurisdictions apply articulation guidelines, while in others these rules do not seem to exist. One public hospital described this phenomenon as “a bureaucracy problem,” since each province has its own administrative circuits for the health care area. Another interviewee illustrated the situation as follows: *“Corrientes and Resistencia perform flow cytometric and cytogenetic analyses, which are complementary procedures to diagnose leukemia, and although there is a bridge connecting the cities, they never coordinate their actions.”* This results in a significant number of patients being referred to Buenos Aires, overstressing the operating capacity of the hospitals located in this province.

In the case of patients with public coverage, the referral depends on the receiving centers' bed availability. It was also emphasized that referrals are usually guided by the relations established between health professionals. The interviewee from the Elizalde Hospital stated that *“physicians refer patients to the hospitals where they were trained,”* and the person interviewed in the Gutiérrez Hospital said: *“My former residents call me directly to refer their cases to me.”*

Some provincial governments have subscribed to service price regulation agreements with public and private service providers, which provides some degree of predictability. It was observed that these agreements can comprise both the provincial population with public coverage and members of the province's social security health organization. In the case of patients with private coverage, the referral decision is made by the medical management, which bases its choice on recommendations from the specialists that evaluate each case. One private health insurance company indicated that the treating practitioner prescribes the patient's treatment, but that the medical audit sector's authorization is required to implement it, adding that *“both clinical and cost-effectiveness parameters are taken into account.”*

As regards the reception of referred patients, it is observed that some public institutions run a Distant Communication Office (Oficina de Comunicación a Distancia, OCD), which is in charge of structuring the request for referrals. By contrast, the interviewee from a public hospital in the AMBA said that this process is carried out through the hospital's emergency service, stressing that *“patients arrive in a chaotic manner.”*

Although all the interviewees from high-complexity hospitals in the public and private sector agreed that the patients should be treated in places close to their homes, serious difficulties were reported with the organization of counter-referrals. An interviewee from a public hospital located in the Greater Buenos Aires area said that during treatment, the patient must remain in the high-complexity hospital and can only be counter-referred in the maintenance stage, as this can be done remotely and jointly with the high-complexity hospital. In any case, it was mentioned that patients usually prefer to stay in Buenos Aires. An interviewee from a Buenos Aires City Hospital mentioned that counter-referral takes place five years after the end of the treatment, because specialized services are required to follow up the sequels. Therefore, in the words of the interviewee, *“We rarely send the patients back; usually, we do the follow-up ourselves.”*

With regard to treatment protocols, as reported, there are no formal regulations guiding the professionals' decisions when they have to define the protocol to be used. On this issue, an interviewee from a community hospital said that although consensus on protocol use is established based on the work of scientific societies, in the absence of a standard regulating their application, the final decision is made by the pediatricians. The interviewee added: *“They prescribe what they want, with or without undue incentives.”*

Several interviewees stated that, by convention, the recommendations issued by the Berlin-Frankfurt-Münster (BFM) Group are followed, and an interviewee from Elizalde Hospital added that *“leukemia*

protocols are super consolidated.... However, this is not the case with solid tumors.” In this respect, the Argentine Group for Acute Leukemia Treatment (GATLA) mentioned that they have managed to create a network involving both public and private service providers, where consultations are made and patient treatments are discussed. In the words of the interviewee: *“There, we agree on the treatment to be applied based on the available scientific evidence.”*

Other interviewees said that the mentioned group systematizes patient data, whereby records are kept by the treating professionals participating in the network, who have databases that would allow evaluating the treatments applied. As regards the dissemination of new scientific evidence and recommendations on the use of protocols, they highlighted the work of the Argentine Society of Pediatric Hemato-Oncology (Sociedad Argentina de Hemato-Oncología Pediátrica, SAHOP) and the Latin America Group for Pediatric Oncology (Grupo América Latina de Oncología Pediátrica, GALOP). However, no mention was made of a space where such work might converge.

An interviewee from a community hospital said that in the private sector there are *“levels of autonomy”* for the use of treatment protocols, alluding to the pressure exerted by the funders on many health facilities when high-cost medication is required. In the interviewee’s words: *“The hospital is independent and provides treatments that produce better outcomes, for example, the treatments to consolidate remission.”* In contrast, some health facilities face great pressure from social security health organizations.” In this respect, in an interview with a private health insurance company, they mentioned that they are on alert to ensure that *“no steps are omitted,”* and that they follow indications set by treatment lines at international level. In their words: *“Sometimes, the audit detects that the process skipped from line one to line three.... Then, our consultant contacts the treating doctor and asks him to justify the request.”*

An interviewee from a public hospital in the AMBA warned that one of the main problems affecting the pediatric oncology sector in Argentina is that hospitals do not report the procedures they perform on the patients or the results thereof. Although it was recognized that the Argentine Hospital Oncopediatric Registry (Registro Oncopediátrico Hospitalario Argentino, ROHA) adds significant value to increase the understanding of the issue, it was pointed out that the registry *“does not record the toxicity level displayed by the patient during the treatment or its cause,”* and concluded that *“if we record what we do, we can understand why some patients do better than others.”*

2.1.3. Equity: Particular features of the local health systems

The pediatric oncology services provided in the country are quite heterogeneous in terms of diagnostic capacity, medical technologies, infrastructure, and professional expertise. This reflects an unequal distribution of the patients, regardless of their place of residence. Some of the interviewees said that it would be preferable for each province to have its own high-complexity center, while others pointed out that, in cost-benefit terms, an investment of that size would be neither profitable nor effective from the social point of view. In the words of one interviewee: *“We are speaking of 1,500 cases per year at most.... You cannot train anyone in that period.... That’s why it’s better to refer.”*

Some interviewees also emphasized the need to have available a wide spectrum of medical specialties when treating childhood cancer patients, which is not always the case in hospitals located in the interior of the country. An interviewee from the private sector referred to nonmedical care quality as an important component of oncological processes. In his words: *“Procedures that seem easy, like how to prepare a catheter or a medication, can impair the patient’s improvement and have an impact on treatment outcomes.”*

All interviewees agreed on the fact that families play a key role in a successful diagnosis, as parents systematically approach the health system to obtain an accurate diagnosis and, if the disease is confirmed,

to properly gain access to the treatment. In this sense, some interviewees added that at times, the families mistrust the quality of the services provided by local health providers, which leads them to directly approach the hospitals in the AMBA through spontaneous demand, saying: *“I want to be treated in the Garrahan Hospital,”* or *“I prefer to come here even if I have to travel 3,000 kilometers.”*

The shortage of human resources trained in this specialty was mentioned as a recurring problem. This is explained in part by the *“precarious working conditions,”* which cause the professionals to migrate to other territories. It was stressed that this phenomenon is seen both in hospitals located in the AMBA as in the interior of the country. The interviewees from the Elizalde and Gutiérrez Hospitals agreed on the scarcity of the professional positions offered: *“We train people and then we cannot offer them a position matching their training level.”*

According to other voices, this is not necessarily the case of the Garrahan Hospital thanks to its scholarship system, supplemented by grants provided by the National Cancer Institute (INC) and implemented in the same center. In this respect, the interviewee from the INC’s Program for Cancer Research Promotion stated that scholarship candidates are selected through an internal evaluation carried out by a committee formed by INC professionals, and an external evaluation performed by specialists invited on the basis of their expertise in the subject matter of each project. With regard to research results, the interviewee answered that they are not available, as they are the intellectual property of their authors (the scholarship holders) and the institute has no power over them.

In terms of social assistance, the interviewees emphasized that access to education, guaranteed coverage of transport costs in case of referral, and accommodation for their family are priority issues for the patients. Most of the voices from the public sector pointed out that education services are available for hospitalized childhood cancer patients, to reduce the loss of school days and daily schooling. Also, some interviewees mentioned that they coordinate the request for home teaching with the Ministry of Education when the child cannot be moved because of the treatment.

As regards transport and accommodation services, it was mentioned that some public hospitals have exclusive spaces to receive the relatives of patients coming from other provinces. Such is the case of the Garrahan, Posadas, and Elizalde Hospitals. For its part, Gutiérrez Hospital has a cooperative commission in charge of raising funds to cover these needs. The interviews reflect a positive opinion of the provincial governments’ actions as regards funding the expenses generated by patient health care migration, while others reported that such needs are covered by nonprofit foundations. The interviewees from the private sector (health organizations and private health insurance companies) unanimously stated that they guarantee coverage for both transport and accommodation costs of the patients and their relatives. In this respect, they explained that transport issues are decided on a case-by-case basis. As regards accommodation, they select hotels located close to the hospitals, with which they have agreements.

2.1.4. Human Resources, Equipment, and Infrastructure

Given the relevance and specificity of the human resources working in the oncopediatric sector, the training of professionals was established as a priority element to improve the services. The interviewees from Garrahan, Gutiérrez, Elizalde, Posadas, and Italian Hospitals and from Sanatorio Güemes stated that they organize training schemes for residents and courses for scholarship holders. No one was able to provide an answer concerning the rules governing the evaluation of the candidates, although all of the interviewees said that the School of Medicine of the University of Buenos Aires was in charge of this task, and that there is a special quota for foreign physicians from the region. It was mentioned that virtual training courses are provided to other hospitals’ medical staff, to promote access to information and useful resources to address

the pathologies. Public sector interviewees stated that human resource training fulfills a double purpose: training health professionals and providing available resources to the hospitals.

Several interviewees from the public sector mentioned the “virtual grand rounds” organized by Garrahan Hospital as spaces useful for information exchange, as they allow professionals from other national or provincial institutions to present cases for joint discussion. In this sense, they pointed out that the grand rounds are organized regularly, although no formal certification is issued to attest to participation. One interviewee emphasized that the particular features of each case are taken into account, but treatment outcomes are not evaluated and no feedback is provided to the treating professional.

From the interviews, it was not possible to determine the criterion for case selection, although Garrahan Hospital stated that extremely urgent cases are considered in alternative meetings “*because we cannot keep the child waiting for a week.*” Although most high-complexity public hospitals said they participate in these exchanges, Gutiérrez Hospital reported that they have their own grand rounds, which are organized by the hospital’s Tumor Committee. The same was detected in the private sector, where each health facility provides a space for joint case discussion.

As regards equipment, the interviewees reported that most high-complexity hospitals of the country provide chemotherapy services. As for radiotherapy services—which are applied to patients over three years of age—one private sector interviewee stressed that although only 15 percent of the total oncopediatric patients require these services, only a few hospitals provide this type of treatment. She also underscored that many private radiotherapy centers belong to the same investor and described this service as a monopoly.

Some interviewees said they had received financial donations to improve health care center buildings. The interviewee from Gutiérrez Hospital said that the hospital received a donation from INCUCAI, which allowed it to expand the bone marrow transplant unit. The interviewee from the Posadas Hospital said that Fundación Flexer would donate 70 percent of the total cost involved in a project that will enlarge the oncopediatric services sector.

2.1.5. Drugs, supplies, and treatment funding

Oncological treatments and drugs are provided according to the patient’s coverage type. Patients with public coverage receive free treatment and, through the hospital providing the treatment, must submit a medication request to the drug bank of their province of residence or, if no such drug bank exists, to the responsible provincial organization. Those that are covered by social security health organizations or have private coverage receive the treatment from the pertinent service provider and must submit a medication request to the funder, whose auditors evaluate each request and approve or reject the treatments prescribed. An interviewee from a major trade union health care organization indicated that to cover its members’ medicines, they have a contract with a single service provider, which owns pharmacies throughout the country.

These managerial institutions that provide coverage through a third party, subscribe to agreements that cover certain practices and drugs. In this regard, the interviewees agreed on the fact that low-cost drugs are generally included, while high-cost drugs are requested from the funder before starting the treatment. In the words of one interviewee, “*high-cost drugs are always excluded from the contracts, because nobody wants to take that risk.*”

Some public service providers have their own procurement budget and usually issue calls for tenders, while others submit the requests to the pertinent drug banks. From the private sector it was mentioned that

procurement mechanisms are defined by each funder, emphasizing that drug prices vary greatly, especially in the case of high-cost products.

The directories regulating service prices (for the treatments provided) also vary according to each service provider. Among public sector hospitals, it was reported that the Garrahan Hospital was one of the most complete, although relatively more expensive, while Gutiérrez Hospital has no incentives to bill the services provided to patients with private coverage, since those revenues are transferred to the government of Buenos Aires City. In the words of one interviewee, *“Whether we bill the service or not makes no difference in terms of our cash account.”* As regards the private sector, there is a degree of consensus on the significant price differences among institutions, often associated with their diverse specialities, services, and structures.

The search and identification of donors for bone marrow transplants are funded through the Solidarity Fund for Transplants managed by INCUCAI. This involves processes linked to confirmatory typing tests performed both on patients and on donors, whose costs are subsequently billed to the pertinent funder. Once the donor has been identified, the authorization of the Obra Social or private insurance is requested, and they cover transplant costs.

The interviewees also voiced their opinion regarding the Single Reimbursement System (Sistema Unico de Reintegro, SUR) managed by the Superintendency of Health Services (SSS), which allows requests for reimbursement of the expense incurred by the purchase of oncological medicines, provided that the drugs are included in the official list of the pathologies covered.¹⁶ In this regard, they mentioned that reimbursements cover approximately 30 percent of the cost and that payments may be delayed for up to three years, thus significantly affecting their real value. In turn, payment requests require the fulfillment of several administrative and bureaucratic steps; the funders described this as an extra cost in terms of the man-hours spent by the funds management institutions. On her part, the interviewee from SUR said that reimbursements include only medication and do not cover treatments or care lines.

Besides the drug supply mechanisms and service provider billing systems, research of the public drug supply function found two complementary structures to submit the request to, if the province does not respond: the National Drug Bank¹⁷ (run by the Health Ministry) and the Directorate for Direct Assistance in Special Situations (Dirección de Asistencia Directa por Situaciones Especiales, DADSE), which reports to the Social Development Ministry.

The National Drug Bank manages a list of drugs that are purchased once a year through tenders, whether through internal funding sources (allotments assigned to the organization), or external sources (international loans). It receives requests from hospitals and/or provincial health ministries and bases its answers on the approved list of products, and is subject to stock availability. Rejections may be based on

¹⁶ In this regard, the interviewee stated that the official list is available in Annex IV of Resolution 465/2021 issued by the Superintendency of Health Services.

¹⁷ The Special Drugs Bank (Banco de Drogas Especiales, BDE) complements provincial governments in accessing medicines for patients with exclusively public coverage who have some type of cancer, acting in a complementary mechanism to equalizing health care standards across subnational levels, and thus achieve greater equity in access to cancer drugs throughout the national territory. In this framework, the BDE complements the provincial supply of medicines in about one hundred oncological pathologies. The BDE makes supply agreements with all provinces, where the strategy for access to oncological and special medicines is agreed upon. The BDE only provides medicines at the request of provincial health authorities, not by request of individual patients, which is the structure DADSE works through to grant subsidies for the purchase of those medicines. The requests made to the National Drug Bank include a set of forms and supporting documentation showing that the patient does not have private coverage. In addition, a copy of the medical history justifying the need for the drug has to be provided. The interviewee from this organization explained that although the procedures are strict, they usually contemplate each particular situation, and, if required, they allow additional time to submit the missing documents to avoid rejections.

two causes: lack of stock, or requests for drugs that are not included in the mentioned official list (pathologies excluded from coverage). Lack of stock or nonexistence of drugs are situations that happen frequently because the tendering processes exhibit some particularities.

The first is the lack of bidders, as some laboratories prefer not to participate in tenders due to payment delays. For this reason, drug companies participate in the tenders “*undertaking the financial cost, but selling at higher prices.*” Alternatively, the lack of supply can be attributed to producers’ lack of interest in the required medicines, as they may have been replaced by alternative or innovative therapies.

The second is that, as the Drug Bank operates a committee charged with established reference prices—criteria applied to all ministerial purchases—tenders exceeding the recommended amounts are reviewed through the price improvement request mechanism,¹⁸ requesting the committee to answer within the next two weeks. In any case, as regards prices, the interviewee stated that, overall, they purchase drugs in competitive as well as noncompetitive markets at 40 percent and 70 percent discounts, respectively, as compared with market prices.

Any drugs not supplied by the Drug Bank can be requested from DADSE. This organization assesses the clinical condition and vulnerability level of each case requiring the drugs, and based on its evaluation and price comparisons, carries out the purchase for each request.¹⁹ According to the interviewee, this procurement mechanism is used because the organization lacks the infrastructure and the authorization required to store drugs.

The interviewees from both organizations stated that, although these agencies presently report to different entities, they are often integrated or divided according to the perspective of each government administration. In this sense, the interviewee from DADSE emphasized that, as this organization reports to the Social Development Ministry, it can apply a more comprehensive approach to the vulnerabilities of oncopediatric patients, illustrating this by means of examples such as the identification of intra-family gender violence situations, the inclusion of unemployed parents in social programs, and the provision of housing subsidies to people living in extreme conditions. Although they said that dialogue mechanisms exist, they underlined that there is no articulation system to resolve requests, as these can be submitted to different entities: to hospitals/and or provincial organizations in the case of the Drug Bank, and through the patients’ relatives in the case of DADSE.

The absence of priority coverage lines was also discussed, taking into account that the responses of both organizations are demand-based, which prevents any future predictability. The interviewee from the National Drug Bank mentioned that recently, with the aim of predicting and organizing demand, they have entered into agreements with some provincial governments pursuant to which the latter will submit projections on the needs to be covered during the annual period.

As regards drug request processes for patients with public coverage, the interviewees said that no formal procedure has been established; therefore, the provinces must buy the drugs required for their population and, if they run out of stock, they must submit additional requests to the National Drug Bank. Subsequently, if the response is negative, they may appeal to DADSE. In practice, many jurisdictions do not undertake primary responsibility for this matter and address requests to the National Drug Bank or to DADSE, and buy only those items that have been rejected.

¹⁸ Through this mechanism, the organization can request the provider to improve the price offered. The interviewee from the National Drug Bank indicated that up to two price rebates can be requested from each bidder, who can choose to improve his offered price or not.

¹⁹ Resolution 2458/04.

The Gutiérrez Hospital emphasized that drug requests addressed to provincial banks usually go through highly bureaucratic processes and that even when every procedure has been fulfilled, no response is received. For this reason, treatments often make use of products from the hospital's own stock. Other interviewees said that this situation has given rise to drug loan and compensation mechanisms between hospitals at interprovincial and intra-provincial levels—which are not formally regulated and barely compliant with the traceability act.²⁰ This revealed that among medical professionals and among the pharmaceuticals of each hospital, there is an informal network that organizes oncological drug “clearing.”

Given the above scenario, one may observe that drug assignment is a critical element in the oncopediatric circuit. It is therefore pertinent to include some clarifications regarding the provinces' behavior. In the first place, the requests state the patient's legal domicile, which causes several problems because the declared domicile often does not coincide with the actual one. In the second place, the province where treatment is provided also influences the decision on drug supply, as the policy of many provincial banks is to provide drugs only to the patients treated within their jurisdiction. Also, the interviewee from the National Drug Bank said that some provinces frequently submit requests, while others—such as Mendoza, San Juan, La Pampa, Corrientes, Tierra del Fuego, and Santiago del Estero—do not make any requests at all because they cover local needs by means of external funding.

Lastly, as explained, many province administrations carry the maximization of their resources to the limit: *“The refusal to supply drugs often has to do with the provinces' level of slyness, not their level of poverty.”*

Finally, a subject discussed in all the interviews were the appeals for legal protection of constitutional rights (“writs of *amparo*”) and the role of the judiciary in medication coverage. As mentioned before, the public or private sector stakeholders involved in the drug supply function have mechanisms through which they can reject requests for prescribed drugs. The interviewees said that, faced with the rejection of their request, families often submit writs of *amparo*. In most such cases, the courts rule in favor of the patients and urge the funder and/or public organization to cover the medication required.

The National Drug Bank explained that this phenomenon happens because there are no priority coverage lines, and this affects both the access to medication by the patient and the financial performance of the organization. In the words of an interviewee, *“We end up buying at high prices and delivering late.”* For his part, an interviewee from a national social security health organization pointed out that there are many cases requiring high-cost medication, which are rejected by the medical audit, and patients end up submitting a writ of *amparo*. In his words: *“In Argentina there is a specialty called judicial medicine, where judges determine what is to be done without having any basis for their decision”*; he concluded that this is *“a lobby problem.”* Additionally, a voice from the private sector indicated that when they reject requests, medical audits must offer the patient an alternative. However, when such alternative does not exist, the request is resubmitted for “compassionate use,” and this usually ends up in court. In line with the above, a significant player from the public sector voiced his concern stating that *“due to the lack of a health plan, the judiciary ends up making decisions in matters that should be ruled by State policy.”*

2.1.6. Dialogue between the public and private sectors

Most interviews reflected a consensus on the fact that the public sector concentrates the largest number of oncopediatric patients. Voices from the Garrahan and Elizalde Hospitals stated that although oncopediatric services are costly due to the specialization level required, the oncopediatric specialty is not profitable in economic terms for private health clinics. One of the interviewees stated the following: *“The equation is not*

²⁰ Act 26906.

attractive because they have to invest a lot and maybe they receive one patient per year.... That is why they leave this area to the public sector." For their part, interviewees from the private sector recognized the specialization level developed in the public sector, although they pointed out that various private centers providing care for this patient segment have enhanced their performance.

In every case, positive opinions were voiced with respect to the service quality and expertise level of the Garrahan Hospital. Nevertheless, several interviewees mentioned that the high standards of this hospital affect the relations with other stakeholders and the network's performance. In particular, one interviewee said that referring patients to the Garrahan Hospital is no simple task, because *"they are selective as to which cases they accept."* In addition, an interviewee from a national social security health organization added that referring patients to the Garrahan Hospital is *"very expensive because they ask you to repeat studies made the week before."* In this respect, the interviewees from the Garrahan Hospital replied that at times the quality of the diagnostic tests performed in other hospitals is far from optimum, both due to the staff's lack of expertise and the condition of the equipment used; this makes it difficult to reach a diagnosis and causes delays, so sometimes the tests need to be run again.

A certain degree of rivalry was perceived between the Garrahan and Gutiérrez Hospitals as well as between GATLA and SAHOP. According to the interviewees, the latter organization is led by the Garrahan Hospital. In this respect, some interviewees said that *"some hospitals are friends with the Garrahan Hospital and others are friends with the Gutiérrez Hospital."* Interviewees from the Garrahan Hospital indicated that their hospital had proposed several times to Gutiérrez Hospital to develop joint training schemes for health professionals and emphasized that such proposals had always failed because of the latter's refusal. For their part, interviewees from Gutiérrez Hospital mentioned that the rivalry stems from the fact that Garrahan Hospital usually offers paid positions to the professionals trained by the Gutiérrez Hospital. *"They have the budget to hire staff, and... we lose the human resources we trained."*

The performance of the Garrahan Hospital was recognized by most interviewees, as was the fluid relationship between this hospital and the private sector. They mentioned that several professionals work both for the Garrahan Hospital and for institutions from another subsector. On the one hand, this fosters a process of continuous learning between establishments regardless of their ownership, but on the other, it enables covert behavior, which is common in other hospitals within the fragmented health system: the use of public institutions to subsidize service provision to patients lacking the exclusive coverage of the hospital. This situation is exacerbated by the lack of registration and billing capacity of many public hospitals in the country.

From the players' perspective, interactions between hospitals are characterized by the absence of protocol in referral and counter-referral mechanisms. Although there is an ad hoc network organizing the reception of referred patients, the high informality levels of these processes may limit the scope of the network, increase the responsibility of health workers, and heighten the patients' risk. In this sense, some cases reveal unnecessary referrals of patients, as well as self-referrals. It was also observed that at times, certain professionals decide to provide care at the local level despite the lack of necessary expertise.

2.2 Analysis of regional experiences

The results of the national stakeholder mapping yielded some relevant conclusions for a road map on the construction of an oncopediatric network in Argentina. This section is also intended to contribute information on the mechanisms used to manage this type of network in other countries of the region. To this end, interviews were held with officials working in this area in Chile, Colombia, Costa Rica, and Uruguay. These countries were selected because of their relatively similar indicators in terms of economic development, health expenditure, and epidemiological profiles, particularly with regard to oncopediatric diseases.

Subregional representations (Andean Region, South America, and the Caribbean) are also included in the study.

The following table displays a set of indicators of economic development, health spending, and epidemiological profile of the countries selected.

Table 4
Main Indicators on Economic Development, Health Expenditure, and Epidemiological Profile for Argentina, Chile, Colombia, Costa Rica, and Uruguay

Purchasing power parity (PPP)

Country	Economic indicators 2021		Health expenditure 2019		Noncommunicable Diseases (NCDs) 2019	Childhood cancer Estimation per 100,000 inhabitants Standardized rate by age in children aged under 19 based on world population	
	Per capita GDP (PPP)* (\$ at current international prices)	Current health expenditure ^e ** (% of GDP)	Current health expenditure (Health PPP)** (\$ at current international prices)	Public health expenditure participation** (% of current health expenditure)	Deaths caused by NCDs*** (% of total)	Incidence rate for 2020****	Mortality rate for 2020****
Argentina	\$23,627.40	9.51	\$2,198.88	62.36	76.69	13.3	3.9
Chile	\$29,104.10	9.33	\$2,424.15	50.92	85.13	14.2	3.1
Colombia	\$16,893.80	7.33	\$1,204.30	71.88	75.65	14.3	5.3
Costa Rica	\$23,387.10	7.27	\$1,636.18	72.54	81.99	16.7	3.6
Uruguay	\$24,625.50	9.35	\$2,309.84	66.60	85.51	15.8	2.4

Source: Authors, based on information from the World Bank and WHO.

Notes: GDP = Gross domestic product; PPP = Purchasing power parity.

*World Bank, 2022, ** World Bank, 2022, ***WHO, 2022, ****WHO, 2022.

In terms of economic development, it is observed that, according to 2021 indicators, these countries exhibit incomes with similar wealth levels, with an average per capita GDP of \$23,528 and extremes in Colombia (\$16,894) and Chile (\$29,104). In 2019, health expenditure (purchasing power parity, PPP) amounted to \$1,954.67 per capita, and public expenditure participation totaled approximately 60 percent and 70 percent in Argentina, Uruguay, Colombia and Costa Rica, except for Chile (51 percent).

Noncommunicable diseases caused approximately 80 percent of the deaths recorded in 2019 in the countries under analysis. With respect to childhood cancer, the cancer incidence rate in children under 19 averaged 14.86 cases per year per 100,000 children. Argentina has the lowest index (13.3), while Costa

Rica reports the highest rate (16.7). With regard to the mortality rate for oncopediatric patients, the death estimates per 100,000 children for 2020 shows that Uruguay has the lowest rate (2.4 deaths per 100,000 children) and Colombia the highest (5.3 deaths).

Chile reports approximately 500 new oncopediatric patient cases every year,²¹ 85 percent of whom receive health services from the public system and 15 percent from health care providers financed by private health insurance institutions known as ISAPREs (Instituciones de Salud Previsional), entities with characteristics similar to prepaid health insurance companies in Argentina.

Health services supply is organized under the National Program for Antineoplastic Drugs for Children (Programa Infantil Nacional de Drogas Antineoplásicas, PINDA),²² which classifies the country's health care centers into three types: integral, partial, and supporting facilities. Each of these institutions has a protocol indicating which patients they can treat and which must be referred to a higher complexity center. There are 11 integral treatment centers, six of which are located in Santiago de Chile. The interviewee from the Explicit Guarantees Program said that, although their resolution capacity is the same, this group includes an integral center specialized in some specific pathologies,²³ which receives a large number of referred patients (20 percent of oncopediatric patients). For their part, given their territorial distribution, "Partial PINDA" and "Support PINDA" centers help to expand network coverage. They promote early diagnosis, maintenance of the treatments under way, and chemotherapy application, and also provide palliative care. However, it was pointed out that up to now it has not been possible to establish the supply of services in every region of the country.

When describing the network, the interviewee said: *"I believe we are converging toward a specialized network where one single center provides health services for extremely complex pathologies, three or four centers deal with more common pathologies, and the rest provide intermediate services."* As regards patient treatment definition and protocol use, the network is provided with two structures: oncological committees and protocol committees. The former work jointly with referral centers and high-complexity centers, allowing the exchange of information on patient treatment among the professionals. Protocol committees meet every month by tumor type with the support of academics and the Chilean Pediatric Society (Sociedad Chilena de Pediatría, SOCHIPE) and, on this basis, they develop protocol guidelines. It was also mentioned that each case registered is followed up by means of the bio-psychosocial protocol, which establishes the actions to be taken during the first 10 years after diagnosis for patients up to 25 years of age.²⁴

As regards the coverage of transport and accommodation costs of patients requiring referral, the interviewee stated that there are accommodation centers that receive public funds, but that those costs are mainly covered by private organizations. No coverage mechanisms were mentioned for the transport and accommodation costs of the patients' relatives. As regards patient accompaniment, the same interviewee said that the SANNA Act²⁵ has established leave permits for the parents of children in serious health conditions.

²¹ According to the interviewee, the law considers that pediatric patients are persons up to 15 years of age.

²² This institution was created in 1988, together with the National Program for Antineoplastic Drugs for Adults (PANDA). Both promote chemotherapy-related funding for cancer patients.

²³ Such as patients with osteosarcoma requiring surgery or specific chemotherapy, patients with retinoblastoma requiring treatment for ocular preservation, and patients requiring bone marrow transplant, among others.

²⁴ When they turn 18, pediatric patients in the follow-up process are referred to PANDA hospitals, which deal with the adult population.

²⁵ Act No. 21063, Article 7.

The scarcity of human resources was identified as the country's main problem in the oncopediatric area. Although teaching hospitals have been established and agreements with universities have been subscribed, there is a shortage of hematology and oncology services, which led to the decision to include pediatricians in the network. In the words of the interviewee, "*We are 45 hemato-oncologist professionals working in the whole country.*" This results in professionals working in both the public and private sectors, which leads to a convergence in the use of protocols and to the consolidation of a mixed network.

The PINDA program and the General Regime for Explicit Health Guarantees (Régimen General de Garantías Explícitas en Salud) guarantee the oncological coverage (access, treatment, and follow-up) of both pediatric patients who are members of the National Health Fund (FONASA, Fondo Nacional de Salud)²⁶ and those covered by ISAPREs. Health services are provided based on coverage type, leading to little or no private-public interaction. Public hospital funding is based on the fulfillment of patient treatment units, such as diagnosis, treatment, and/or palliative care. The centers have a certain deadline to confirm, for example, patient diagnosis, after which they receive funding transfers. This system promotes early detection, a crucial process in pediatric patients with oncological pathologies.

Colombia reports approximately 1,700 new oncopediatric patient cases every year. Given the characteristics of the Colombian health system,²⁷ the persons interviewed stated that the oncopediatric network "*is mixed,*" alluding to the presence of both the social insurance scheme (involving public health service providers and institutions managing social funds (Entidad Promotora de Salud, EPS) and the private sector (which participates in both the fund management and service provision areas).

The Health Service Providers (EPS) distributed across the national territory provide coverage to the citizens and contract the necessary medical services based on the number of members and the characteristics of this population. Service supply is divided into three large groups: Health Service Institutions (Instituto Prestador de Salud, IPS), which supply the services they are authorized to provide;²⁸ Functional Units for Childhood Cancer (Unidades de Atención de Cáncer Infantil, UACAI); and high-complexity hospitals specialized in oncopediatrics,²⁹ which are located in large cities.

Once the diagnosis is confirmed, the patient starts to be treated in his/her city of origin, or is referred to a center included in the list of institutions under contract with the corresponding EPS that provides the services required. In this regard, the interviewees from the Health Ministry affirmed that about 35 Health Service Institutions (IPS) at national level could become oncopediatric care centers, but not all of them have yet been authorized to provide such services.

Although there are several Functional Units for Childhood Cancer (UACAI), as the supply of oncological services is structured on the basis of demand, "*those units require large investments and due to low incidence of childhood cancer, it is not profitable to create them.*"

²⁶ FONASA, created by Decree-Act No. 2763, is the agency in charge of resource administration and health funding in Chile, and operates as social health insurance for the population with formal employment and contributions, as well as for their dependents.

²⁷ This system is funded through two mechanisms: a contributive regime and a subsidized scheme. The former covers the contributing population based on their employment status—approximately 50 percent of the total population—while the second absorbs the unemployed population. According to the interviewees, most Health Promotion Organizations (Entidades Promotoras de Salud, EPS) are private, but there are also some public Health Service Institutions (Instituciones Prestadoras de Servicios de Salud, IPS). These organizations manage the population's contributions.

²⁸ Primary health care is organized on the basis of the services provided, which require prior authorization.

²⁹ The Health Ministry indicated that such hospitals are located in Bogotá, Cali, Medellín, Bucaramanga, Barranquilla, and Cartagena. The performance of Hospital de la Misericordia in Bogotá and of the National Cancerology Institute was highlighted.

Patients referred to other cities must pay their transport and accommodation costs. One person interviewed indicated that this is a problem for the population belonging to the subsidized regime (with medium- and low-income levels), as they usually lack the resources required to meet such expenses. It was also mentioned that some foundations and/or private institutions make donations to pay for the temporary accommodation of the families.

The health insurers' (EPS) risk management is evaluated by the Health Ministry based on indicators reflecting their performance.³⁰ In this respect, the interviews reflect that in the last years “*at least 10 insurers*” were closed down because of their performance, and the patients were transferred to other EPSs, which, to a certain extent, affected the continuity of their treatment. Although it was stressed that everybody can freely choose their EPS, these migration processes are generally organized according to membership size a

nd the capabilities of the current insurers. In this respect, the interviewee added: “*This has been a critical issue for our country.*”

Once the services are provided and the medication is administered, the medical audit unit of each EPS evaluates the services provided by the Health Service Institution (IPS) and makes the pertinent payment. In situations requiring high-cost drugs that exceed the prepaid premium, the patient is treated and billing is then performed on an ex-post mechanism. In this case, the insurer (EPS), based on a prior evaluation by the medical audit unit, reports the expenditure to the Health Ministry and to the Administration of the Resources of the General Social Security Health System (Administradora de los Recursos del Sistema General de Seguridad Social en Salud, ADRES). As to drug procurement, there is no mechanism providing for joint purchasing. For this reason, each EPS purchases the products based on its patients' needs. In the opinion of the persons interviewed, this does not cause any delays in patients' care: “*We have worked hard to ensure minimum diagnosis and treatment initiation times in the oncopediatric area.*”

In contrast with the other cases documented, **Costa Rica** has an integrated health system that is based on a public health network funded through subsidies to the supply, and is organized into three care levels: The first level of care addresses prevention and early detection, the second level performs clinical diagnoses, and the third level carries out the treatment. There are 29 hospitals, classified into general hospitals (9), regional hospitals (7), and peripheral hospitals (13). In this regard, the interviewee from the Costa Rican Social Security Fund (Caja Costarricense de Seguro Social, CCSS)³¹ stated that the National Children's Hospital (Hospital Nacional de Niños, a general hospital), located in San José, the capital city, is the only center treating malignant diseases in pediatric patients. Therefore, if there are oncological signs, patients are immediately referred to this institution. The interviewee also stated that it was impossible to carry out early detection campaigns in the first care level, due to the diversity and low incidence of oncopediatric tumors. In the interviewee's words: “*It makes no sense to carry out such campaigns.... Moreover, they are not profitable (Note: cost-effective).*”

Given the characteristics of the network, a mechanism covering patient transfers was developed allowing the families to use this service free of charge. The interviewee also said that the patients' families pay accommodation costs.

³⁰ Some examples mentioned were the following: number of days required to confirm the diagnosis in cases showing oncological signs, and number of days required to start treatment once the diagnosis has been confirmed.

³¹ The CCSS is the only social security institution in Costa Rica and it manages the financial, human, and infrastructure resources run by the state.

Among the main challenges hindering the network's operation, the interviewee identified communication failures between care levels that affect treatment initiation: *"It is urgent to streamline communications between first care levels and the National Children's Hospital."* He also explained that once a case arrives at the hospital, the required care is efficiently provided through the work of multidisciplinary teams.

He identified the shortage of human resources as another challenge. Also, oncopediatric health services are provided by only one center in the country, which often causes situations where the services are overstretched, affecting service quality. For this reason, the operation of the network has been evaluated and alternative schemes aimed at strengthening the Basic Teams for Integral Health Services (Equipos Básicos de Atención Integral en Salud, EBAIS) have been considered, to *"improve oncological assistance operations."*

In Costa Rica, the main institution delivering health services and the main drug purchaser is the Costa Rican Social Security Fund. It is funded by employer and worker contributions and also receives financial support from the state, and is responsible for purchasing drugs to guarantee supply for the majority of the population. The interviewee mentioned that the procurement process for oncological and other drugs is governed by the Regulations on the Procurement of Drugs, Raw Materials, Containers, and Reagents (Reglamento para Compras de Medicamentos, Materias Primas, Envases y Reactivos).³² If the drugs required are not included in the Regulations, an evaluation is performed to determine whether the request is to be approved. The interviewee said that tendering processes are launched with the participation of the companies included in the Health Ministry's suppliers register and that the decision to purchase is made on the basis of the prices offered.

Uruguay's National Integrated Health System³³ provides universal coverage to the whole population through public service providers managed through the State Health Services Administration (Administración de los Servicios de Salud del Estado, ASSE) and social security health organizations ("mutuales"). The system as a whole directs the management of high-cost services to the National Resource Fund (Fondo Nacional de Recursos, FNR), a public institution that subscribes contracts with service providers throughout the country. As regards oncopediatrics, the focal points of this institution emphasized the performance of the Pediatric Hemato-Oncology service, a unit of the Pereira Rossel Hospital, and described it as one of the centers with the highest complexity levels in Uruguay. They also pointed to the quality of the health care provided by public service providers: *"In the last few years, ASSE has come much closer to the level of private providers."*

The Integral Healthcare Plan (Plan Integral de Atención en Salud, PIAS), regulated by the Public Health Ministry, establishes the health services and drugs to be supplied by the service providers and identifies the high-cost drugs to be covered by the National Resource Fund.³⁴ Thus, low-cost drugs, treatments, radiotherapies, and medical services are provided by each managing institution, which are funded through a health contribution composed by capitation and a target contribution (to be accredited only if the provider achieves the target) established by the Health Ministry.

The National Resource Fund receives 80 percent of the transfers made by the National Health Fund (FONASA),³⁵ transfers from private service providers serving persons without FONASA coverage, and

³² Regulations No. 6914.

³³ Act No. 18211.

³⁴ The National Resource Fund must cover all patients, regardless of the provider that delivers the service (public or private sector).

³⁵ Act No. 18131 established FONASA as the state body responsible to fund health care service coverage in Uruguay.

other transfers made directly from the Ministry of Economy for ASSE users who lack any formal coverage.³⁶ The remaining percentage comes from taxes such as gambling tax, food labeling, the fight against drug trafficking, etc. The fund negotiates drug prices with the laboratories according to annual estimates based on the number of oncopediatric cases and tumor prevalence. One interviewee stated that there are different types of agreements with the laboratories: based on volume, shared risk, flat rate, and adhesion, among others. She also added that these mechanisms *“have allowed the Fund to incorporate technologies with the same money.”*

As regards procedures, the service provider submits a drug request to the fund, which is discussed in a grand round acting as a medical audit, where a group of professionals and specialists in the pathology evaluate the case. Writs of amparo are a common strategy among the cases rejected by the fund. *“In general, the judiciary requires that the medication be provided even in the case of drugs not included in the vademecum.”* For authorized cases, the purchase is made and the product is then delivered to the pertinent service provider. Drug purchases are made on a monthly basis, so professionals are required to update drug requests from one month to the other. This in turn allows to for midterm evaluations to observe advances in the treatment received by the patient.

The above interviews provide an overview of oncopediatric services in the countries considered. Table 5 summarizes the main findings. In the first place, it is important to note that referral processes are structured around the relations between professionals, the characteristics of the health care system, or the available supply, depending on each individual case. Only Chile has protocols that regulate referral processes on the basis of each service provider’s resolution capability. The same is observed in the use of clinical protocols.

Oncological drug procurement mechanisms are diverse, although Costa Rica and Uruguay display models that have allowed them to establish joint procurement systems that, according to the interviewees, allow for a more efficient use of resources.

³⁶ The Ministry of Economy transfers the cost generated by each patient. This is not a fixed monthly contribution but an ex post payment.

Table 5
Comparative Country Analyses

Country	Referral process	Funding	Procurement mechanism	Use of protocols	Coverage of family transport and accommodation
Argentina	Based on informal relations and on the availability of each receiving center	Mixed	Variable (depending on service provider)	Heterogeneous. Based on the professional's decision, on SAHOP recommendations, on the provincial committee's decision	Transport: Yes, guaranteed by the service provider and/or the provincial government Accommodation: Heterogeneous, depending on the patient's province of origin and on the presence of a social structure in the receiving hospital.
Chile	Based on strict protocols	Mixed	No data	Regulated by public committees	Transport: Not mentioned Accommodation: Mainly funded by private organizations
Colombia	Based on contracts managed by each EPS	Mixed	Each EPS makes its own purchases	Defined by the service provider based on the Clinical Practice Guidelines established by the Health Ministry	Transport: No Accommodation: Mainly funded by private organizations
Costa Rica	All cases are referred to a single center	Mixed	Joint procurement (CCSS) through tendering processes	Supervised in Multidisciplinary Sessions of the National Children's Hospital, where the therapy is decided	Transport: es, guaranteed by the National Oncological Network Accommodation: No; families' out-of-pocket expenses
Uruguay	Managed by FNR	Mixed	Joint Procurement (FNR) through agreements with laboratories	Defined by FNR	No data

Source: Authors, based on interviews.

Notes: SAHOP = Argentine Society of Pediatric Hemato-Oncology; EPS = Health Service Providers (Colombia); CCSS = Costa Rican Social Security Fund; FNR = National Resource Fund (Uruguay).

In every country, some patients have to be treated in hospitals located far from their city of origin. Thus, it is surprising that in most countries both transport and family accommodation costs are funded by private organizations or considered out-of-pocket expenses. In Costa Rica, the National Oncological Network guarantees patient transport coverage, and only Argentina provides partial public coverage of both services. As a factor to keep in mind, with the exception of Colombia, the health systems considered that provide for an oncopediatric strategy are centralized in nature, which facilitates resource management and central decision making. Mechanisms operating in decentralized and fragmented settings such as in Argentina increase coordination challenges.

2.3. Provincial experiences: The Cases of Chaco and Corrientes

The national stakeholder mapping performed in this study has shown that operation of the oncopediatric service supply in Argentina displays some particular features, with clear differences between jurisdictions and in its relationship with the Buenos Aires metropolitan region. For this reason, the study included an analysis of two provinces to highlight some of these particularities when planning a network strategy and its counterparts at local levels. This section presents the stakeholder mapping performed at provincial level, the methodology applied and the main lines that guided the interviews, and then analyzes the findings and combines them with the information provided by ROHA for each province.

Most of the interviews were face-to-face and were guided by a semi-structured questionnaire comprising four lines: patient identification, care, and treatment path; role of the private sector; funding; and network operation. With the interviewee's consent, the working team recorded or took notes of each interview. The information on the stakeholders interviewed was broken down by sector and organization and is detailed in the methodology section of this document.

2.3.1. Chaco

Pediatric Hospital Dr. Avelino L. Castelán, located in Resistencia, is the only center in the province providing oncopediatric health services. For this reason, all cases presenting oncological symptoms or signs, regardless of their coverage type, are referred to this hospital, where the diagnosis is confirmed and treatment provided. In the interviews with the stakeholders from this hospital, it was reported that approximately 50 new oncopediatric cases are identified every year, and that the cases can be divided into three major groups according to coverage type: patients with exclusive public coverage, patients covered by health organizations, and patients covered by the Incluir Salud Program.³⁷

The Pediatric Hospital coordinates actions with the Julio C. Perrando Hospital³⁸ on a daily basis, since the latter hospital offers pathological anatomy services and thus can address high-complexity situations despite the lack of specialized human resources. The interviewees reported that when treatment is needed, patients with public coverage are referred to the Garrahan Hospital in the first place, and alternatively, to Gutiérrez, Posadas, or Elizalde hospitals.³⁹ Patients covered by a health organization are referred to the public or private center with which the funder has an agreement.

Professionals usually refer the patients to the Garrahan Hospital, not only because of its medical service quality but also because of the professional relations built between the players.⁴⁰ The interviewees said: *“As we studied there, it is very easy for us to refer the patients... We know all the professionals.”* Other factors that reinforce the bias toward the Garrahan Hospital were also mentioned: its specialization in central nervous system (CNS) tumors; the high levels of informality of other hospitals when making referrals; its geographical location; its proximity to the hotel where families lodge; and its patient counter-referral mechanisms. The last point came up in all the interviews, where it was indicated that the Garrahan Hospital has a tradition of *“returning”* the patients, allowing them to continue their treatment in their provinces. By contrast, it was mentioned that other centers decide to continue providing treatment even

³⁷ These are patients whose relatives apply for the disability certificate when the oncological diagnosis is defined. This is done to access pension benefits, and such patients are automatically included in the mentioned program.

³⁸ According to the interviewees, the Julio C. Perrando and Garrahan Hospitals signed an agreement that improved the delivery times of such requests, thus accelerating patient treatment.

³⁹ The interviewees did not mention whether any formal agreements exist between those institutions.

⁴⁰ The Garrahan Hospital's grand rounds were underlined as an important factor when deciding to make a referral.

when the high-complexity clinical procedures that caused the referral have been completed, thus forcing the families to remain in Buenos Aires for lengthy periods.

“The best option always is to undergo treatment in your province, close to your family.... The idea is to refer those patients that we really cannot treat.”

As noted, the worst shortcoming of the A. L. Castelán Pediatric Hospital was the neurosurgery department, as none of the three neurosurgeons working there is a pediatrician. Due to low tumor incidence and scarce expertise on the part of the professionals, the department's performance is unsatisfactory and is a major reason for referrals.

In Resistencia there are private health facilities providing pediatric services, such as Sanatorio Güemes, Femechaco, and Antártida, but when these centers identify oncological cases, they immediately refer them to the A. L. Castelán Pediatric Hospital.

Requests for medication⁴¹ are submitted to social security health organizations following a standard procedure⁴² that includes the treatment protocol justifying the number of doses requested. This helps to avoid delays in the auditing processes usually performed by social security health organizations. Most patients with health coverage belong to the Institute for Social Security, Insurance and Loans (Instituto de Seguridad Social, Seguros y Préstamos, INSSSEP).⁴³ This organization stated that the hospital regularly submits bills for the services provided, which are paid to the Public Health Ministry of the province.⁴⁴ Drug requests for pediatric patients are submitted on the same day as the request, as all the requirements have been centralized.

In contrast, the interviewees from the hospital mentioned some difficulties in accessing drug and supplies reimbursements when the patient is a beneficiary of the Incluir Salud Program,⁴⁵ which entails losing time in fruitless administrative procedures.

As regards agreements with the private sector, the interviewees from INSSSEP stated they have signed agreements with Garrahan Hospital, the Italian Hospital, Sanatorio Güemes, and the Austral University Hospital, thus streamlining the referral process. At times, when children have been diagnosed at the local level, the families travel to Buenos Aires at their own expense and turn up at Garrahan Hospital for treatment, and are later counter-referredcounter-referred.

As to treatment costs, the interviews confirmed that all institutions have their own directories, which vary greatly: *“Hospital X charges at least three or four times more than Garrahan Hospital.”* Also, some services are included in the directory and others are not, resulting in different billing procedures. Excluded services are usually billed on the basis of the US dollar value.

The provincial Drug Bank reports to the Public Health Ministry and is physically located in the Julio C. Perrando Hospital. Drugs and supplies are procured through public tenders (usually three per year) organized by the ministry, which requires public hospitals to submit product requests every four months.

41 The hospital provides the documentation, but the patient's relatives submit the request to the social security health organization.

42 This includes a series of documents such as medical history summary, photocopy of the diagnosis and pathological report, and the specific request for drugs to provide treatment for a certain period, which is usually one month.

43 Chaco's social security health organization.

44 This procedure is required because the agreement between INSSSEP and the public sector is framed under the umbrella of the Public Health Ministry of the province.

45 Although the hospital's professionals usually recommend that patients who have accessed the pension formally waive coverage of the mentioned program to avoid such complications, the families do not follow this advice because they are afraid of losing the economic benefit (noncontributive pension).

The interviewees stated that drug delivery takes place after the completion of such processes and underlined that there are frequent delays, although no mention was made of the number of days.

In 2016, due to changes in the political administration, a series of modifications were made to the drug supply procedures. Although the Provincial Drug Bank historically served the Pediatric Hospital, in 2016 they started to submit supplementary requests to the National Drug Bank, so they had two different entities to approach. One interviewee emphasized that although drug requests were fulfilled with average delays of one to three months, placing requests in two institutions allowed them to stock up on some products. These mechanisms were used until 2020, when the former procedure was reinstated.

The interviewees from the Pediatric Hospital mentioned that they often reject the products offered by suppliers because of their prices.⁴⁶ In the words of one interviewee, *“On occasions, an implantable catheter worth \$30,000 is offered at \$150,000,”* although not all suppliers have that capacity. All suppliers need to be authorized to operate, as required by the Court of Auditors (Tribunal de Cuentas). The interviewee also said that INSSSEP’s expenditures are evaluated by the Court of Auditors, not by a medical professional, and that the court does not necessarily have accurate information on the products’ real prices.

Finally, as regards the operation of the oncopediatric network, there is a consolidated structure mainly supported by the relationship established among the provincial Health Ministry, public services, and INSSSEP. The interviewees underlined the fluid interaction among those organizations, which allows them to apply the approach they deem adequate in urgent cases.

Institutions such as the Ministry of Education and the social area of the provincial government also make a positive contribution to the network. One of the interviewees pointed out that the Ministry of Education’s intervention aims at ensuring the education of school-age patients by managing exclusive spaces within the hospital, where classes take place every day. The social area of the province guarantees accommodation for the families of patients residing far from Resistencia. These aspects are supplemented by the foundations working in the hospital to provide assistance and emotional support both to the patients and their families.

In federal terms, no consolidation was observed in the relationship with other provinces. When asked about exchanges with neighboring provinces, the interviewees from L. N. Castelán Hospital stated that no patient exchanges take place due to the lack of agreements on service price regulation.

2.3.2. Corrientes

The Juan Pablo II Pediatric Hospital in the city of Corrientes is the only center in the province providing oncopediatric services. Therefore, any case showing oncological signs identified in the interior of the province is referred to this hospital. One of the interviewees from this hospital indicated that the service was reinstated approximately two years ago and that *“for four or five years, we basically referred all patients with oncological diagnoses to the Garrahan Hospital.”*

The hospital receives patients with public coverage, patients covered by social security health organizations, and patients from PAMI. The hospital bills the services provided to each funder and requests oncological drugs, a process requiring at least three or four weeks.

⁴⁶ In the case of patients with private coverage, the request for medical supplies is submitted directly to each health organization. The latter sends a purchase order to the supplier. Then, a medical supply authorization is provided to the patients detailing the products and prices offered by the supplier. The patients must have the procedure authorized by the hospital, so the professionals check the prices offered and have the option of accepting or rejecting the medical supply authorization.

The cases that cannot be treated locally due to lack of expertise on tumor specificity, inadequate technology, or when a surgical procedure is needed, are usually referred⁴⁷ to the Garrahan Hospital, to the Gutiérrez Hospital, and to the Clínicas Hospital.⁴⁸ In this regard, the interviewees from the Juan Pablo II Hospital said: *"We were trained at the Garrahan, so it is our foremost reference hospital."* With respect to patient returns, they reported that the service providers decide when to make a counter-referral, although usually each case is followed jointly.

Most of the interviewees indicated that medical professionals provide services in the public and private sectors simultaneously: *"You should take into account that, besides working at the Juan Pablo II Hospital, we see patients in our own offices.... Our salaries are very low."* Due to the low salaries offered by the province, many professionals migrate to other jurisdictions.

A problem in the access to radiotherapy services was also reported. One interviewee from the Juan Pablo II Pediatric Hospital reported that despite the existence of private centers providing these services,⁴⁹ they usually have to refer patients to the Garrahan Hospital, and added that *"most of the times, the patients are irradiated too late."* This situation is explained by the high cost of the practice, which normally has to be authorized by the funder.

As to social security, the Health Organization for Business Workers and Civil Activity Personnel (OSECAC) has a health facility in the city of Corrientes that receives patients from the whole province. The interviewee from OSECAC said that when they receive high-complexity cases, they usually refer them to the Juan Pablo II Hospital. In addition, depending on the particularities of each case, they may decide to refer them to other provinces, such as Santa Fe, Córdoba, or Buenos Aires.⁵⁰

The health facility Clínica del Niño, in the city of Corrientes, and the Anna Rocca de Bonatti Oncology Center,⁵¹ located in Curuzú Cuatiá, complete the roster of private health service providers in the province. The former treats benign tumors and the latter provides services to adults. In both cases, oncopediatric patients are referred to the Juan Pablo II Hospital or directly to hospitals located in the province of Buenos Aires. The interviewee from the Anna Rocca de Bonatti Oncology Center said that *"to be able to treat oncopediatric patients, we would have to make a significant investment and we would use it very little.... If we put together all the pediatric patients identified in the south of the province, we would have at most 10 cases per year."*

The social security health organizations with the highest number of patients in the province are the Social Security Institute of Corrientes (Instituto de Obra Social de la Provincia de Corrientes, losCor) and PAMI. The interviewees from the Juan Pablo II Hospital reported serious difficulties in recovering the cost of the treatments and drugs provided to patients with PAMI coverage.

As regards agreements with the private sector, interviewees from losCor said that the institute has signed an agreement with the Garrahan Hospital and that most patients are referred to that hospital.⁵² They also

⁴⁷ Patients under one year of age are considered high-risk patients and are therefore referred.

⁴⁸ Adolescent patients are referred to the Clínicas Hospital. The interviewees did not know whether any agreements exist with the mentioned public health service providers.

⁴⁹ The province's private centers use a protocol that allows them to irradiate patients aged seven and over.

⁵⁰ OSECAC operates a health facility in Buenos Aires City (Sanatorio Sagrado Corazón), to which they refer most of their oncopediatric cases.

⁵¹ This establishment was donated by the Ana y Elena Rocca de Bonatti Foundation, owned by Techint group, and is characterized by its public-private status, as it is managed by the foundation, and the medical professionals' salaries are paid by the government of the province.

⁵² They have no agreements with private institutions.

underlined the existence of counter-referral mechanisms normally used by that hospital that allow patients to return to their province. As regards drug procurement, the interviewees from losCor pointed out that the institute does not have its own drug bank; instead, it outsources pharmacy services to a pharmaceutical company.

The province has a drug bank reporting to the provincial Health Ministry and operating from the Vidal Hospital. Purchases are made on a monthly basis at the expense of the ministry, based on projections submitted by the Vidal Hospital and by means of price surveys. The Juan Pablo II Hospital does not have a stock of oncological drugs. Each family submits the request for drugs to the province drug bank, which responds within two days for making the delivery. Most of the interviewees stated that in case of high-cost drugs, the Provincial Drug Bank sends the requests to the National Drug Bank: *“Apparently, the budget here is insufficient.”*

An interviewee from losCor indicated that their resources are insufficient to cover high-cost drugs. They therefore decided to transfer consultation costs to the patients by charging a fee. In the interviewee’s words: *“We had to opt and we decided that the patient should pay the cost of the diagnosis.... This way, they make a copayment for the consultations and after the diagnosis is confirmed, losCor covers the cost of the treatment.”*

The Juan Pablo II Hospital acknowledges that communications with the jurisdictions in the interior of the province are scarce, sometimes leading to late diagnoses of oncological patients and affecting the performance of local oncopediatric services. Although informative sessions have been held in various localities of the interior to raise awareness about early diagnosis, the precariousness of the intra-provincial network is undeniable: *“The way we structure the provincial network is by providing our telephone number.”*

The hospital runs an in-hospital school that usually assists the patients by providing both educational services in the hospital itself and home teaching in specific cases. Its social service area assists the patients that are referred between provinces.

Finally, interactions with the neighboring provinces are very limited; as mentioned, no referrals are made to Resistencia, nor does it receive cases from that city.

2.3.3. Comparative analysis and oncopediatric indicators

Based on the interviews, certain similarities and differences have been identified in the management of the oncopediatric sector of both provinces. The following table presents a comparison of the main findings.

Table 6
Comparative Analysis—Chaco and Corrientes

Item	Chaco	Corrientes
Network head of network	Dr. A. L. Castelán Pediatric Hospital	Juan Pablo II Pediatric Hospital
Existence of own drug bank	Yes, operating within the J. C. Ferrando Hospital	Yes, operating within the Vidal Hospital
Role of the private sector	X	OSECAC (treatment and referral management)
Oncopediatric care institutions in inner cities	X	X
Referral institutions	Garrahan Hospital; Gutiérrez Hospital; Posadas Hospital; Elizalde Hospital	Garrahan Hospital; Gutiérrez Hospital; Clínicas Hospital (adolescents)
Coverage of accommodation and intra/inter-provincial transport	Yes; public centers for relatives in the province + coverage of transport and accommodation costs	Coverage of transport and accommodation costs only between provinces
Articulation between stakeholders	Yes, between provincial social security health organizations and the public sector. No articulation with other provinces observed	X

Source: Authors, based on interviews.

Note: OSECAC = Health Maintenance Organization for Business Workers and Civil-Activity Personnel.

In both provinces, public pediatric hospitals absorb the demand for oncological services. Although both provinces have drug banks, the A. L. Castelán Pediatric Hospital operates a hospital supplies department, which allows it to manage its own stock of oncological drugs, while the Juan Pablo II Pediatric Hospital resorts to the supply provided by the Vidal Hospital. With regard to the private sector, OSECAC has a clinic in Corrientes that treats and/or refers oncopediatric patients as required. In Chaco, the remaining supply does not play a significant role in this specialty.

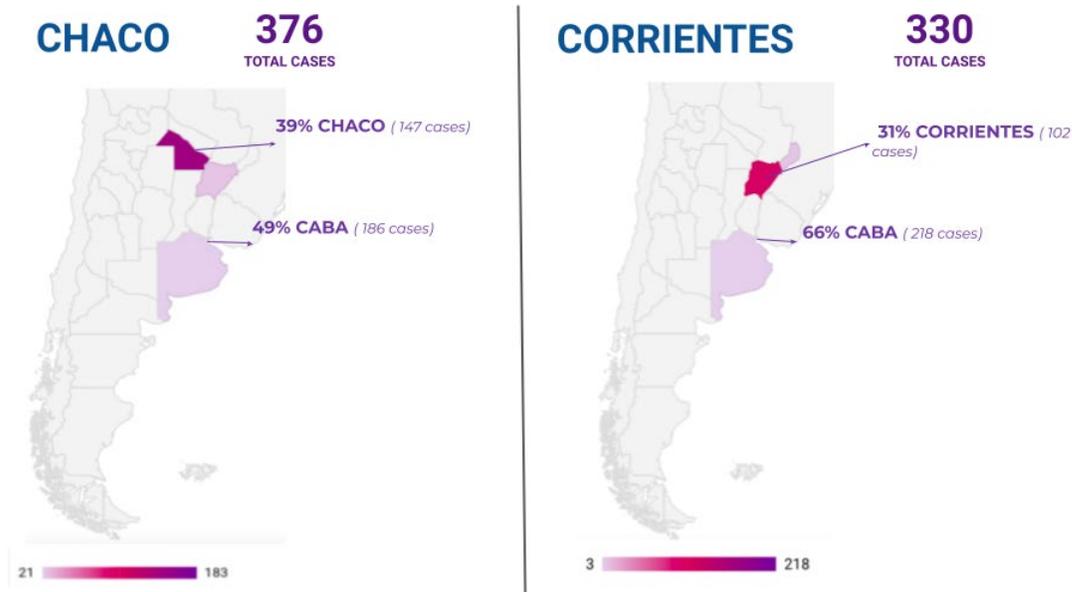
As regards protocols, the interviewees from both provinces mentioned that they base their actions on the recommendations of the Argentine Society of Pediatric Hemato-Oncology (SAHOP) and underscored the contributions from the Argentine Group for Acute Leukemia Treatment (GATLA). The province of Corrientes also operates a tumor committee, which controls the oncological protocols used in the province.

The reference center for referrals from high-complexity public hospitals is the Garrahan Hospital for both provinces. The relationships established among the professionals strengthen the network. However, no articulation was observed between the provinces; rather, they engage in bilateral contacts with the mentioned hospital. Also, a higher level of articulation is observed between INSSSEP and the A. L. Castelán Pediatric Hospital in Chaco, than between their peers in Corrientes.

As regards ROHA indicators, the number of cases recorded in both provinces during the period 2000–2019 (834 in Chaco and 820 in Corrientes) was similar, as was the prevalence by pathology type, with leukemia as the most frequent pathology (36 percent and 42 percent, respectively).

The following figure depicts patient health care migration by province of origin (Chaco and Corrientes) and by province of destination for the period 2012–2019.

Figure 3
Patient Health Care Migration by Province of Origin, 2012–2019 (Segment Aged 0–14)



Source: Authors, based on ROHA publication (2021).

The indicators show that both provinces have managed to absorb similar percentages of referred cases within their own territory (39 percent and 31 percent, respectively). In the case of Chaco, 61 percent of the cases reported during the period were referred to Buenos Aires (Buenos Aires city absorbed 49 percent and the province of Buenos Aires 5 percent) and Corrientes (7 percent). This last information coincides with the data provided by the interviewees from the A. L. Castelán Pediatric Hospital, who pointed out that referrals to Corrientes are infrequent due to high service costs. In Corrientes, the cases referred during the period under study represent 69 percent of the total. This agrees with the testimony of one of the pediatricians interviewed in Juan Pablo II Hospital, who reported that the services provided by the hospital were suspended for a long period due to problems in the hospital building. Referrals were made to Buenos Aires (Buenos Aires city absorbed 66 percent and the province of Buenos Aires, 1 percent) and to Misiones (2 percent).

The evidence obtained from these case studies indicates that in both Chaco and Corrientes, the articulation with high-complexity centers located in Buenos Aires and with the central organizations in the network is fluid, although difficulties are observed in the dialogue between the provinces. The lack of collaboration agreements has negative effects on the performance of the network at interprovincial level, which affects both the patients—who are generally transferred to Buenos Aires—and their families. Considering the proximity between both jurisdictions and the complementarity of the oncopediatric services provided in each case, the development of agreements could be mutually beneficial and would represent an experience that could be replicated in other territories of the countries.

As regards network performance in each of these provinces, some threats were identified that should be addressed. Corrientes displays a low degree of articulation between the players located in the capital city and those in the interior of the province. Taking into account that losCor, encompassing a large segment of the population with coverage provided by the province, transfers

a portion of diagnosis costs to its members, the articulation with the public sector could be reassessed. The issue of supplies and drug overprices in the province of Chaco—also observed in other jurisdictions—requires the establishment of joint procurement mechanisms allowing the proper use of the public resources available to the province.

2.4 Treatment, referrals, and information from different network spaces

Today, the Argentine Hospital Oncopediatric Registry (Registro Oncopediátrico Hospitalario Argentino, ROHA) is the most complete source of information on this health care area and shows great potential to support the design of an institutionalized oncopediatric network. ROHA's current design can contribute its present structure to use and enhance already existing institutional resources—in terms of professionals, infrastructure, and supplies—identify bottlenecks and facilitate a coverage scheme that is more effective, equitable, and efficient as regards the use of resources.

For the purposes of this study, the National Cancer Institute supplied, at various stages of the project, information adding consistency to the input provided by the stakeholder mapping and sheds light on some existing processes. Due to the need to protect statistical secrecy and considering the time frame for the development of this study, the research team did not access ROHA microdata. However, the information provided is adequately detailed to identify some trends in the mechanisms used for patient referral by tumor groups, from a provincial, regional, and economic development viewpoint and by province clusters.

On the other hand, the research team had access to the microdata generated by the Sumar Program run by the National Health Ministry. This program provided information on the consultations held during the two years prior to the pandemic in the country's public primary health care centers associated with suspected cancer signs in patients under 19 years of age, and in the province where the health center is located.

Lastly, INCUCAI allowed the team to access its information repository, so it could identify, by donor institution and by receiving institution, from 2000 up to now, the number of donors by type of organ, jurisdiction, health institution, and coverage of the recipient patient. A review of these data leads to determine the presence—and absence—of valuable information systematically gathered in the country, which may contribute to the global strengthening of a potential oncopediatric network, from primary health care, detection, treatment, and transplant structure through to the final outcome, and identify differences between jurisdictions and treating institutions.

2.4.1. Argentine Hospital Oncopediatric Registry

The team determined the main oncopediatric indicators by analyzing ROHA publications, the information provided by the National Cancer Institute on the particular subject of patient health-related migration in 2018–2019, and the information provided by the Garrahan Hospital. According to ROHA's last available report (2021), 1,410 cases of childhood cancer are diagnosed every year in Argentina on average.⁵³ The global estimated rate of survival five years after diagnosis is 67.6 percent. The prevailing pathologies (Table 7) are leukemias (representing more than one-third of the total cases documented in the database), with a five-year survival rate of 67.9 percent. The second-most frequent pathologies are central nervous system tumors and lymphomas, together representing close to 30 percent of the cases, with five-year survival rates of 56.4 percent and 78.8 percent, respectively. As shown in the last column, the five-year survival rates

⁵³ Based on the period 2015–2019.

vary widely according to pathology types, the extremes being retinoblastomas, with a survival rate of 91.2 percent, and bone tumors, with a survival prognosis of 50.2 percent.

When analyzing health service supply, the ROHA register shows that 80 percent of pediatric oncological patients receive treatment in public hospitals, and the remaining 20 percent in private centers. For its part, public health care is strongly concentrated in two pediatric hospitals: in the period 2012–2019, these two hospitals treated 46 percent of the cases reported, led by the Garrahan Hospital, which in 2018 and 2019 treated 39.05 percent of the cases registered in ROHA.

Designing an oncopediatric network—exposes the tension between specific knowledge -which is based on experiencing multiple cases treated- and the proximity of the treating institution. The higher the number of hospitals, the lower the rate of treatments in each of them, reducing scale and cumulative experience.

The institutional volume reflects the annual average of new oncological patients diagnosed/treated in the treating institution. Table 8 reflects the cases recorded, the deaths and the survival rates after 12, 24, and 36 months, for four groups of institutions defined according to their volume. A comparison of the death rates out of the total cases registered among the low (1–20) and high (>100) institutional volume centers shows a similar rate of nearly 30 percent.

Table 7
Estimated Survival Rate Five Years after Diagnosis, by Pathology Type (ICCC)* in Argentina, 2005–2014

ICCC	<i>Estimated survival five years after diagnosis, by pathology type (2005–2014)</i>		
	<i>Registered cases</i>	<i>% Cases/Total</i>	<i>% Survival after five years</i>
I Leukemias (Global)	5,016	36.91	67.90
III CNS tumors	2,589	19.05	56.40
II Lymphomas (Global)	1,510	11.11	78.80
IX Soft tissue tumors	831	6.11	62.30
IV Neuroblastoma and other peripheral nervous system tumors	814	5.99	61.20
VIII Bone tumors	683	5.03	50.20
VI Kidney tumors	612	4.50	81.70
X Germ cell tumors	507	3.73	86.60
V Retinoblastoma	491	3.61	91.20
XI Carcinomas and other epithelial tumors	271	1.99	No data
VI Liver tumors	183	1.35	55.20
XII Various nonspecific tumors	84	0.62	No data
Global survival rate	13,591	100	67.60

Source: Authors, based on ROHA (2021).

Notes: According to the American Cancer Society, “No accurate percentages are available for all tumor types, often because they are rare or difficult to classify.” This may explain tumors for which no data are available.

* International Classification of Childhood Cancer.

With regard to death risk (Hazard Ratio, HR), taking as reference the patients treated in high-volume centers (>100 patients/year), the death risk for patients in medium volume institutions (40–100 patients/year) is 16 percent higher, for patients in low-medium volume institutions (21–40 patients/year) it is 40 percent higher, and for patients in low-volume institutions (1–20 patients/year) it is 7 percent higher.

Although the best prognosis corresponds to the two public pediatric hospitals, a comparison between low, low-medium, and medium institutional volume does not confirm that a higher institutional volume yields better results in terms of survival rates after 36 months.

However, the aggregate analysis does not enable us to reach any solid conclusions, as the complexity level of the tumors treated in each institution group cannot be identified. For example, the referral of terminal or more difficult cases may increase the fatality levels of the higher-scale centers; however, the death rate is not a synonym for effectiveness.

To gain more knowledge about the referral and treatment mechanisms, we now present an overview of the patient medical care migration process, and then a pathology-based analysis for both referring and

receiving centers.

According to ROHA, for the period 2012–2019, 48 percent of patients, at some time of their treatment, migrated to higher-complexity centers located in a province other than their province of origin. In particular, at some stage of their treatment, 39 percent of patients with leukemia and 62 percent of patients with central nervous system tumors migrated. Excluding the cases with no migration data (registered by the Directorate of Health Statistics and Information [Dirección de Estadísticas e Información de la Salud, DEIS] and by the provinces), the indicator amounts to 54 percent.

Table 8
Survival of Cases Reported to ROHA during the 2000–2007 Period, Stratified by Hospital Volume

Institutional volume	Composition	Recorded cases	Deaths	% Death rate	Survival (in months)			36 months follow-up
					12*	24*	36*	Hazard Ratio*** (IC 95%)
1–20	- 51% public hospitals - 49% private health care centers	2,123	641	30.19	81.7 (79.9; 83.3)	72.1 (70.1; 74.1)	66.3 (64.0; 68.4)	1.07 (0.97; 1.18)
21–40	-71% public hospitals** - 29% private health care centers	1726	638	36.96	74.7 (72.5; 76.7)	64.7 (62.3; 67.0)	59.1 (56.5; 61.5)	1.42 (1.29; 1.57)
41–100	- 100% public hospitals	1874	603	32.18	80.1 (78.2; 81.9)	69.6 (67.3; 71.7)	64.7 (62.3; 67.0)	1.16 (1.05; 1.28)
> 100	- 2 public pediatric referral hospitals	3436	1042	30.33	82.6 (81.3; 83.9)	72.3 (70.7; 73.7)	68.5 (66.8; 70.0)	1

Source: Authors, based on ROHA (2012) publications.

Notes:

*Prob (%) IC 95 percent.

** Most of the general hospitals in provinces with low Human Development Index (HDI) (baseline 2006) are included.

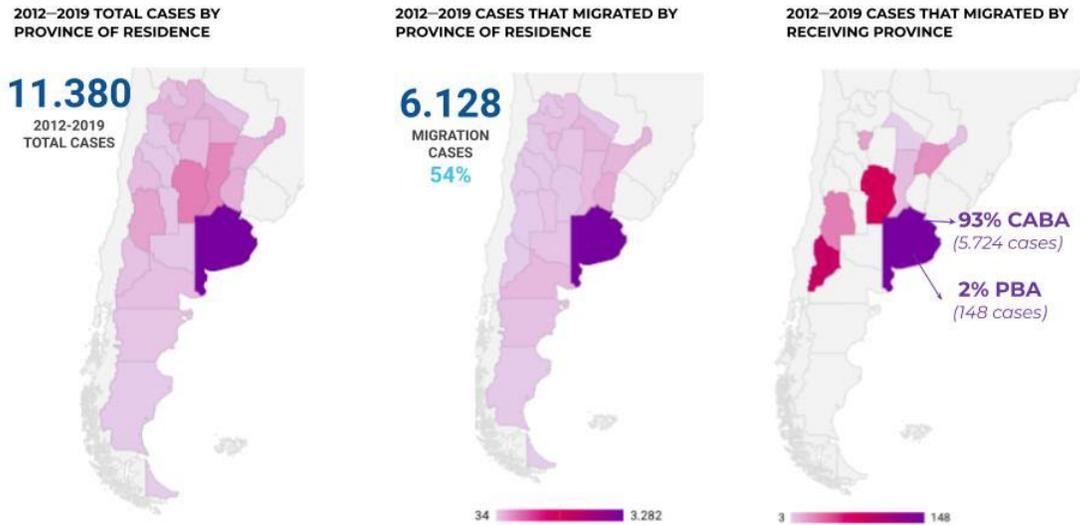
*** Hazard ratio: Mortality rate ratio of a given category to the mortality rate of the benchmark category. The null value for Hazard ratio (HR) is one.

Distributed by region, the treatment of childhood cancer patients is highly concentrated in the Autonomous City of Buenos Aires (Ciudad Autónoma de Buenos Aires, CABA). In the Cuyo Region, only 30 percent of cases migrated to advance their treatment (78 percent to CABA, 13 percent to Mendoza, 7 percent to Córdoba, and 2 percent to Province of Buenos Aires (PBA), while in Patagonia most cases were referred to another province for treatment (84 percent). It should be noted that 15 percent of the migrated cases were treated in Neuquén and 76 percent in CABA. In La Pampa, 100 percent of patients were referred to another province for treatment, mainly to CABA (89 percent) and only 1 percent went to a neighboring jurisdiction such as Córdoba, with no cases referred to Mendoza or Neuquén, where there is a higher resolution capacity.

The following figure shows the estimated patient health care migration by province of residence and treating center.

Figure 4

Estimated Patient Health Care Migration by the Province of Residence and Treating Center, 2012–2019



Source: Prepared by the authors based on ROHA (2021).

Based on the information provided by the INC for the 2018–2019 period, it is observed that, although on average 28 percent of the cases diagnosed in 2018 and 2019 migrated at some point during their treatment, the migration rate varies widely depending on pathology type. Table 9 breaks down this information, showing for each of the 12 tumor types, the total number of cases diagnosed during that period, and the percentage of each of them over the total. The other columns in the table list the total number of migrant cases by category and percentage. These same values focused on CABA and the Province of Buenos Aires as the two major system recipients.

Of the total number of pathologies, retinoblastoma shows the highest patient health care migration (60 percent of the total number of cases, and 87 percent when excluding cases residing in AMBA), with the Garrahan Hospital being the main referral center (87 percent of cases treated). Next is liver tumors (39 percent and 55 percent when excluding cases residing in AMBA), which, like retinoblastomas, are mostly referred to Garrahan Hospital (61 percent). Then come central nervous system tumors (37 percent and 59 percent when excluding cases residing in AMBA), which were mainly referred to the Garrahan Hospital (45 percent), followed by the Gutierrez Hospital (14 percent) and private CABA health care centers (29 percent).

The pathologies with the lowest patient health care migration are germ, trophoblastic, and gonadal cell tumors (20 percent of total cases and 29 percent when excluding cases residing in AMBA), lymphomas (21 percent and 33 percent when excluding cases residing in AMBA) and leukemias (24 percent and 34 percent when excluding cases residing in AMBA). In any case, among the referred cases, migration was mainly to Garrahan Hospital (40 percent of leukemias; 43 percent of germ cell, trophoblastic, and gonadal cell tumors; and 52.5 percent of lymphomas).

Table 9
Patient Health Care Migration (0 to 19 Years of Age) by Pathology Type (ICCC), 2018–2019

ICCC	Total	Migration total	% of migration cases	Total PBA migration	% PBA migration	Total CABA migration	% CABA migration
I – Leukemia	1,140	277	24	32	12	212	77
III - CNS tumors and other intracranial and intraspinal tumors	614	228	37	2	1	208	91
II - Lymphomas and reticuloendothelial tumors	379	80	21	7	9	64	80
IX - Soft tissue tumors	241	68	28	3	4	57	84
X - Germ cell, trophoblastic, and gonadal tumors	226	46	20	1	2	37	80
VIII - Bone tumors	203	62	31	1	2	56	90
IV - Neuroblastoma and other peripheral nervous system tumors	180	49	27	2	4	40	82
VI - Renal tumors	116	31	27	1	3	29	94
XI - Carcinomas and other epithelial tumors	97	23	24	1	4	20	87
V - Retinoblastoma	89	53	60	4	8	47	89
99 - Not applicable	79	12	15		0	11	92
VII - Hepatic tumors	46	18	39	1	6	16	89
XII - Other nonspecific tumors	14	4	29		0	4	100
Total amount	3,424	951	27.77	55	5.78	801	84.23

Source: Authors, based on INC data.

Notes: ICCC = International Classification of Childhood Cancer; PBA = Province of Buenos Aires; CABA = Ciudad Autónoma de Buenos Aires.

Below, and to identify regional patterns within the current structure of oncopediatric care, the referral and treatment acceptance of patients with a diagnosis date in 2010 is studied, aggregating death rates according to the referring and referral center and for three tumor clusters: (i) leukemias and lymphomas, (ii) central nervous system, and (iii) solid tumors. The information source is INC-ROHA, and patients who were included in other registries (DEIS, RITA, etc.) are excluded.

Two key indicators are taken to understand treatment center performance: The first is whether referral is involved; the second indicator is the rate of deaths. To this end, first, the performance of the center of origin will be studied concerning health care referral and the death rate, with the understanding that the lower the rate, the better the results. Subsequently, the same information will be examined, but from the main referral centers' perspective.

The data provided by the INC reflect 1,297 patients diagnosed in 2010, of which 619 (48 percent) belong to the leukemia and lymphoma cluster, 240 (18 percent) to the central nervous system cluster, and 438 (34 percent) to the solid tumors cluster. These cases represent 94 percent of those reported in the ROHA report (2021) for the year 2010. It should be noted that the available information does not specify the date of

death, which is why we will refer to the death rate when this occurred during the 19 years under analysis. Likewise, the database does not provide information on the time of referral—whether it was at the beginning of treatment or later—or on the possible involvement of intermediate health care centers.

In general terms, and as previously mentioned, the treatment of the pathologies analyzed is highly concentrated, approximately 76.0 percent of the cases were treated in 13 centers, 60.4 percent of the total in CABA, 6.0 percent in Buenos Aires, 5.0 percent in Neuquén, 2.5 percent in Córdoba, and 2.0 percent in Mendoza. Eighty-five percent of childhood cancer patients were treated in public hospitals and the remaining 15 percent in private centers, similar to the trend observed in the latest ROHA report (2021).

From a geographical perspective, 93 percent of the referred cases were treated in the City of Buenos Aires, while the Patagonian region emerges with the highest referral percentage of its cases (85 percent). As an exception to this pattern, Neuquén is the only jurisdiction with fewer referrals than cases treated locally (41 percent of cases), receiving 16 percent of the cases referred by the region, mostly leukemias and, to a lesser extent, solid tumors.

In the Central Region, and due to the strong influence of the Province of Buenos Aires, 53 percent of the cases migrated and 71 percent of their cases were referred intra-regionally. In Cuyo, except for San Luis, which referred 100 percent of its cases, Mendoza and San Juan referred 14 percent and 30 percent of their cases, respectively. Meanwhile, in the Northeast Region, except for Formosa (only 9 percent local treatment), between 40 percent and 60 percent of the cases were resolved in the center's province of origin, and 91 percent of the cases that relocated were to CABA. Finally, in the Northwest, referrals were made for 54 percent of the cases. We highlight the case of La Rioja, which referred 100 percent of treatments, 71 percent of which migrated to Córdoba.

The aforementioned performance indicators (referral or nonreferral by patient referral center, and death rate by center) cannot be considered separately because this could lead to a biased analysis. Thus, indicating that a hospital refers or treats a large number of cases does not necessarily reflect its performance. Some biases are corrected when viewed as a whole. For example, there may be hospitals that handle a high percentage of the cases they receive, but have a very high death rate, so the combined indicator would reveal poor performance. On the other hand, there may be centers that treat a large number of patients and have a low death rate, showing alignment in their processes and results.

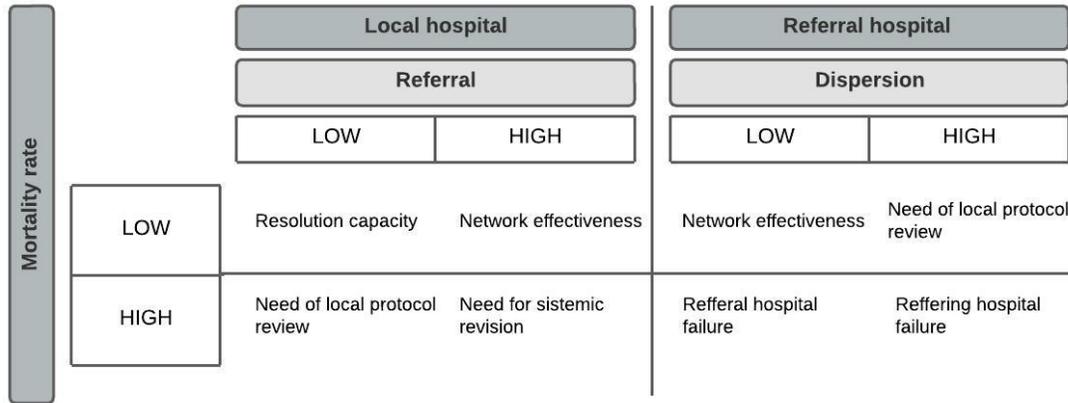
The same exercise can be carried out to examine the performance of patient referral centers. There may be centers that receive a high number of referral patients, whose death rates are high or centers with the same characteristics, but with low mortality rates.

The latter case does not pose any problems, but the former (high referral and high mortality) can give rise to two interpretations: The first is that the center's performance is unsatisfactory despite receiving patients with timely diagnoses. The second is that the center's performance is not as expected, but this is not due to its resolution capacity, but to the fact that it accepts patients with advanced pathologies as a result of a late referral, which affects their survival rate.

An analysis is proposed to explain health care centers' performance since indicators do not identify the level of responsibility each of them has. Figure 5 illustrates the concepts discussed, points out network-strengthening dynamics, and warns about behaviors that should be revised. It should be noted that the "low" and "high" referral and mortality rate categories represent a threshold based on the resolution capacity of each of the referring health care centers.

Figure 5

Referral Logic, Indicators Analysis, and Performance of Health Care Centers



Source: Authors.

The first half of the diagram analyzes the referring center's performance: low mortality and low referral rate define a health care center with a successful resolution capacity in treating its patients, while a low mortality and high referral rate shows its effective integration into the network. If mortality is high and referral is not, the center exhibits an institutional risk, in that it keeps patients with a higher risk than it can address. Finally, if mortality is high despite a high referral rate, it indicates a network failure in its patient management structure.

On the right side of Figure 5, the referral center's performance is analyzed, with a similar reading. Instead of the "referral" variable, however, the dispersion of this indicator according to the referring centers is considered along with the referral rate, giving rise to two arguments that make it possible to assess—given the available information—the effectiveness of the referral hospital or health care facility.

- Those referral health care facilities with a high mortality rate and a homogeneous mortality rate among provinces would reveal performance failures (regardless of the patient's place of origin, the high-complexity facility fails to solve a relevant number of cases treated).
- Alternatively, if mortality does not follow a systematic pattern, there is a problem in the referral circuit involving the referring institution, which requires a revision of the network's referral mechanisms.

The available information also makes it possible to consider the existence of specificities according to the type of tumor and health care center. The latter can be achieved by observing the cases accepted and referred by pathology type in the case of local centers and replicating the exercise for the referral high-complexity centers. Testing the hypotheses in light of the pathology treated will make it possible to control results and observe preexisting specialty patterns.

Table 10 shows the aforementioned indicators by region and province, while Table 13 shows an aggregate overview of the benchmark recipient centers' performance. There are local health care centers (located in Buenos Aires, Córdoba; Santa Fe, Tucumán, Salta, Corrientes, Misiones, Chaco, and Neuquén) whose indicators show a certain level of alignment, although not for all pathology clusters. The treatment of central nervous system tumors generally shows lower performance.

On the other hand, there are provinces whose health care centers are natural referring centers, such as Formosa, San Luis, La Rioja, La Pampa, Santa Cruz, Tierra del Fuego, Chubut, and Río Negro. Although there is no evidence of regional homogeneity in terms of the performance of local health care centers, there

are provinces—Cordoba, Santa Fe, Mendoza, Chaco, Corrientes, and Neuquén—with referral rates below 35 percent and death rates below 50 percent.⁵⁴ These territories could become potential network hubs.

In turn, the referral centers' indicators show that the first hypothesis cannot be confirmed, since in all cases the mortality rate is not homogeneous among provinces. However, on observing the performance of patients received by the primary referring centers, it is evident that in some cases there are high mortality rates.

In addition, referrals from some provincial facilities also show high mortality rates. However, their indicators at the local level report low death rates, even below those of the referral centers receiving their patients. In such cases, it would be advisable to review the current referral protocols.

This methodological approach would be strengthened and enhanced by the inclusion of more observations, as well as other available information, including a detailed description of the time intervals of reception, treatment, referral, and discharge or death.

Given that oncopediatric care by its nature involves a small number of patients, searching for behavior patterns by center type (referring/referral) and by pathology would surely strengthen the network structure, as well as increase ROHA's potential as an analysis and decision-making platform.

Table 10
Province of Origin of Patients Diagnosed in
2010 Disaggregated by Pathology, Place of Treatment, and Death Rate

Province of origin		Leukemias and lymphomas				Central nervous system				Solid tumors			
		Cases		Death rate		Cases		Death rate		Cases		Death rate	
Region	Province	Total	% of patients who migrated	% Migrated	% Did not migrate	Total	% of patients who migrated	% Migrated	% Did not migrate	Total	% of patients who migrated	% Migrated	% Did not migrate
Central		377	44	26	33	167	59	36	49	284	60	30	31
	CABA	42	0	n.a.	21	19	0	n.a.	26	27	0	n.a.	22
	Córdoba	34	9	33	29	16	6	0	53	35	9	67	47
	Santa Fe	45	13	50	46	17	29	40	58	25	28	29	28
	Buenos Aires	248	62	25	35	103	79	32	59	183	79	30	26
	Entre Ríos	8	50	0	25	12	100	67	n.a.	14	100	21	n.a.
Cuyo		39	46	17	33	12	50	50	83	35	29	30	36
	Mendoza	14	7	0	31	9	44	50	100	13	0	n.a.	31
	San Luis	12	100	17	n.a.	1	100	0	n.a.	2	100	50	n.a.
	San Juan	13	38	20	38	2	50	100	0	20	40	25	42

⁵⁴ For the central nervous system pathologies cluster, death rates can be as high as 58 percent in the aforementioned provinces.

Table 10 (continued)
Province of Origin of Patients Diagnosed in
2010 Disaggregated by Pathology, Place of Treatment, and Death Rate

		<i>Leukemias and lymphomas</i>				<i>Central nervous system</i>				<i>Solid tumors</i>			
Province of origin		Cases		Death rate		Cases		Death rate		Cases		Death rate	
<i>Region</i>	<i>Province</i>	<i>Total</i>	<i>% of patients who migrated</i>	<i>% Migrated</i>	<i>% Did not migrate</i>	<i>Total</i>	<i>% of patients who migrated</i>	<i>% Migrated</i>	<i>% Did not migrate</i>	<i>Total</i>	<i>% of patients who migrated</i>	<i>% Migrated</i>	<i>% Did not migrate</i>
Northeast		75	48	53	23	21	86	50	33	42	62	46	19
	Corrientes	18	28	60	31	3	100	33	n.a.	12	50	50	1
	Misiones	22	50	64	27	10	100	40	n.a.	10	50	80	20
	Chaco	23	35	50	13	3	33	100	50	15	73	45	25
	Formosa	12	100	42	n.a.	5	80	75	0	5	80	0	0
Northwest		90	47	45	31	26	65	59	78	53	62	33	45
	Jujuy	11	45	100	50	2	100	50	n.a.	10	80	25	0
	La Rioja	4	100	0	n.a.	1	100	0	n.a.	2	100	0	n.a.
	Tucumán	15	47	29	38	10	50	40	80	10	40	50	33
	Salta	28	43	58	25	9	67	67	67	11	36	0	57
	Catamarca	11	55	50	20	3	67	100	100	4	75	33	0
	Santiago del Estero	21	38	25	31	1	100	100	n.a.	16	75	50	75
Patagonia		38	82	42	43	14	86	50	50	24	83	35	0
	La Pampa	3	100	33	n.a.	2	100	50	n.a.	3	100	33	n.a.
	Santa Cruz	3	100	33	n.a.	1	100	100	n.a.	2	100	50	n.a.
	Tierra del Fuego	2	100	50	n.a.	0	n.a.	n.a.	n.a.	2	100	0	n.a.
	Neuquén	8	13	100	43	5	60	33	50	9	56	40	0
	Chubut	5	100	80	n.a.	4	100	50	n.a.	1	100	100	n.a.
	Río Negro	17	100	29	n.a.	2	100	50	n.a.	7	100	29	n.a.
TOTAL		619	47	33	32	240	63	42	53	438	59	33	32

Source: Authors, based on information provided by the INC.

Notes: CABA = Ciudad Autónoma de Buenos Aires; n.a. = not applicable; provinces are arranged by region in decreasing order according to Human Development Index (HDI) 2006.

A complementary view suggests that the performance of local health care centers could be explained based on the province's economic development level. Therefore, the Human Development Index (HDI) was taken as a proxy indicator (Table 11). Note that there is no correlation between HDI and death rates per pathology cluster. There are provinces with relatively high HDI, with lower-than-expected performance in the management of patients (above average death rates). On the other hand, there are other jurisdictions with a lower HDI, with lower death rates for all tumor types.

This analysis indicates that there is a different resolution quality in centers with oncopediatric treatment capacity in the provinces, regardless of socioeconomic status. This could be considered a positive sign when designing a national oncopediatric network with intermediate referral facilities by region, especially in the north of Argentina where economic development levels are more challenging.

Regarding specialty patterns, it should be noted that local health care centers—except for those that refer all their cases—show a better performance in the treatment of patients with pathologies in the leukemias and lymphomas cluster, since referral and death rates for patients treated locally are lower than for the other two tumor types. The pattern repeats itself in solid tumors (better performance at the local level) with respect to central nervous system tumors.

Nor can it be stated that there are specialization patterns in the referral centers (Table 14). As mentioned above, few centers concentrate the care of the majority of patients with different pathologies: two public referral centers concentrate 68 percent of the patients referred with leukemia and lymphoma, 74 percent of the patients referred with central nervous system tumors, and 77 percent with solid tumors. In turn, hospitals with a smaller number of patients show an even treatment capacity by pathology type, and only five centers (three public and two private) treat only leukemias and lymphomas.

Finally, and given that the database analyzed only includes patients diagnosed in 2010, the number of observations is small. A future working agenda should contemplate the possibility of replicating the hypotheses with a broader case base. Beyond that, the findings evidenced in this section in light of the literature review (Part I) and the key stakeholders' perspectives (Part II), lead to considerations of the positive impact of early detection on patient survival and the importance of promoting it. Analysis of the Sumar Program databases is presented below, which shows the policy results regarding the oncopediatric segment primary care.

The following tables (11, 12, 13, and 14) add relevant information associated with the province of origin of patients diagnosed in 2010, sorted by the human development index (HDI) and disaggregated by pathology and death rate; the percentage of patients who migrated by treating center stratified by institutional volume, outcome, and pathology; main referral centers by region, patient's province of origin, and pathology; and breakdown of death rate, and the number of cases treated locally in main patient referral centers, respectively.

Table 11
Province of Origin of Patients Diagnosed in
2010, Sorted by HDI and Disaggregated by Pathology and Death Rate

<i>Province</i>	<i>HDI 2006</i>	Leukemias and lymphomas	Central nervous system	Solid tumors
		<i>% Death rate</i>	<i>% Death rate</i>	<i>% Death rate</i>
CABA	0.88	21.4	26.3	22.2
La Pampa	0.83	33.3	50.0	33.3
Santa Cruz	0.82	33.3	100.0	50.0
T. del Fuego	0.80	50.0	0.0	0.0
Neuquén	0.79	50.0	40.0	22.2
Mendoza	0.79	28.6	77.8	30.8
Santa Fe	0.77	46.7	52.9	28.0
Córdoba	0.77	29.4	50.0	48.6
Buenos Aires	0.725	29.0	37.9	29.5
Chubut	0.73	80.0	50.0	100.0
Entre Ríos	0.72	12.5	66.7	21.4
San Luis	0.72	16.7	0.0	50.0
Jujuy	0.72	72.7	50.0	20.0
Tucumán	0.70	33.3	60.0	40.0
La Rioja	0.70	0.0	0.0	0.0
Río Negro	0.70	29.4	50.0	28.6
Corrientes	0.69	38.9	33.3	33.3
Misiones	0.68	45.5	40.0	50.0
San Juan	0.67	30.8	50.0	35.0
Salta	0.67	39.3	66.7	36.4
Chaco	0.66	26.1	66.7	40.0
Catamarca	0.65	36.4	100.0	25.0
Sgo. del Estero	0.63	28.6	100.0	56.3
Formosa	0.58	41.7	60.0	0.0
TOTAL		32.5	46.3	32.2

Source: Authors, based on information provided by the INC.

Notes: HDI = Human Development Index; CABA = Ciudad Autónoma de Buenos Aires.

Table 12

Patients Who Migrated by Treating Center Stratified by Institutional Volume, Outcome, and Pathology

Treating center				Leukemias and lymphomas		Central nervous system		Solid tumors		Total	
Center	Province	Region	Type	Total % ARG	% Death rate	Total % ARG	% Death rate	Total % ARG	% Death rate	Total % ARG	% Death rate
16	CABA	Central	Public	21.7	33.3	12.4	46.0	22.9	28.0	56.96	33.9
15	CABA	Central	Public	6.8	37.5	3.7	34.6	5.3	37.8	15.77	36.9
19	CABA	Central	Public	3.4	29.2	0.7	40.0	2.7	52.6	6.82	39.6
20	CABA	Central	Private	1.6	9.1	0.3	0.0	2.1	33.3	3.98	21.4
14	CABA	Central	Private	0.0	n.a.	3.1	40.9	0.0	n.a.	3.13	40.9
4	Buenos Aires	Central	Public	1.8	46.2	0.0	n.a.	0.0	n.a.	1.85	46.2
61	CABA	Central	Private	0.4	33.3	0.4	33.3	1.1	12.5	1.99	21.4
23	CABA	Central	Private	0.6	75.0	0.1	100.0	0.6	100.0	1.28	88.9
42	Neuquén	Patagonia	Private	1.3	11.1	0.0	n.a.	0.0	n.a.	1.28	11.1
22	CABA	Central	Private	0.7	40.0	0.3	50.0	0.0	n.a.	0.99	42.9
13	CABA	Central	Private	0.6	0.0	0.1	0.0	0.0	n.a.	0.71	0.0
I.V. Medium		Central	Public	0.4	0.0	0.3	0.0	0.1	0.0	0.85	0.0
I.V. Medium-low		Cuyo – Northeast	Public	0.9	33.3	0.1	100.0	0.1	0.0	1.14	37.5
I.V. Low		Central - Patagonia - Northeast – Northwest Public/Private		1.6	45.5	0.0	n.a.	1.7	41.7	3.27	43.5
Total				41.8	33.0	21.6	42.1	36.6	32.6	100.0	34.8

Source: Authors, based on information provided by the INC.

Notes: Institutional volume categories are defined in relation to the total number of patients treated and are sorted according to the following categories: 1–20: low; 21–40: medium-low; 41–100: medium; and above 100: high; CABA = Ciudad Autónoma de Buenos Aires; n.a. = not applicable.

Table 13
Main Referral Centers by Region, Patient's Province of Origin, and Pathology

Center of origin Region Province HDI			Leukemias and lymphomas								Central nervous system								Solid tumors								Total								
			Center 16		Center 5		Center 19		Center 20		Center 16		Center 5		Center 19		Center 20		Center 16		Center 15		Center 19		Center 20		Center 16		Center 15		Center 19		Center 20		
			D	Q	D	Q	D	Q	D	Q	D	Q	D	Q	D	Q	D	Q	D	Q	D	Q	D	Q	D	Q	D	Q	D	Q	D	Q	D	Q	
Central Region			25	90	11	35	6	23	0	6	21	54	6	21	0	3	0	1	22	97	12	33	9	16	5	10	68	241	29	89	15	42	5	17	
Santa Fe	0.77	3	3	0	0	0	0	0	0	0	3	0	0	0	0	0	0	0	2	2	0	0	0	0	2	2	3	11	0	0	0	0	2	2	
Córdoba	0.77	1	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	3	5	0	0	0	0	0	0
Buenos Aires	0.73	21	82	11	35	6	23	0	6	15	43	4	17	0	3	0	1	17	80	12	30	9	16	3	7	53	205	27	82	15	42	3	14		
Entre Ríos	0.72	0	3	0	0	0	0	0	0	6	8	2	4	0	0	0	0	3	9	0	3	0	0	0	1	9	20	2	7	0	0	0	1		
Cuyo Region		0	7	2	6	0	0	0	0	0	1	0	0	2	2	0	0	2	4	0	0	0	2	0	0	2	12	2	6	2	4	0	0		
Mendoza	0.79	0	0	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0	0		
San Luis	0.72	0	3	1	5	0	0	0	0	0	1	0	0	0	0	0	0	1	3	0	0	0	2	0	0	1	7	1	5	0	2	0	0		
San Juan	0.67	0	4	1	1	0	0	0	0	0	0	0	1	1	0	0	0	1	1	0	0	0	0	0	0	1	5	1	1	1	1	0	0		
Northeast Region		13	26	1	1	0	0	1	3	7	14	0	0	0	0	0	0	10	21	1	1	1	1	1	0	2	30	61	2	2	1	1	1	5	
Corrientes	0.69	3	4	0	0	0	0	0	0	0	1	0	0	0	0	0	0	3	5	0	0	0	0	0	0	1	6	10	0	0	0	0	0	1	
Misiones	0.68	4	8	0	0	0	0	0	0	4	9	0	0	0	0	0	0	3	4	1	1	0	0	0	0	11	21	1	1	0	0	0	0		
Chaco	0.66	3	6	0	0	0	0	0	1	1	1	0	0	0	0	0	0	4	10	0	0	1	1	0	0	8	17	0	0	1	1	0	1		
Formosa	0.58	3	8	1	1	0	0	1	2	2	3	0	0	0	0	0	0	0	2	0	0	0	0	0	1	5	13	1	1	0	0	1	3		
Northwest Region		10	25	2	3	0	0	0	1	8	12	1	2	0	0	0	1	8	25	0	2	0	0	0	2	26	62	3	7	0	0	0	4		
Jujuy	0.72	3	3	1	1	0	0	0	0	0	0	1	2	0	0	0	0	1	4	0	2	0	0	0	1	4	7	2	5	0	0	0	1		
Tucuman	0.70	0	5	0	0	0	0	0	0	1	4	0	0	0	0	0	0	1	2	0	0	0	0	0	1	2	11	0	0	0	0	0	1		
La Rioja	0.70	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	1	0	0	0	0	0	0		
Salta	0.67	3	5	1	2	0	0	0	1	4	5	0	0	0	0	0	1	0	4	0	0	0	0	0	0	7	14	1	2	0	0	0	2		
Catamarca	0.65	3	5	0	0	0	0	0	0	2	2	0	0	0	0	0	0	1	3	0	0	0	0	0	0	6	10	0	0	0	0	0	0		
Sgo. del Estero	0.63	1	7	0	0	0	0	0	0	1	1	0	0	0	0	0	0	5	11	0	0	0	0	0	0	7	19	0	0	0	0	0	0		
Patagonia Region		3	5	2	3	1	1	0	1	4	6	2	3	0	0	0	0	3	14	1	1	0	0	0	1	10	25	5	7	1	1	0	2		
La Pampa	0.83	1	1	0	1	0	0	0	1	0	0	1	1	0	0	0	0	1	2	0	0	0	0	0	1	2	3	1	2	0	0	0	2		
Santa Cruz	0.82	0	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	0	1	0	0	0	0	0	0	0	1	1	1	0	0	0	0		
Tierra del Fuego	0.80	0	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	0	0	0	3	1	1	0	0	0	0		
Neuquén	0.79	1	1	0	0	0	0	0	0	1	2	0	0	0	0	0	0	1	4	1	1	0	0	0	0	3	7	1	1	0	0	0	0		
Chubut	0.73	1	1	1	1	1	1	0	0	2	2	0	1	0	0	0	0	0	0	0	0	0	0	0	0	3	3	1	2	1	1	0	0		
Río Negro	0.70	0	1	0	0	0	0	0	0	1	2	0	0	0	0	0	0	1	5	0	0	0	0	0	0	2	8	0	0	0	0	0	0		
TOTAL		51	153	18	48	7	24	1	11	40	87	9	26	2	5	0	2	45	161	14	37	10	19	5	15	136	401	41	111	19	48	6	28		

Source: Authors, based on information provided by the INC.

Notes: Q = Total cases; D = Deaths; HDI = Human Development Index.

Table 14
Breakdown of Death Rate and Number of Cases Treated Locally
In Main Patient Referral Centers

Main centers	Leukemias and lymphomas		Central nervous system		Solid tumors	
	<i>Cases</i>	<i>% Death rate</i>	<i>Cases</i>	<i>% Death rate</i>	<i>Cases</i>	<i>% Death rate</i>
Center 16	19	26.3	5	40.0	11	18.2
Center 15	5	20.0	2	50.0	7	35.7
Center 19	7	0.0	1	0.0	2	0.0
Center 20	2	100.0	0	n.a.	2	50.0
Total	33	24.2	8	37.5	22	22.7

Source: Authors, based on information provided by the INC.

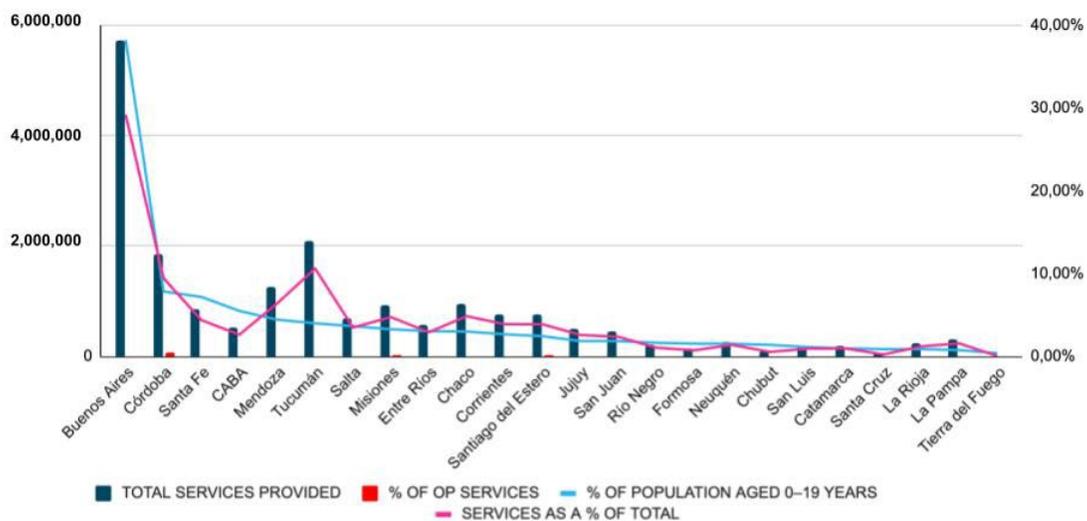
Notes: n.a. = Not applicable.

2.4.2. Sumar Program

In 2019, the Sumar Program funded 19,631,012 medical services for the 0 to 19 age group, of which 14,008 were linked to the Oncopediatric care lines, which accounts for 0.07 percent of the total. The analysis of services for the population under 19 years of age shows great heterogeneity in the program's coverage among provinces. As an example, Figure 6 characterizes each jurisdiction based on four indicators: total program services and weight of those related to oncopediatrics, and this is then compared with the weight of these services over the total and the share of the target population.

The consultation reporting gap is extremely diverse, as is the impact on oncopediatric visits. By way of example, for 2019, Tucumán is the sixth province with an under-19 population, but the second with the highest number of invoiced services and weight of oncopediatric care higher than the national average. Meanwhile, the City of Buenos Aires is the fourth province with the largest target population, the twelfth province in terms of invoiced medical services, and a weight for those related to this study of approximately one-third compared to that of its northwestern counterpart.

Figure 6
Sumar Program–Funded Services for the Population under 19 Years of Age by Province, January–December 2019*



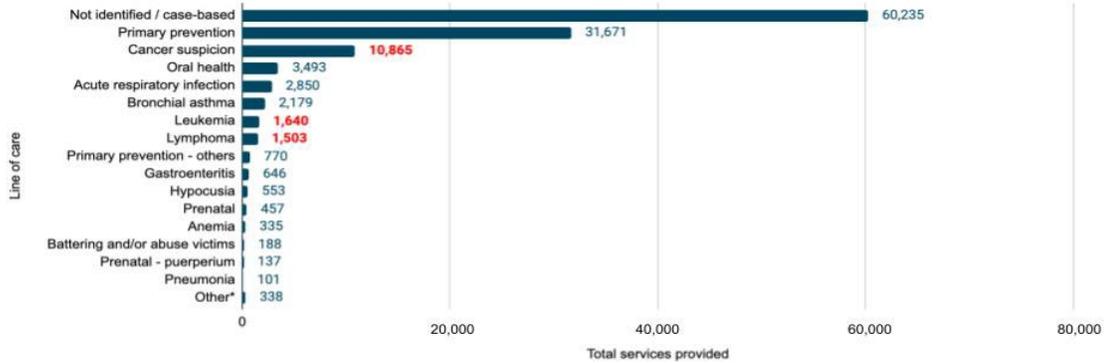
Source: Authors, based on service usage reports for the 2019 Sumar Program available in Open Data from the Health Ministry and information provided by Sumar.

Notes: OP = oncopediatrics.

* Provinces are sorted in descending order according to the estimated population aged 0–19.

Figure 6 shows that in 2019 11,044 patients received at least one oncopediatric consultation. Within that total number of patients, the distribution of their 117,961 consultations follows the frequency shown in Figure 7.

Figure 7
Frequency of Lines of Care of the 2019 Total Medical Services to OP 2019 Users



Source: Authors, based on 2019 medical services usage reports for beneficiaries identified with OP services in 2019 provided by the Sumar Program.

Notes: OP = oncopediatrics.

*Other: includes all lines of care with less than 100 medical services.

The suspected oncological pathology, leukemia, and lymphoma lines of care appear in third, seventh, and eighth place, respectively, the latter two with a very small prevalence. On the other hand, of the total number of medical services provided, only 12 percent (14,008) are related to childhood cancer. The most frequent medical services are consultation for suspected cancer (cephalea) (43 percent), and consultation for suspected cancer (multiple pervasive pain) (25 percent). In third place is the consultation for clinical follow-up in patients treated for lymphoma (9 percent), and consultation for clinical follow-up after leukemia treatment (7 percent). When the information is broken down by province and taken as a basis for analysis of the number of medical services per million potential Sumar beneficiaries, the large disparities in the use of the program mentioned above are more clearly identified (Figure 8).

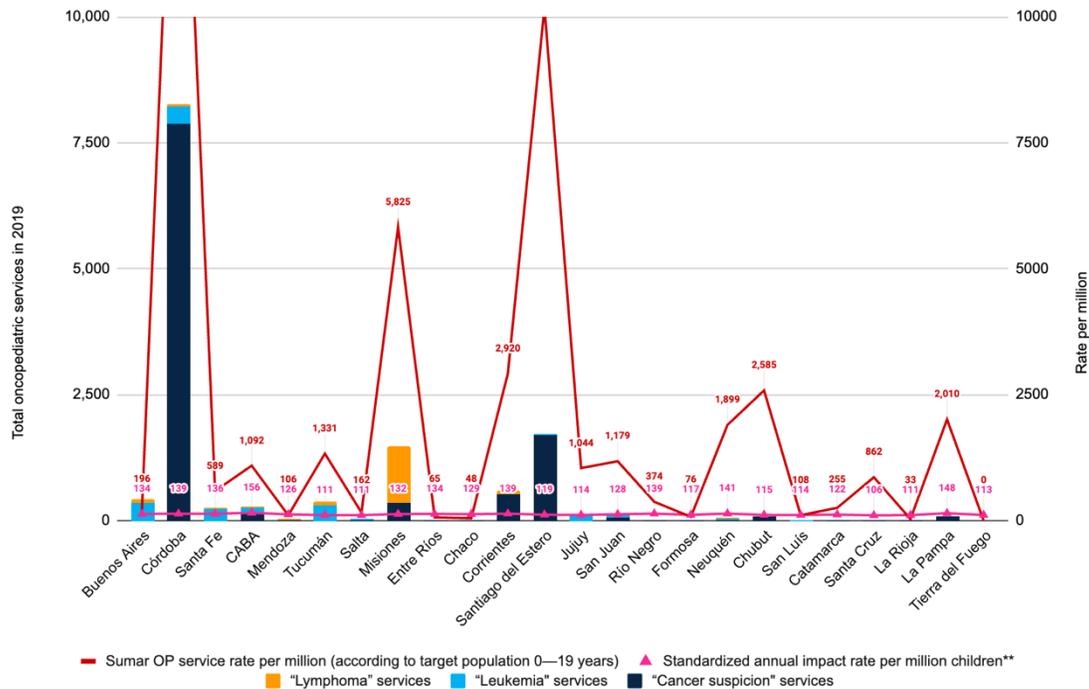
The provinces of Córdoba, Misiones, and Santiago del Estero show the highest service rates per million children and adolescents, while Tierra del Fuego, La Rioja, Chaco, and Entre Ríos show the lowest national average rates.

When comparing these usage rates with those corresponding to the 2020 period, according to the August 2021 report from the National Health Ministry's Medical Coverage Department,⁵⁵ of the benefits provided and reported to the Sumar Program's invoice database, the "Consultation for suspected cancer" service was the most invoiced (6,067 times). In turn, leukemia and lymphoma lines of care reflect 736 Sumar beneficiaries and the most reported service was the posttreatment follow-up. The provinces of Chubut, Formosa, San Luis, and Tierra del Fuego, as well as Tucumán, CABA, Misiones, and Córdoba, were the provinces that invoiced the highest number of services, especially for lymphoma (20 percent, 26 percent, and 80 percent for Tucumán, CABA, and Misiones, respectively), and 69 percent of the services for suspected cancer and diagnostic studies for Córdoba.

⁵⁵ Health Ministry 2021b.

Figure 8
Breakdown of Oncopediatric (SUMAR) Services in 2019
by Province*

Total services by line of care, standardized annual impact rate, and estimated services per one million inhabitants aged 0 to 19 years (based on SUMAR's target population**)



Source: Authorms based on 2019 medical services usage reports for beneficiaries identified with oncopediatrics services in 2019 provided by the Sumar Program, ROHA report (2021), and SUMAR monitoring reports (4th quarter 2019 and 1st quarter 2021), published by the Office of the President.

Notes:

* Provinces are sorted in descending order according to the estimated population aged 0–19.

**The target population estimate was made according to the Office of the President (2021b), Sumar Monitoring Report, first quarter 2021. For more information, see Annex C–V. Interaction with the Sumar Program.

The general conclusion of the information gathered from Sumar reflects some key elements to consider when designing an oncopediatric network. In the first place, program compliance continues to be irregular among jurisdictions, despite the time that has elapsed since its creation in the early 2000s. In the second place, it is clear that coordinated management between Sumar and an oncopediatric program could enhance early detection in patients who use the public subsystem as their first source of care, generating timely information for the more complex medical care levels. Finally, Sumar's action, by definition, is within the public sphere, leaving a vacant gap for convergence with the rest of the health system. This last issue, although of great relevance for the organization of the health system, is far removed from the specific objectives of an effective oncopediatric network.

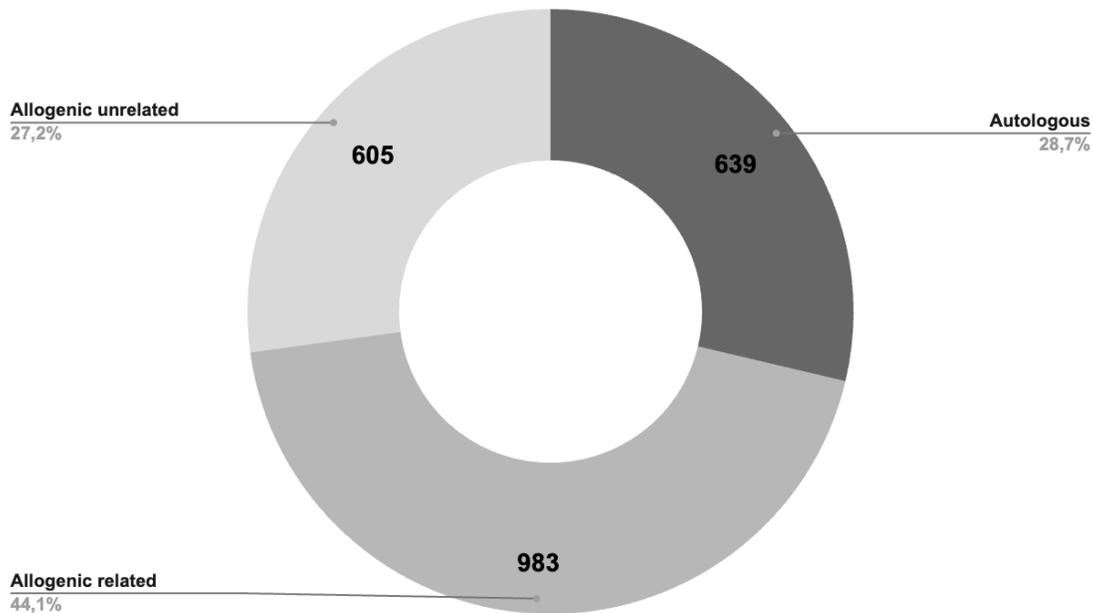
2.4.3. INCUCAI

At the national level, governance of the organ donation and transplantation system is the responsibility of the Single Central National Institute for the Coordination of Ablations and Implants

(INCUCAI). The public and private sectors must notify and record in the National Information System on Procurement and Transplants of the Argentine Republic (Sistema Nacional de información de Procuración y Trasplante de la República Argentina, SINTRA) the activities related to organ donation and transplant. In turn, INCUCAI has its own registry of 300,000 donors in Argentina and belongs to a worldwide network that allows validating compatibility with 41 million registered people. Regarding oncopediatric patients, reliance on this institute resides is due to the treatment of leukemia and lymphoma, for which bone marrow transplantation is sometimes required.

According to information obtained through SINTRA, Argentina's total transplantation rate for 2021 was 258.8 per 10 million inhabitants, and again shows a wide disparity by province. For example, the City of Buenos Aires had the highest rate (539 per 10 million), while Santiago del Estero had the lowest (71 per 10 million). Regarding the pediatric population, between 2009 and 2022,⁵⁶ 2,227 bone marrow transplants were recorded, with an average of 160 transplantations per year⁵⁷ and an average patient age of eight years. Figure 9 shows that the most frequent type of bone marrow transplantation is the allogeneic matched related transplantation.

Figure 9
Transplantation Category based on Tissue, 2009–2022



Source: Authors, according to information from SINTRA for 2009–2022.

As regards the province of treatment, 57 percent of the transplantations recorded were done in CABA, 22 percent in Buenos Aires, 16 percent in Córdoba, and 4 percent in Santa Fe, which reflects consistency with the information from ROHA—discussed previously—which arranges the oncopediatric patients treated and referred in the same way and with similar percentages.

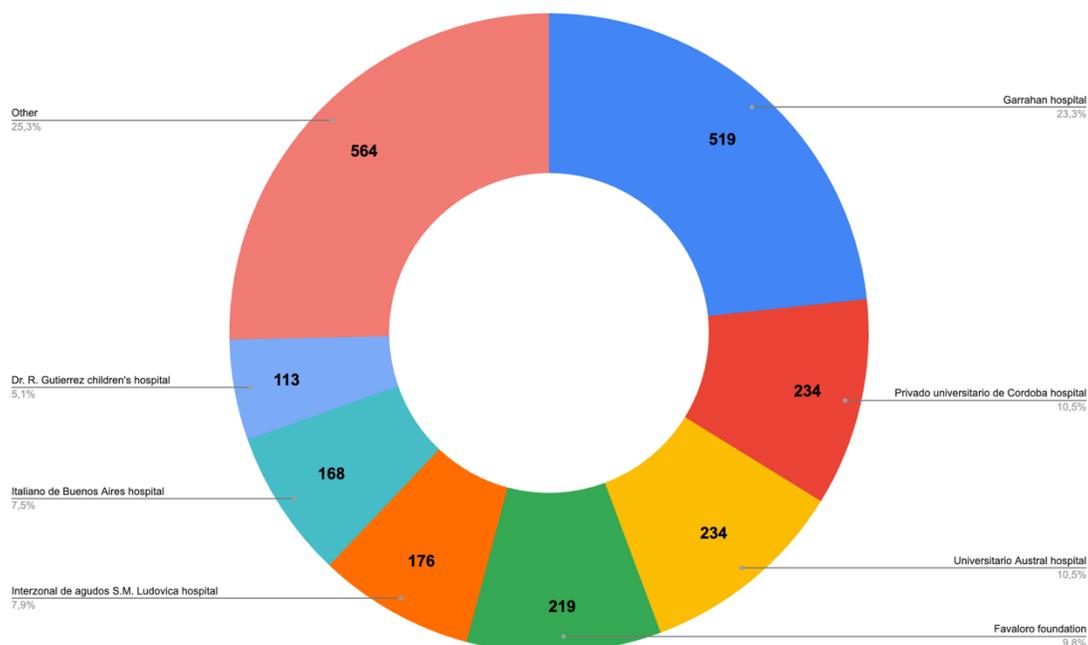
In terms of coverage, 35 percent of transplant patients fall into the public system, 54 percent into the social security system, and 10 percent into the private system. In contrast to the oncopediatric network, 43 percent of transplant services are provided by the public sector and 57 percent by the

⁵⁶ Data updated as of September 9, 2022, in SINTRA for 2009–2022.

⁵⁷ For the 2009–2021 period according to SINTRA.

private sector. The main treating institutions (Figure 10) were the Garrahan Hospital (23.3 percent), the Private Hospital of Córdoba (10.5 percent), the Austral Hospital (10.5 percent), and the Favaloro Foundation (9.8 percent).

Figure 10
Number of Transplantations by Treating Center, 2009–2022



Source: Authors, based on information from SINTRA for 2009–2022.

To disaggregate the coverage of transplant patients, a breakdown is made of the type of funder in the aforementioned treating centers. Table 15 shows that the Gutiérrez Hospital treats mostly patients with public health care coverage (82 percent) while the Garrahan Hospital treats patients with both public (56 percent) and Social Security (42 percent) health care coverage. Likewise, both the Favaloro Foundation and the Austral Hospital treat a very low percentage of patients with public health care coverage (3 percent and 8 percent, respectively).

As a final comment on this section, it is worth highlighting several indicators that allow us to argue for the need for a systemic equity-based reading of the Argentine health sector to be applied to the specific characteristics of the oncopediatric case.

On the one hand, it is verified that even among patients with only public health care coverage at the primary care level (Sumar Program perspective), public health care presents gaps between jurisdictions, the most favored being those with the greatest institutional capacity (CABA, Tucumán, Córdoba). On the other hand, organ donors (INCUCAI perspective) are concentrated in public health care centers, while those who benefit most from the Argentine model of organ recruitment have social security and private health insurance coverage.

However, and in contrast, the most highly complex treatment for these patients lies in public centers—mainly the Garrahan Hospital, followed by the Gutiérrez—which could eventually facilitate a health road map that contributes to an efficient agenda, while converging to a more equitable approach, to the extent that it enables the generation of adequate monetary incentives to cover access gaps.

Table 15
Main Health Care Centers Ranking according to the Volume of Bone Marrow Transplantation and by Category of Transplant Funder, 2009–2022

Transplant center	<i>Patient coverage type (funder category)</i>				
			% Public	% Private	% Social security
Garrahan Hospital	519	23.30%	56	2	42
Private University Hospital of Córdoba	234	10.51%	39	6	55
Austral University Hospital	234	10.51%	8	21	71
Favaloro Foundation*	219	9.83%	3	16	80
Sor María Ludovica Interzonal Hospital for Emergency Care	176	7.90%	68	2	30
Italian Hospital of Buenos Aires**	168	7.54%	11	14	73
Dr. R. Gutierrez Children's Hospital	113	5.07%	82	4	14
Other	564	25.33%	26	15	59
Total***	2,227		54	10	35

Source: Authors, based on information provided by SINTRA for 2009–2022.

Notes: *1 percent —; **2 percent —; ***0,36% —; — = Not available.

Having an Oncopediatric Registry has made it possible to analyze not only the results of interventions but also trends. In general terms, childhood cancer care in Argentina is strongly clustered in two centers in CABA—both in the public sector. Within the current care structure, certain regional patterns of patient referral can be noted, especially within the public subsystem and between subnational jurisdictions established based on the capabilities of some public hospitals and private centers. However, it cannot be asserted that there are referral specialization patterns or referral centers. Furthermore, this analysis reveals some key elements to be taken into account when designing an oncopediatric network. On the one hand, there is the need to achieve coordinated management between the different programs of the Health Ministry and an oncopediatric program that enhances early detection in patients who rely on the public subsystem as their primary source of care. On the other hand, to achieve the specific objectives of an effective oncopediatric network, it is necessary to establish formal mechanisms for dialogue between the providers of the three subsystems and between the 24 provincial health ministries. The frequent contracting of services provided by public referral hospitals by funders in both the private and social security subsectors is noteworthy.

2.5 Price vector of related services

Price variation of treatments delivered by each health care provider was a topic frequently raised during the interviews. A set of nine services commonly rendered in oncopediatrics was selected to compare the price of the service provided by six high-complexity centers both in the public (two) and private (four) sectors in the Buenos Aires Metropolitan Area. Each of the centers under consideration has its health care services directory, which is updated and shared with the funders every year.

Table 16 documents the information collected, which was selected based on the International Classification of Childhood Cancer (ICCC) classification of services by specific pathology type. Also, they were ranked by complexity level according to an index that takes values from 1 to 4, where 1 represents the lowest complexity level, and 4 the highest complexity level. Based on the price grid—base 100—for Public Hospital A, the price variance of the remaining providers was calculated. The information was expressed in percentage differences concerning the "benchmark center" to simplify the analysis. Except for Public Hospital A, it was not possible to access all the prices per service listed, which were indicated in the table with the n/d (no data) notation.

The data allow us to identify some patterns that require further study, as well as some peculiarities. First, the price heterogeneity between centers can be observed throughout the selected services group. Although among private centers, one has systematically higher prices, it is possible to establish a similar relative structure among them.

The differences can be attributed to several circumstances, some of which are not necessarily mutually exclusive. One of them can be explained by the fragmented nature of the system, such as different geographical coverage areas or a different mix of associated funders, which generates differential market niches. Another alternative is institutional specialization: different centers have professionalization biases in one type of tumor or intervention, generating lower/higher specialization costs.

Another factor that could influence the price difference is the quality component offered by each hospital or center, whether it is real—better equipment, professionals, follow-up—or apparent, perceived by the funding institutions or by the families themselves—such as loyalty to the "institutional brand," trust, track record, previous experience—which encourage the payment of higher prices. Since the valuation of these elements is different among different insurance mechanisms and different families, the price vector diverges from a single set.⁵⁸ Within this group of valuations is the human resources training component that several of them hold as part of their institutional objectives, not only internally, but also as a trademark that they "export" to other hospitals and centers, generating professional respect and sometimes building a professional network that promotes loyalty.

It is also evident that private centers tend to set higher prices than public hospitals for services involving a low level of complexity, probably due to the nature of patients or partner funders, who may consider the quality of their services to be higher than that of public centers. One exception is Public Hospital B, which has significantly higher and relatively lower prices for the services under study (hemogram with platelets and abdominal ultrasound, respectively).

As the levels of complexity increase, private institutions lower their relative prices with respect to Public Hospital A. The latter can be seen in services numbers 7 and 9. A reasonable explanation for this is that those centers with greater health risk absorption have a higher level of specificity or resolution capacity, which leads to greater sectoral power. Given that this is a public hospital, and that it has a price directory for patients with private or social security coverage, it can be considered a cost recovery mechanism, a strategy that is not applied to patients with sole public coverage.

Bearing in mind that this analysis takes into account only six high-complexity health care service providers from the public and private sectors and a small number of interventions, it is necessary to broaden these findings and see if they can be applied to all the services offered throughout an

⁵⁸ Economic literature has extensively developed the concept of product differentiation as a key component to explain price diversity in any market. Horizontal differentiation refers to what occurs with differences in choice or proximity (or coverage type in this case), while vertical differentiation is based on different qualities. To the extent that quality has different components in a health care system (comfort, effectiveness, wait times, medical quality, efficiency) and that this quality is not always visible to the patient or the funder, the "measure" of quality is correlated with "brand" confidence (Shaked and Sutton 1987).

oncopediatric network. Therefore, future lines of research should consider a bigger data set to validate or rule out trends associated with each clinical specialty.

Table 16
Price of Procedures by Provider*

Number	Service			Service provider						
	Complexity level	Name of service rendered (procedure/exam)	Pathology – ICCC	Type	% Public hospital A	% Public hospital B	% Private center C	% Private center D	% Private center E	% Private center F
1	1	Hemogram with platelets	I – Leukemias	Acute myeloid leukemia	100	228	309	91	96	69
2	1	Abdominal ultrasound	IV. Neuroblastoma and other peripheral nervous system tumors	Neuroblastoma and ganglioneuroblastoma	100	-35	356	69	118	148
3	2	Fine needle aspiration biopsy	II. Lymphomas and reticuloendothelial tumors	Non-Hodgkin's lymphoma	100	40	49	-58	—	—
4	2	Computed tomography (CT) – Abdomen and pelvis under anesthesia	VI. Renal tumors	Wilms' tumor and other neopithelial renal tumors	100	1	161	-33	146	—
5	3	Bone marrow aspiration procedure	I – Leukemias	Acute Lymphoblastic Leukemia	100	-49	-15	-15	-5	—
6	3	Lymph node biopsy	II. Lymphomas and reticuloendothelial tumors	Hodgkin's lymphoma	100	49	207	170	—	—
7	3	Flow cytometry	II. Lymphomas and reticuloendothelial tumors	Non-Hodgkin's lymphoma	100	-75	-66	-83	—	—
8	3	Brain MRI with gadolinium	III. Central nervous system tumors	Astrocytoma	100	0	40	0	—	7
9	4	MIBG scintigraphy	IV. Neuroblastoma and other peripheral nervous system tumors	Neuroblastoma and ganglioneuroblastoma	100	38	-22	-49	—	—

Source: Authors, based on information provided by key stakeholders.

Notes: ICCC = International Classification of Childhood Cancer; MRI = Magnetic resonance imaging; MIBG = Metayodobencilguanidina; — = Not available.

*The amounts were calculated in Argentine currency at running prices and are expressed in percentage terms based on Public hospital A rates (benchmark hospital).

**To protect the identity of each of the service providers and for benchmarking purposes, a letter has been assigned to them.

PART III

Discussion

The evidence collected has allowed us to shed light on the difficult path that patients navigate in the current oncopediatric care structure framework. Figure 11 shows each of the steps along this pathway, which allows us to set out challenges and opportunities aimed at strengthening it.

In the first place, and as the regional and international literature review shows, the family identifies the child's first symptoms and turns to the health system. Some parents have more information than others about symptoms that lead to suspicion of cancer, which is why the future oncopediatric network should consider a **communication strategy** targeted in this direction.

Based on this, a second element should be addressed: the poor understanding that both health care services and users have of the **health network organized by levels of resolution**, which leads to limited attendance in health centers and instead direct visits to hospital emergency rooms, or specialists, without seeing the general practitioner first. This element, also reported in local and global literature, goes beyond the construction of an oncopediatric network but conditions its performance in terms of delays between detection and diagnosis. This interaction with the health system, on the other hand, reveals another structural challenge: the **fragmentation between subsystems**—public, social security, and private health insurance—which results in different approaches and qualities of care beyond the identified health need. As mentioned above, the strong interplay between national referral public hospitals with patients with different health care coverage schemes could contribute to reducing access gaps.

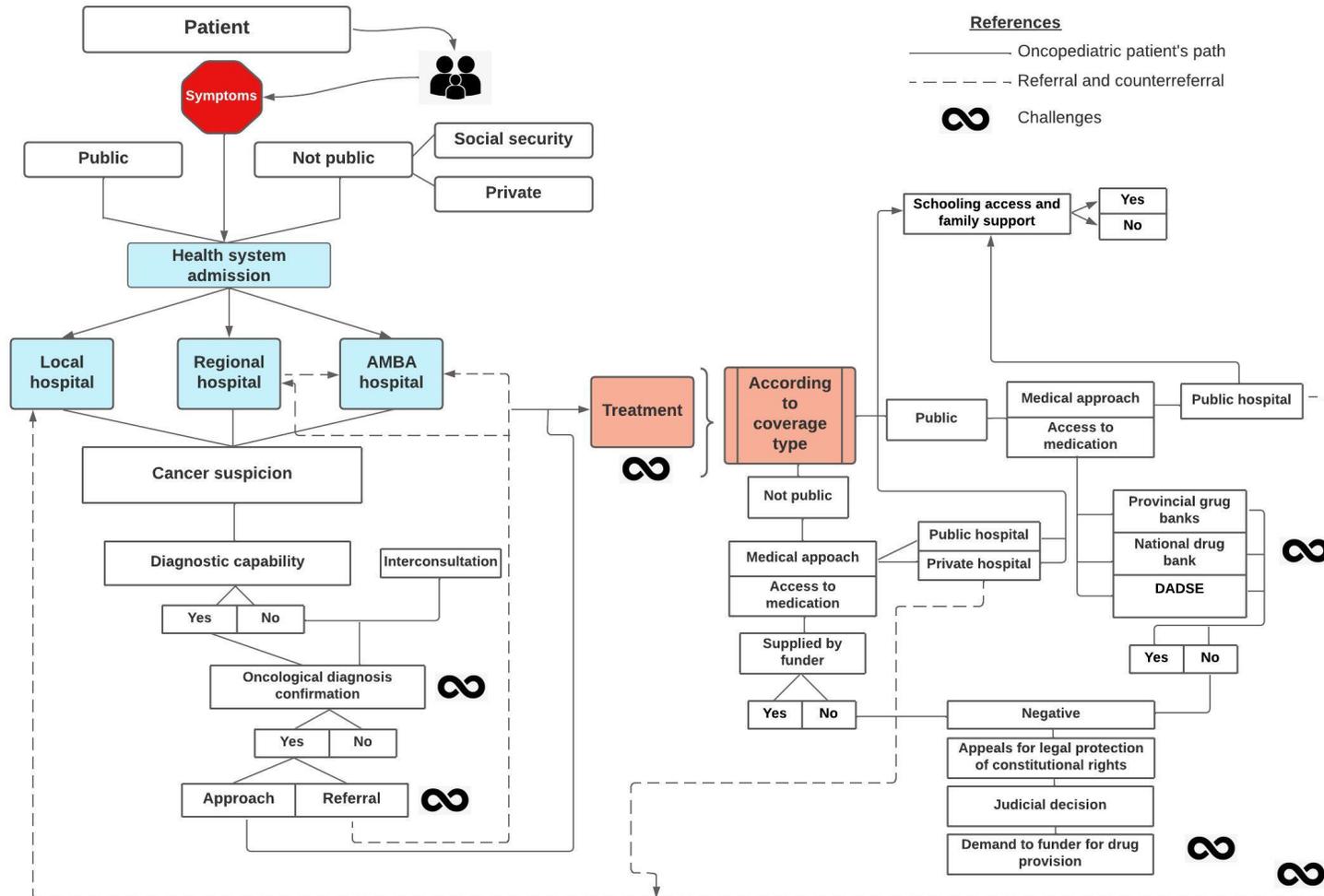
Once the patient is admitted to the hospital or clinic—whether local, regional, or in the Buenos Aires Metropolitan Area (AMBA), the practitioner makes the clinical diagnosis to confirm or rule out the pathology. Due to the disparity of human resources, technologies, and infrastructure, there are centers capable of performing both screening and diagnosis; others that can perform the tests but do not have diagnosis specialists; and centers that cannot perform either of the two tasks. The latter two cases require an inter-consultation with a specialist and a referral for the corresponding tests, respectively. Therefore, the time involved in the diagnostic stage is not uniform for all health care providers.

Once the pathology has been confirmed, the practitioner then decides where the patient will be treated: in the hospital of origin or in a higher-complexity hospital, for which referral will be required. No uniform **mechanisms were observed when referring and counter-referring** patients. It is usually the informal relationships between health care professionals that prevail and determine patients' referral to one center or another.

Given that most patients are of school age, access to education is a central element in the medical pathway. Should the patient require hospitalization and/or rest at home, the treating medical center takes the corresponding actions to **assure the continuity of the child's schooling**. Based on the elements gathered during the mapping of players, classroom spaces within hospitals for hospitalized patients, as well as home teachers for patients at rest are reported.

Figure 11

Flow Chart of Oncopediatric Patient's Path



Source: Authors, based on the interviews conducted.

Notes: AMBA = Buenos Aires Metropolitan Area; DADSE = Direct Assistance Directorate for Special Cases.

Each hospital is responsible for coordination with the Education Ministry on a case-by-case basis. Also, if a patient is referred to a health care center located in another province, there are family support mechanisms in place. Both private sector and social security funders, as well as high-complexity hospitals, provincial governments, and civil society foundations, **provide financial assistance to families to cover transportation and lodging costs** in the destination city.

Once the treatment and treating center have been defined, the **necessary treatment drugs are requested**, and access is defined—again—according to household health care coverage: the corresponding funder purchases the requested medication for those patients with private or social security coverage, while the provincial drug banks must provide the drugs for patients with public health care coverage. Medication is delivered at the hospital or attending center in either case.

In this regard, it is important to note that the private and social security subsector has formally established mechanisms for requesting medication, which generally contemplates maximum response times. In the public drug supply system, there is no formal mechanism to guide requests, but rather each province chooses where to make the request, **either at the Provincial Drug Bank, the National Drug Bank, or the DADSE** (Directorate for Direct Assistance in Special Situations). Each agency and/or funder (public, private, and social security sectors) has its own procurement mechanism, and therefore there are price differences.

Since each practitioner decides which treatment protocol to follow, the drug type prescription may differ. When this happens, public entities and funders—through their respective agencies—may reject the request. If this should occur, there is the phenomenon of **appeals for legal protection of constitutional rights** filed by the families, which results in the judiciary deciding on the treatment to be provided to the patient. To this end, as noted, usually the financing institution is compelled to issue the medication.

3.1. Challenges and Opportunities

The abovementioned patient's critical path makes visible several challenges to consider when designing an oncopediatric network. First, it should be noted that the latter includes a set of elements that define it.

It is a high-cost network, due both to the treatment cost—which may involve days, months, or years of hospitalization—and to the drugs required to treat each case. It is also a network that deals with a sense of urgency since oncopediatric patients require a correct diagnosis and an effective treatment initiation. Thus, the human resources devoted to this task must be specialized.

Next, it is worth asking who the stakeholders and/or organizations involved are. Some interviewees described the network by referring to the use of the ROHA by a group of medium- and high-complexity public hospitals. However, an enhanced approach should consider the role of families, primary health care centers (Centros de Atención Primaria de la Salud (CAPs), and health agents. In this regard, the literature analyzed has shown the powerful impact of the latter stakeholders and the value of empowering them to achieve large-scale benefits (Lupo and Spector 2020). Stakeholder mapping included in Part II revealed the coverage scope of the private and social security subsystems, which prompts us to consider social security organizations and private health insurance companies within the network.

Therefore, the health system fragmentation in Argentina can be considered an area of opportunity. As stated at the beginning of this paper, the health system is segmented into three subsectors based on their funding source, there are glass walls that divide patient treatment according to coverage type: patients with public health insurance coverage are mostly treated in public hospitals, while those with social security or private health insurance coverage go to private health care centers.

When looking at oncopediatric services, it is evident that the glass wall collapses, since funders of both the private and social security subsectors frequently refer and/or contract services provided

by public hospitals. Given their level of specialization, the latter have managed to position themselves as referral institutions, thus blurring some of this public-private divide. Likewise, patient referrals within the public subsystem, between subnational jurisdictions, occur more frequently than in other lines of care.

Based on this organizational structure of the health system, a set of main themes that need to be addressed in the construction of a future working agenda are detailed below. The themes selected to sort the analysis were the network creation and processes protocolization; the drug supply function under a systemic thinking approach; stakeholders' incentives to join the network; and the strengthening of initiatives along with the network's governance issues to be considered.

3.2. Network creation and processes protocolization

The lack of official family-oriented guidelines to identify cancer suspicions, and the absence of protocols to regulate health care professionals' decision making at each of the key stages of the patient's critical path leads to inequity scenarios in health care access, as well as inefficient resource allocation. Although there are currently guidance documents that aim to favor timely diagnosis and appropriate referral in due time and form (INC and SAP 2019; INC 2016, 2018a) the creation of a network should involve process protocolization.

Initially, continuous training schemes should be developed to enable health professionals in primary health care centers (CAPs) and medium-complexity hospitals to achieve early pathology identification, reducing detection times and treatment-associated costs. In turn, there should be widespread dissemination of official guidelines to provide parents with cancer suspicion-related information, thus strengthening the alert mechanisms for case identification in the pediatric segment. Strategies that promote a fluid exchange between these stakeholders (health care professionals and families) should be assessed. As noted in the literature review (Codarini et al. 2018), interventions such as the National School Health Program (Programa Nacional de Salud Escolar, PROSANE) can serve as an example since they deliver a double impact: optimal target population outreach and effective pathology detection.

The perceived differences between public and private sector stakeholders' positions regarding early detection mechanisms lead to question on their efficacy. Based on the literature reviewed (Lupo and Spector 2020; Heirs et al. 2013; Fragkandrea et al. 2013), it is essential to reassert that prevention and awareness-raising activities could improve early diagnosis indicators.

Despite the implementation of the Sumar Program, which targets the affiliation of families to primary health care centers (CAPs), one can observe that most of the Argentine population does not have a primary health care reference center. With a few exceptions, the same is true in the private and social security subsectors.

Thus, the health care agent, who could contribute to the development of a prevention and/or early detection strategy, is not fully utilized. Training the primary health care system could lead to an improvement in the network's performance. To this end, the Sumar Program lines of care could be the basis on which to establish training schemes for professionals in primary health care centers (CAPs), and at the same time generate dissemination mechanisms for available services, which, as shown in the previous section, are scarcely used.

The existence and application of protocols for pediatric patients with cancer suspicion will make it possible to homogenize diagnosis and medical intervention times within each of the health system's subsectors.

Data analysis provided by INC-ROHA has revealed certain trends regarding the current referral circuits that in some way configure established regional corridors based on the capacities of some public hospitals and private centers.

Figure 12 shows the current network operation in terms of patient referrals at country level and evidences the existence of regional nodes, beyond the high concentration levels of patients referred

to the AMBA (Buenos Aires Metropolitan Area). In the Northeast of Argentina, Corrientes and Chaco receive patients from Misiones and Formosa. In the Northwestern Region, Tucumán takes referrals from Salta and Santiago del Estero. Mendoza gets patients from San Juan and San Luis. In the Central Region, Córdoba and Santa Fé take patients referred from different regions (Entre Ríos, Catamarca, La Rioja, Santiago del Estero, San Juan, San Luis, La Pampa, and Rio Negro). Finally, Neuquén receives patients from Patagonia.

Patient referrals with public health care coverage between provinces entail a change in the funder, which generates the transfer of financial and health risks from provinces with a lower resolution rate to provinces with a higher resolution rate. Beyond invoking solidarity between jurisdictions, the design of an oncopediatric network that systematically relies on referrals between provinces should consider monetary and nonmonetary incentive schemes for its implementation. Otherwise, this would mean setting up a network that operates based on goodwill and short-term care capacity, which constitutes a risk transfer to oncopediatric patients.

As exemplified in the provincial case studies, included in Part II, the phenomenon of systematic referral of patients from other provinces led Corrientes to stop receiving cases, generating a split within the network. In addition, the Chaco case showed that public health care provider agreements make referral circuits more efficient.

Observation of private and social security subsector funders shows that this phenomenon does not take place, since these players can resort to the hospital and referral centers' fee registry. In turn, most of the funders have signed agreements with high-complexity centers—both public and private—on which referral procedures are established.

Thus, network consolidation should consider the development of formal agreements between public hospitals in the provinces where they are located—which could be expanded to the private and social security sectors if funders so wish—to facilitate the referral process, sustain cases resolution at the intermediate network level (regional nodes), and allow for financial reimbursement to the receiving provinces.

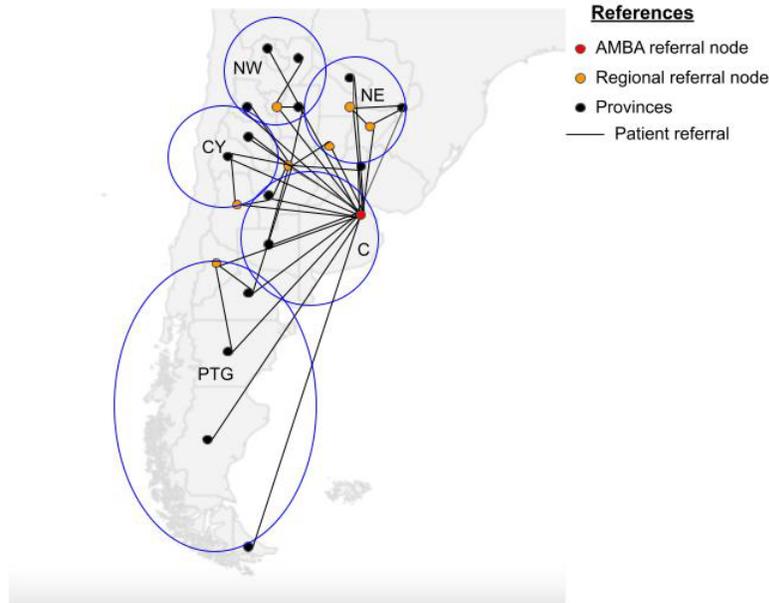
Or, otherwise, establish automatic mechanisms for health care cost deduction for social security organizations through the National Social Security Administration (Administración Nacional de la Seguridad Social, ANSES), reducing transaction costs to the system.

This institutionalization process (in referral protocols and payment agreements) could contribute to the resolution of a problem that has been extensively documented throughout the mapping of players: the systematic referral of patients to high-complexity hospitals in the AMBA node, regardless of the cases' risk level, which could be managed in a regional hospital.⁵⁹

⁵⁹ Economic literature thoroughly reviews the mechanisms that characterize the need for a microeconomic unit to incorporate new productive processes within the unit, or to seek ways of contracting that enable the execution of these tasks outside the unit. Coase, R. (1937) definition of the "limits of the firm" is a step in this direction, a subject later addressed by Williamson's (1989) Transaction Cost Theory. He suggests that the definition of whether or not to integrate new processes rests on two elements: the frequency of the activity and the specificity of the inputs needed to carry it out. The lower the frequency—such is the case for the demand for oncopediatric services at the provincial level—the lower the opportunity to develop the process internally. The greater the specificity, the greater the probability of integration to the extent that there is no unit in the institutional environment capable of dealing with the required service. In the case of the potential oncopediatric network, this level of specificity is "transferred" to the more complex units of the network, increasing efficiency and reducing operating and management costs. For this to be possible, it is necessary to guarantee referral protocols and ensure the coverage of transfers within the network, to maximize "joint" oncopediatric productivity.

Figure 12

Regional Corridors for Oncopediatric Patient Referrals



Source: Authors, based on data provided by the INC.

Note: AMBA = Buenos Aires Metropolitan Area; NW = Northwestern region; NE = Northeastern region; CY = Cuyo region; C = Center region; PTG = Patagonia region.

Unfortunately, the stakeholders' mapping identified not only unnecessary costs of patient referrals to transfer (which sometimes originate in patient "self-referrals"), but also choosing to keep patient treatment within the local setting without having the skilled human resources or equipment to do so. The search for expertise and lack of oversight and reporting jeopardizes patients' health.

In light of this, knowing the characteristics of each of the hospitals and centers in the network will make it possible to establish health care service providers' capabilities and select the treating center on a case-by-case basis. Therefore, based on this stratification—which should consider not only public hospitals but also social security and private sector hospitals—formal rules can be established to guide the actions of professionals, avoiding biased decision making. Once the regional nodes have been formalized, the application of these rules should take into account both referral center proximity and the patient's complexity level.

It will be necessary to establish incentives to facilitate the use of the aforementioned protocols. Therefore, periodic audits that certify hospital performance can be used to establish rewards or penalties.

The lack of clear referral and counter-referral mechanisms characterizes the interaction between hospitals. High levels of informality in these processes can limit the network's reach, increasing health care worker liability and adding to patient risk. Nonetheless, it has been proven that the presence of discretionary mechanisms—not always in compliance with the regulations—sometimes contributes to the network's performance, filling regulatory voids (Crojethovic and Maceira 2009; Maceira and Kremer 2012). In light of the above, institutionalizing these processes would make it possible to organize referral patient acceptance, thus avoiding overburdening some hospitals and enhancing the supply of available service providers.

Improved coordination processes can bring other benefits such as avoiding duplication of studies and diagnostic tests. It will also guide the counter-referral of patients, allowing local hospitals to continue treatment—if possible—or engage in case follow-up.

3.3. Drug supply function

Most of the drugs required for pediatric oncology treatment are high-cost drugs. The public drug supply function poses unique challenges that ought to be addressed. Given that the agencies involved—National Drug Bank, Provincial Drug Banks, and DADSE—are not operating as part of a network, there is evidence of incentives for cross-transfer of financial risks, function overlapping, and access inequality. In addition, the fact that some provinces solve the issue of supply at the provincial level through money granted by international loans constitutes unsustainable behavior in the medium term.

Given that Argentina is one of the few countries in the region that has developed public drug production schemes, the question arises as to the possibility of considering its integration into the network. Although its performance is especially irregular among institutions, efforts have been made in recent years within National Public Laboratories Administration (Agencia Nacional de Laboratorios Públicos, ANLAP) to standardize the certification process and enhance its production capacity, mainly for drugs with lower technological challenges.

Individual procurement mechanisms reduce the bargaining power of players, which has an impact on network funding and undermines its performance and sustainability. It is therefore advisable to consider public schemes that ensure the tendering of drugs by price vector, thereby generating options that guarantee drug procurement with less budgetary exposure. In this way, logistics is managed at the national level, but not the jurisdictions' budgets, only modifying the drug pricing mechanism and substantially improving the stakeholders' bargaining power. If this type of mechanism were to be implemented, the national or provincial drug banks, the DADSE, and other private or social security coverage mechanisms that subscribe to it could take advantage of this option.

Meanwhile, the efforts made by social security organizations to address this issue have not gone beyond the scope of each institution's jurisdiction. Interviews with representatives of these agencies revealed that there is still a potential for collective action through the Single Reimbursement System (Sistema Único de Reintegro, SUR). Delays in reimbursement and the lack of mechanisms for price updating to recover the real costs discourage the use of this tool and, at the same time, lead to a transfer of financial risk to social security organizations. Thus, agreements between the Superintendency of Health Services (SSS) within the SUR program framework and Social Security Organizations could be assessed to speed up administrative procedures, especially in cases of oncopediatric patients who urgently require expensive drugs.

National and provincial public institutions mentioned the connection between the lack of drug coverage and the existence of appeals for legal protection of constitutional rights. This reflects two issues. On the one hand, the patient's treatment is delayed, which has a direct impact on his or her survival; on the other hand, given the majority of judicial rulings, the funder is forced to purchase the medication at a much higher price than the market price due to the urgency of the situation.

From a systemic thinking perspective (Peters 2014), a common governance framework should be considered to articulate the work of each stakeholder, establish rules to regulate the requisition process, generate communication mechanisms to respond to emergencies, and ensure the proper use of the available stock.

3.4. Stakeholder incentives to join the network

A structured oncopediatric network will require the articulation of several stakeholders, with different incentives to engage. Therefore, a case-by-case approach should be applied to each case. Health

care professionals in medium- and high-complexity hospitals should be invited to join the network, thus allowing for constant exchange and learning. In addition, a system should be implemented to promote the training of human talent, guiding the allocation of scholarships to stimulate cancer research effectively, and seeking to strengthen intermediate referral centers and specialties associated with each region's demands.

Moreover, the network should generate information mechanisms related to oncopediatric service providers—taking into account prices, quality of service, and availability—that will allow social security organizations and private health insurance companies to make their referral decisions based on a cost-effectiveness principle. In this way, there will be incentives for these players to engage in the network and report the identification of oncopediatric patients. In addition, patient referral schemes should be established for both the public and private sectors. Thus, private health care centers would have the incentive to take part in the project.

The National Health Ministry should operate in coordination with the Provincial Health Ministries to implement processes to improve oncopediatric service indicators. It is reasonable to assume that the provinces will not make investments that they cannot raise with their own resources. Within this framework, a network-funding model should be established to make it possible to articulate the initial actions and subsequently generate its sustainability. One alternative is for both parties to sign agreements that reflect management commitments on the part of the Provincial Ministries and allocate a budget amount to achieve these goals. The expansion of the Sumar Program's oncopediatric services will also make it possible to reinforce awareness and detection schemes at the primary level of care.

The decision to join the network should be voluntary. However, as mechanisms are developed to increase efficiency in the processes, being part of the network will be more convenient than operating individually. Thus, the network will be strengthened to the extent that clear rules are defined and the interests of the parties are aligned.

3.5. Network governance and key components

To generate incentives for collective agreements, a network governance mechanism and a network regulatory framework should be contemplated. The latter should be defined and applied by a national public agency that is involved in the matter. Given that the Health Ministry is the national health guarantor institution, the administrative unit for oncopediatric coordination should be established within the ministry to strengthen the steering role and technical assistance to the provinces in a decentralized context.

Likewise, to establish cross-controls between administrative and regulatory management, on the one hand, and the network's clinical management, on the other, it is suggested that this second medical unit operates under the orbit of a consortium of hospitals, possibly located at Garrahan Hospital as the head of the network and that it should have collegiate governance.

Funding—both for the coordinating center itself and for the resources available to set up the network—also contributes to consolidating the Health Ministry as the host institution of the Administrative Unit: usually, programs by line of care are managed in separate spheres and with resources aligned with specific objectives, without a systemic vision. Having a ministerial administrative unit could contribute—from a systemic view of the ministerial role—to greater coordination with programs focused on the primary level of care, with the provision of drugs, and with those that seek to generate lines of care. It would also be an opportunity to advance in specific areas of interaction, beyond the rhetoric—between the public system, social security, and the private sector; provider and insurer—launching a path of joint work based on a priority pathology, with the intent to expand to other areas of care.

In turn, the coordinating medical center will have to implement the corresponding network management processes, its main role being to organize the flow of patients. As these are operational functions, their actions should be based on the network's regulatory framework

mandate. Hence, substantive decisions will be the responsibility of the entity that authorizes the regulatory framework, exempting the coordinating center from being trapped in politically motivated arguments.

Monetary and nonmonetary incentives could help reduce tensions and align stakeholders, bringing legitimacy and sustainability to the network. The coordinating center's manager position will be occupied on a rotating basis by professionals from the AMBA node high-complexity institutions and will contemplate the invitation of professionals from provincial hospitals and centers to generate not only technical but also managerial learning (nonmonetary incentives). It will be necessary to have a specialized hub that can provide recommendations related to treatments by pathology, as well as suggest possible options in emergency cases.

The reputation of health care service providers was one of the issues discussed by national stakeholders. Highly specialized hospitals have significant social recognition, which influences the decisions of families when choosing where to treat their children. This reveals a lack of confidence in the quality of care provided by some local hospitals, which leads to an overload in the demand for services from renowned providers.

One possible solution is to consolidate the already existing grand rounds coordinated by the Garrahan Hospital as a diagnostic setting and to ensure that the treatments are not provided by an individual professional or institution, but are endorsed by the network. A network certification seal will make it possible to level the reputation of the affiliated providers, offering families confidence in the fact that the treatment proposed at the local level has been validated by the network as a whole.

In this way, grand rounds would allow professionals with different backgrounds to share lessons learned that contribute to collective knowledge and installed capacity. Under this initiative, it is suggested that an explicit standard be established for case selection and that the meetings should continue to be held frequently, as has been the case to date.

The initiative should be carried out in such a way that it is open to all stakeholders involved in the network, both public and private health care service providers. This would promote convergence in the use of clinical protocols, which, in turn, could lay the foundations for homogeneity in medication management.

Human resources training should be another objective of the coordinating center. Due to patient referral overload to high-complexity centers, the training of professionals belonging to intermediate hospitals is a key element to be strengthened, thus allowing certain cases to be dealt with at the local level.

Likewise, the scholarships granted by the INC—and the internships at Garrahan Hospital and other teaching institutions—could be used as tools to achieve this objective. Being awarded according to the level of professional engagement in the network would generate monetary incentives, and professional skills would be boosted, covering needs that would strengthen joint production. Furthermore, given that it is the coordinating center that defines both its designation and the topic to be investigated, research schemes can be geared to meet network demands. As the results of the projects managed by the INC are currently not available out of respect for the intellectual property of their authors and to avoid similar scenarios, special emphasis should be placed on the fact that the products generated within the network's framework should be proprietary to the network.

Finally, considering how sensitive the issue of oncopediatrics is, it will be vital for the network to have a communication strategy that promotes dialogue and understanding between health care providers and families. Within this framework, a figure that manages to establish a smooth dialogue between health professionals' decisions and families could facilitate understanding among stakeholders and enhance proper coordination of subnational service providers. In addition, they could cover issues related to the need for support and guidance required by both patients and their relatives.

PART IV

Conclusion

4.1 Road Map for the Consolidation of an oncopediatric network

This study has shown that the Argentine health system has characteristics that affect the performance of any network. Its fragmentation level leads to differential coverage associated with affiliates' income level, with a distinction between the flow of patients with private and social security coverage and those with public health care coverage. Thus, the system's equity is affected.

As mentioned in the previous section, oncopediatric services do not necessarily follow this pattern, but some public hospitals—with high specialization levels—absorb a significant share of the demand, taking in patients from all subsectors. This could be an asset when designing a care scheme that overcomes the glass walls of the Argentine model.

Special attention should be paid to the above when thinking about the road map for the consolidation of an oncopediatric network. Although the structural elements cannot be modified, there are clear opportunities that should be seized. The strength of public providers is a key element in this regard since the inequity problems that characterize the health system can be avoided by strengthening these areas.

Figure 13 allows for an analysis of the foregoing based on four elements inherent to any system: basic conditions, structure, stakeholders' behaviors, and system performance. The basic conditions in the case of the oncopediatric network are those guidelines that make up the health system and shape the structure, the setting in which the future network's stakeholders operate. Stakeholders' behaviors adjust to the boundaries set by the structure, impacting the oncopediatric network's performance indicators.

The existing network was plotted on the left side of the chart. A potential network was plotted on the right side. This road map contemplates the incorporation of another agency in the structure that encourages articulation among stakeholders, modifying their behavior. The components that address network regulation, financing, and prevention are especially relevant. This road map focuses on the regulation since this role is the key factor in the network design strategy.

The following is the suggested action plan, following on the challenges discussed in the previous section to achieve network consolidation.

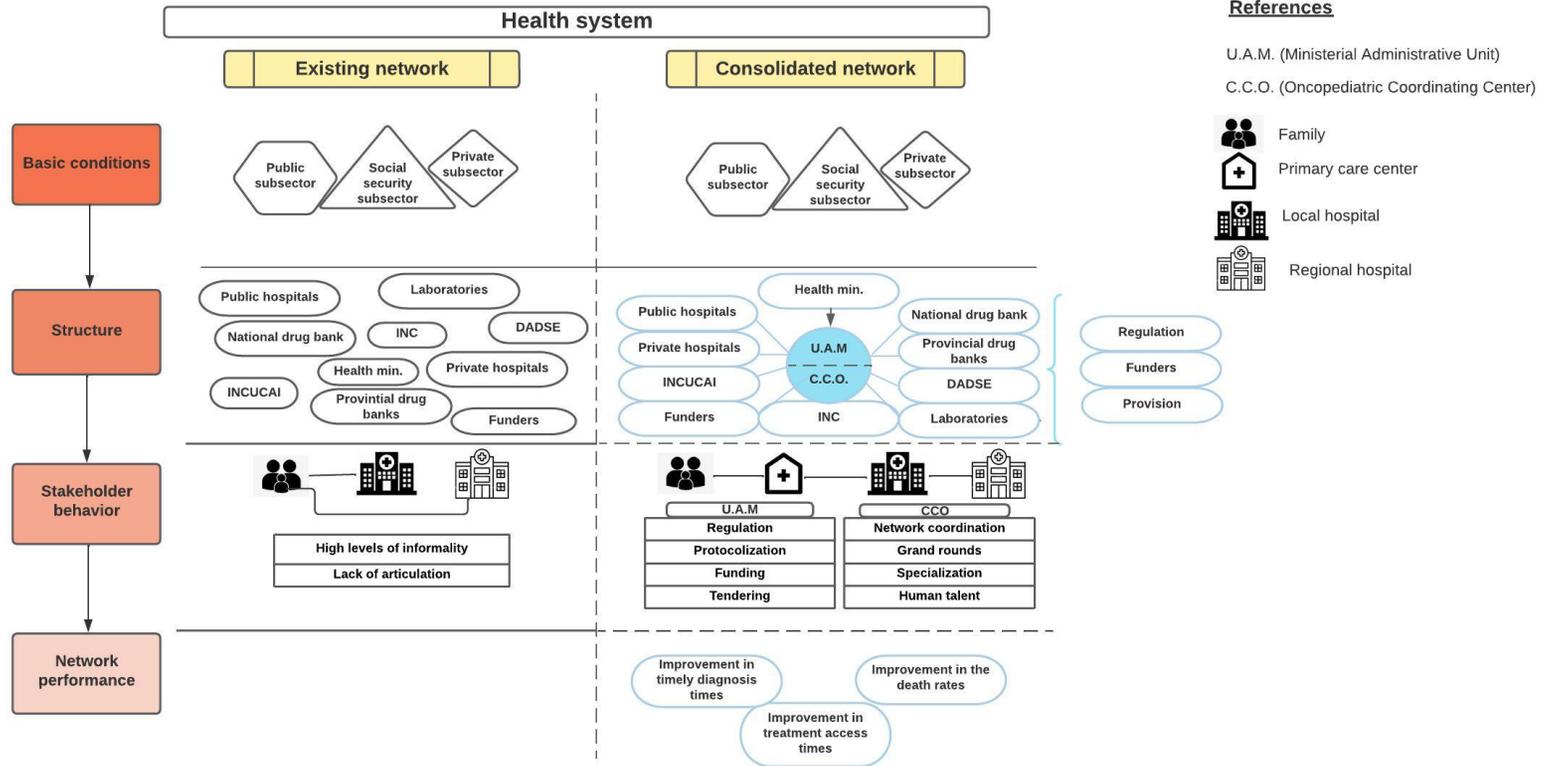
First step: Creation of the Network Administrative Unit within the Health Ministry, and the Oncopediatric Coordinating Center (Centro Coordinador Oncopediátrico, CCO). Approval of the network's regulatory framework.

The network's governance should be based on three instruments: a regulatory framework, a Ministerial Administrative Unit (Unidad Administradora Ministerial, UAM), and an Oncopediatric Coordinating Center (CCO). The first should address and regulate every aspect of the network and should be exercised by the National Health Ministry, through an institutional mechanism created to this end. The Ministerial Administrative Unit (UAM) will report to the aforementioned ministry, and its objective shall be to guide stakeholders' behavior, thus carrying out the execution and monitoring of agreements with each of the provinces, defining the investment scheme, scholarship funds, and professional assignments based on the CCO's suggestions. The UAM will be responsible for defining the regulatory structures for cooperation between the public system, social security, insurance, and private service providers.

The Oncopediatric Coordinating Center will be responsible for managing the network, that is, arranging oncopediatic patient flow and strengthening its medical management. The center will be managed on a rotating basis by professionals appointed by the high-complexity hospitals of the AMBA, and by professionals invited from other public hospitals and private centers in the country. Likewise, the creation of a center-dependent tumor committee should be contemplated, to provide recommendations for each of the cases that come into the network. The National Cancer Institute and ROHA management make up the technical advisory body of this Oncopediatric Coordinating Center, and some of the tasks mentioned in the following steps build on the INC's contributions in recent years.

Figure 13

Structure-Behavior-Performance Paradigm Applied to Network Road Mapping



Source: Authors, based on the findings of this study.

Notes: U.A.M. = Ministerial Administrative Unit; CCO = Oncopediatric Coordinating Center; DADSE = Directorate for Direct Assistance in Special Situations; INCUCAI = Single Central National Institute for the Coordination of Ablations and Implants.

Second step: Processes protocolization

Each of the stages the oncopediatric patient goes through will be protocolized. In this way, the network will generate several outputs that will be at the service of both patients and their families, as well as of the provincial agencies that notify health professionals. They are, as follows:

- An official guide that offers childhood cancer suspicion-related information. This should be properly disseminated through the primary care centers' health care professionals.
- A protocol for receiving pediatric patients with cancer suspicion. This protocol will dynamically determine the maximum times for diagnosis confirmation, initially defining deviations in delays based on agreed external parameters, and then converging to specific measures based on each center's patterns, benchmarking performance against regional and national parameters.
- A protocol to guide the actions of each center according to its medical capacity. It will also regulate patient referral and counter-referral processes. This output will depend on the treating centers' stratification results (detailed in the third step).
- Along the same lines, the ROHA should incorporate complementary data-collection modules to monitor the times associated with the diagnosis and treatment processes, as well as referral and counter-referral. In this way, each step of the patient's critical path will be captured by ROHA, pinpointing process bottlenecks and delays.
- To avoid the use of risk selection mechanisms by service providers, the Oncopediatric Coordinating Center (CCO) will be responsible for assessing referrals made based on the complexity of each case.
- Regarding the public drug supply role, the drug requisition process should be institutionalized, contemplating where the procedure should be initiated—that is, to which agency it should be addressed, and what steps should be taken upon refusal in each case.

Third step: Contribute to a National Fund for Oncopediatric Financing based on the expansion of services rendered within the Sumar Program framework.

Actions aimed at strengthening an oncopediatric network should be funded, based on the experience gained through payments for performance in lines of care of the Sumar Program, directed toward the prevention, detection, and diagnosis of oncologic pathologies in pediatric patients at the primary level of care. The purpose is not to create a parallel fund but to contribute to the existing Fund for High-Complexity Diseases that is financed under the Sumar Plan (congenital heart disease). Furthermore, we suggest moving forward in the discussion of a Single Fund for the transfer of resources from the Health Ministry to the provinces that includes all the lines of care in which the federal authority is involved. To be able to invoice these services, the provinces should join the oncopediatric network. In addition, a National Fund should be established to generate investments to strengthen the regional nodes and guide the behavior of network stakeholders, based on investment plans agreed upon between the nation and the provinces. This fund will be executed by the Ministerial Administrative Unit (UAM), which will sign agreements with each of the provinces where management commitments will be defined and specific financing will be allocated to this end. The provincial Health Ministries will act as executing bodies for the strengthening of the network.

The following commitments will be undertaken within this framework:

- Certification of the clinical approach capabilities of each provincial hospital and center—stratification (both public and private). Agreements must contemplate the contracting of independent entities to perform such assessments based on the criteria previously defined by the CCO and the INC.
- Implementation of the ROHA in medium- and high-complexity hospitals. This will make it possible to fully record the patient's history, easing the referral processes and the flow of data between the

network's member institutions through the CCO, while respecting the personal data protection protocols.

- Dissemination of official family-oriented publications on childhood cancer suspicion.
- Achievement of continuous training—based on the official content generated by the INC—aimed at health agents and health care staff of Primary Care Centers (CAPs) and medium-complexity hospitals.
- Implementation of early detection activities at the primary and secondary levels of health care in the province.
- Adequate systematization of the information pertinent to oncopediatric services, reporting, and periodic feedback with the SUMAR Program.
- Enforcement of and compliance with the protocols mentioned in the second step. Special attention should be paid to compliance with the maximum times established in each of the stages of the patient's critical path (confirmation of oncological diagnosis, referral, initiation of treatment, and counter-referral). Also, a correct referral of those cases that require it must be assured.
- Call for and certification of health professionals from provincial hospitals belonging to the network to participate in the grand rounds and training sessions organized by the INC.
- The signing of a minimum number of agreements between local hospitals and high-complexity referral centers (both public and private sector). This will reduce transaction costs for those patients (with public coverage and with provincial social security coverage) who need a referral. The UAM will make available to the provinces model framework agreements with high-complexity public hospitals throughout the country. Social security organizations and private health insurance companies will be able to access the model framework agreements if interested.

Management indicators will be established for each of the agreements signed, which will make it possible to monitor the performance of each of the executing agencies. Since disbursements will be subject to the fulfillment of the agreements—measured by management indicators—each province will receive funding to the extent that it can successfully establish the proper operation of the local network. In addition, the UAM will carry out auditing processes to assess the undertaken agreements. The Sumar Program experience offers lessons learned that make it possible to identify successful management tools for results-based payments as well as challenges that should be taken into account when making disbursements that align the network's objectives with each participating unit's management. The congenital heart disease network experience is a valuable input in this direction.

Each province will regularly get feedback on the results of each of its local centers, the regional average, and the national average. In this way, the executing agencies will be able to track their individual and comparative performance, which will make it possible to identify areas for improvement in the management of oncopediatric services.

As the network is expected to become more robust over time, the goals will be variable and will be adjusted according to the improvement of oncopediatric indicators in each of the provinces.

The fund will also contemplate the payment of specific requests for those patients with limited public health care coverage who cannot be financially supported by their provinces. This will allow high-complexity public service providers to obtain monetary compensation for all the patients they receive, regardless of the type of coverage. Given that—as noted in Part II—there is a broad price dispersion in terms of oncopediatric services, it will be necessary to agree, on a cost study basis, on a common price directory among all referral service providers in the network.

Finally, those provincial facilities that make up regional hubs will be able to submit to UAM oncopediatric services investment plans (infrastructure and technologies) to be cofinanced by the network.

Fourth step: Formalize the network's participating institutions and regional nodes.

Institutional engagement will be formalized through the following milestones. These tasks will be performed using the contributions generated by the INC over the last few years:

- Definition of institutional capabilities (public and private) and their role within the network.
- The participating institutions will receive a badge certifying the collective work. Thus, each of the diagnoses and treatments performed will be certified with a network stamp.
- Consolidation of preexisting regional nodes and setting of formal referral circuits according to the facilities' capabilities.
- The grand rounds conducted by the Garrahan Hospital will become formal articulation spaces; therefore, a mechanism for patient selection should be established.

Fifth step: Generate improvement mechanisms in the drug supply process.

The National Drug Bank will carry out public tenders for drugs by price vector. This kind of tender makes it possible to define—based on the estimated demand—the price of the products to be acquired.

The procedure will be as follows:

- Once a year the National Drug Bank will make a call to collect the drug procurement expectations of each provincial bank and/or equivalent agency.
- Once the information is collected, it will call for a public tender for drugs by price vector.
- The participating laboratories will be assessed based on price, coverage of the tendered items, and quality of the products offered.

Once the tender is finalized, the network will have information on drug prices and suppliers for the coming year. The provinces that have taken part in the tender will have to sign a deed of commitment stating that they will make their procurements using the aforementioned system. Thus, each jurisdiction will continue to make decentralized procurements at the price defined by centralized tenders. These tasks shall be agreed upon between the national ministry and its provincial counterparts, probably within the framework of the Federal Health Council (Consejo Federal de Salud, COFESA). Likewise, under the Superintendency of Health Services (SSS) coordination, social security organizations and private health insurance companies will be able to join this procurement mechanism.

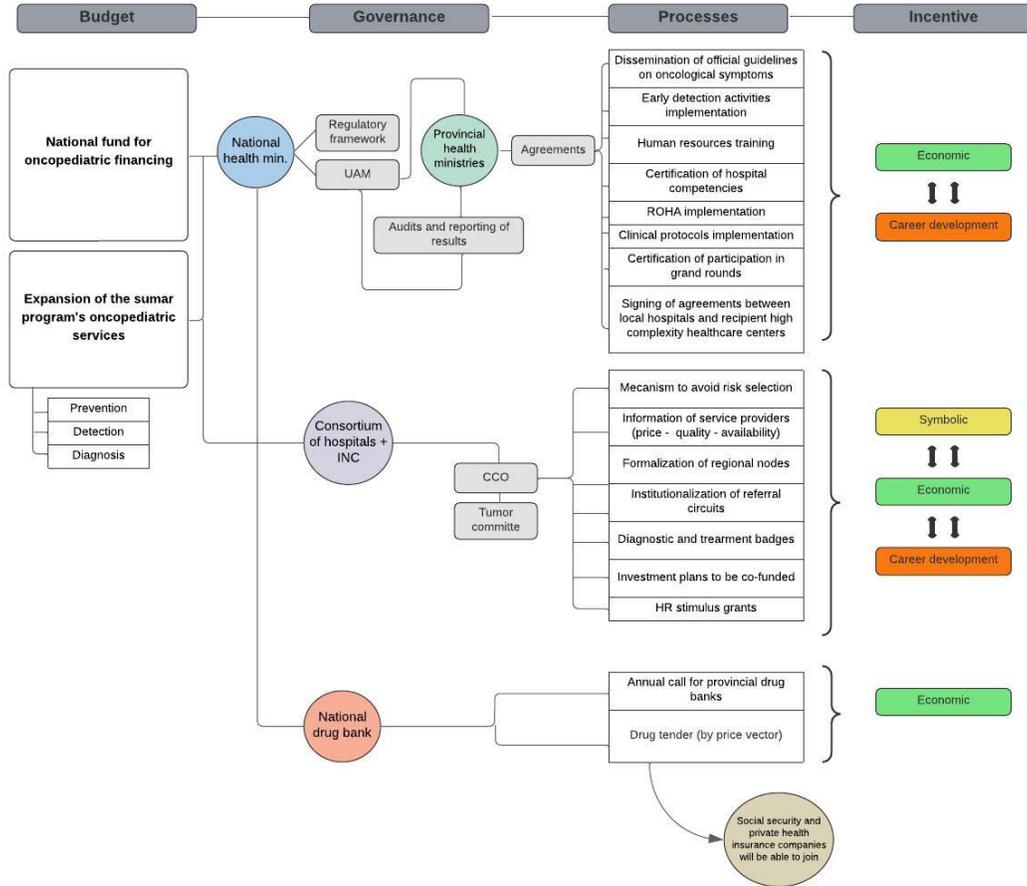
To avoid undesirable behavior, provinces that do not subscribe will not be able to submit medication requests to the National Drug Bank.

Sixth step: Monetary incentives setup

A human talent training system will be implemented by the Oncopediatric Coordinating Center, through scholarships to stimulate cancer research aimed at network hospital health care professionals. Research results will be proprietary to the network so that the coordinating center will have free access to project results. The following figure summarizes the steps described above.

Figure 14

Summary Diagram of the Suggested Actions to Achieve Network Consolidation



Source: Authors, based on the findings of this study.
 Notes: U.A.M. = Ministerial Administrative Unit; CCO = Oncopediatric Coordinating Center; ROHA = Registro Oncopediátrico Hospitalario Argentino (The Argentine Hospital Oncopediatric Registry; HR = Human resources.

REFERENCES

- Aires, L. C. P., E. Kotzias Atherino dos Santos, O. M. Bruggemann, M. T. Stein Backes, and R. Costa. 2017. "Reference and Counter-Reference Health Care System of Infant Discharged from Neonatal Unit: Perceptions of Primary Care Health Professionals." *Escola Anna Nery Revista de Emergencem*. DOI: 10.5935/1414-8145.20170028.
- Angarita Ribero, C. T., L. L. Duitama Vergara, M. J. Hurtado Sánchez, M. A. Córdoba Núñez, and P. C. Guzmán Cruz. 2013. "Caracterización clínica y paraclínica de los pacientes pediátricos con diagnóstico de leucemia linfocítica aguda atendidos en el Centro Javeriano de Oncología" ("Clinical and Paraclinical Characterization of Pediatric Patients Diagnosed with Acute Lymphocytic Leukaemia under Treatment at Centro Javeriano de Oncología"). Colombia, Bogotá: Pontificia Universidad Javeriana.
- Atun, R., Bhakta, N., Denburg, A., Frazier, A.L., Friedrich, P., Gupta, S., Lam, C.G., Ward, Z.J., Yeh, J.M., Allemani, C., Coleman, M.P., Di Carlo, V., Loucaides, E., Fitchett, E., Girardi, F., Horton, S.E., Bray, F., Steliarova-Foucher, E., Sullivan, R., Aitken, J.F., Banavali, S., Binagwaho, A., Alcasabas, P., Antillon, F., Arora, R.S., Barr, R.D., Bouffet, E., Challinor, J., Fuentes-Alabi, S., Gross, T., Hagander, L., Hoffman, R.I., Herrera, C., Kutluk, T., Marcus, K.J., Moreira, C., Pritchard-Jones, K., Ramirez, O., Renner, L., Robison, L.L., Shalkow, J., Sung, L., Yeoh, A., Rodriguez-Galindo, C. Sustainable care for children with cancer: a Lancet Oncology Commission. *Lancet Oncol.* 2020 Apr;21(4):e185-e224. doi: 10.1016/S1470-2045(20)30022-X. PMID: 32240612.
- Arora, B., and S. D. Banavali. 2009. "Pediatric Oncology in India: Past, Present and Future." *Indian Journal of Medical and Paediatric Oncology: Official Journal of Indian Society of Medical and Paediatric Oncology* 30 (4): 121–23. <https://doi.org/10.4103/0971-5851.65333>.
- Arun Kumar, A. R., B. S. Aruna Kumari, C. Ramachandra, C. R. Vijay, C. Ramesh, L. Appaji, T. Avinash, et al. 2020. "National Childhood Cancer Comprehensive Management Policy—A Road Map." *Oncology and Radiotherapy* 1 (51) 2020: 001-005
- Atun, R., Bhakta, N., Denburg, A., Frazier, A.L., Friedrich, P., Gupta, S., Lam, C.G., Ward, Z.J., Yeh, J.M., Allemani, C., Coleman, M.P., Di Carlo, V., Loucaides, E., Fitchett, E., Girardi, F., Horton, S.E., Bray, F., Steliarova-Foucher, E., Sullivan, R., Aitken, J.F., Banavali, S., Binagwaho, A., Alcasabas, P., Antillon, F., Arora, R.S., Barr, R.D., Bouffet, E., Challinor, J., Fuentes-Alabi, S., Gross, T., Hagander, L., Hoffman, R.I., Herrera, C., Kutluk, T., Marcus, K.J., Moreira, C., Pritchard-Jones, K., Ramirez, O., Renner, L., Robison, L.L., Shalkow, J., Sung, L., Yeoh, A., Rodriguez-Galindo, C. 2020. "Sustainable care for children with cancer: a Lancet Oncology Commission". *Lancet Oncology*, Apr;21(4):e185-e224. doi: 10.1016/S1470-2045(20)30022-X. PMID: 32240612.
- Barrios, M., & Acha, T. (2015). Guía de detección temprana cáncer en niños y adolescentes. *Asociación Española de Pediatría (AEP) España*. <https://www.aepap.org/biblioteca/guias/guia-de-deteccion-temprana-del-cancer-en-ninos-y-adolescentes>
- Bhakta, N., A. L. Martiniuk, S. Gupta, and S. C. Howard. 2013. "The Cost Effectiveness of Treating Paediatric Cancer in Low-Income and Middle-Income Countries: A Case-Study Approach Using Acute Lymphocytic Leukaemia in Brazil and Burkitt Lymphoma in Malawi." *Archives of Disease in Childhood* 98 (2): 155–60. <https://doi.org/10.1136/archdischild-2011-301419>.

- Blaauwbroek, R., W. Tuinier, B. Meyboom-de Jong, W. A. Kamps, and A. Postma. 2008. "Shared Care by Paediatric Oncologists and Family Doctors for Long-Term Follow-Up of Adult Childhood Cancer Survivors: A Pilot Study." *Lancet Oncology* 9 (3): 232–38. [https://doi.org/10.1016/S1470-2045\(08\)70034-2](https://doi.org/10.1016/S1470-2045(08)70034-2).
- Blaauwbroek R., Nynke Zwart, Martijn Bouma, Betty Meyboom-de Jong, Willem A. Kamps, and Aleida Postma. 2007. "The Willingness of General Practitioners to Be Involved in the Follow-Up of Adult Survivors of Childhood Cancer." *Journal of Cancer Survivorship*.
- Bona, K., V. Dussel, L. Orellana, T. Kang, R. Geyer, C. Feudtner, and J. Wolfe. 2014. "Economic Impact of Advanced Childhood Cancer on Families." *Journal of Pain and Symptom Management* 47 (3): 594603.
- Burns, E., Collington, M., Eden, T., Freccero, P., Renner, L., Paintsil, V., Dolendo, M., Islam, A., Khaing, A.A., Rosser, J. 2018. "Development of Paediatric Oncology Shared-Care Networks in Low-Middle Income Countries." *Journal of Cancer Policy* 16: 26–32. ISSN 2213-5383, <https://doi.org/10.1016/j.jcpc.2018.03.003>.
- Busse R, Blümel M. 2015. "Payment Systems to Improve Quality, Efficiency and Care Coordination for Chronically Ill Patients – a Framework and Country Examples". In: Mas N, Wisbaum W (eds.), editors. The "Triple Aim" for the future of health care. Madrid: Spanish Savings Banks Foundation (FUNCAS).
- Cetrángolo, O, and A. Goldschmit. 2018. "Las Obras sociales y otras instituciones de la seguridad social para la salud en Argentina. Origen y situación actual de un sistema altamente desigual" ("The HMO's and Other Health Social Security Institutions in Argentina. Origin and Current State of a Highly Unequal System"). Buenos Aires, Argentina. Centro de Estudios Para el Cambio Estructural (CECE). <https://fcece.org.ar/obras-sociales-en-argentina-origen-y-situacion-actual-de-un-sistema-altamente-desigual/>
- Crojethovic, M. y Maceira, D. 2009. "Los Límites del sistema burocrático y las prácticas informales en las organizaciones hospitalarias. Abastecimiento de medicamentos en el caso de los hospitales porteños". *Medicina y Sociedad. Revista Trimestral* Año 28, Nº 2.
- Coase, R. 1937. "The Nature of the Firm," *Economica* 4.
- Codarini, G., M. Andracchio, F. Viggiani, P. Gonzalez, and D. Lev. 2018. "Intervenciones Sanitarias—Programa Nacional de Salud Escolar: Una Política de cuidado de niñas, niños y adolescentes en edad escolar de Argentina." ("Health Interventions—National School Health Program: A Care Policy for Children and Adolescents of School Age in Argentina") *Revista Argentina de Salud Pública* 9 (35): 38–41.
- Cogliatti, S. B., U. Novak, S. Henz, U. Schmid, P. Möller, and T. F. Barth. 2006. "Diagnosis of Burkitt Lymphoma in Due Time: A Practical Approach." *British Journal of Haematology* 134 (3): 294–301.
- Cunha, K. S., G. D. C. Higashi, A. L. Erdmann, C. Kahl, C. Koerich, and B. H. S. Meirelles. 2016. "Myocardial Revascularization: Factors Intervening in the Reference and Counter-Reference in Primary Health Care." *Rev Esc Enferm USP* 50 (6): 963–70. DOI: <http://dx.doi.org/10.1590/S0080-623420160000700013>.
- Ferreira, M. L., M. A. d. O. Vargas, A. M. F. B. Marques, A. Huhn, S. R. d. Andrade, and C. P. Vargas. 2017. "Nursing Actions in Reference and Counter-Reference in Health Care for Persons with Amputation." *Cogitare Enfermagem* 22 (3). <http://dx.doi.org/10.5380/ce.v22i3.50601>.

- Flodgren, G., M. P. Eccles, S. Shepperd, A. Scott, E. Parmelli, and F. R. Beyer. 2011. "An Overview of Reviews Evaluating the Effectiveness of Financial Incentives in Changing Healthcare Professional Behaviors and Patient Outcomes." *The Cochrane Database of Systematic Reviews* (7): CD009255. <https://doi.org/10.1002/14651858.CD009255>.
- Fragkandrea, I., J. A. Nixon, and P. Panagopoulou, P. 2013. "Signs and Symptoms of Childhood Cancer: A Guide for Early Recognition." *American Family Physician* 88 (3): 185–92.
- Friedrich, P., C. G. Lam, E. Itriago, R. Perez, R. C. Ribeiro, and R. S. Arora. 2015. "Magnitude of Treatment Abandonment in Childhood Cancer." *PloS One* 10 (9): e0135230.
- Fuentes-Alabi, S. 2022. "Costo-efectividad en Cáncer Pediátrico" ("Cost-effectiveness in Childhood Cancer"). Webinar OPS (Pan American Health Organization, PAHO). <https://www.paho.org/es/documentos/costo-efectividad-cancer-pediatico-soad-fuentes-alabi>
- Fuentes-Alabi, S., N. Bhakta, R. F. Vasquez, S. Gupta, and S. E. Horton. 2018. "The Cost and Cost-Effectiveness of Childhood Cancer Treatment in El Salvador, Central America: A Report from the Childhood Cancer 2030 Network." *Cancer* 124 (2): 391–97. <https://doi.org/10.1002/cncr.31022>.
- Fung, A., S. Horton, V. Zabih, A. Denburg, S. Gupta. 2019. "Cost and Cost-Effectiveness of Childhood Cancer Treatment in Low-Income and Middle-Income Countries: A Systematic Review." *BMJ Global Health* 4:e001825.
- Garrida, S. 2012. "Impacto del Plan Nacer sobre la Mortalidad Infantil en Argentina" ("Impact of Nacer Plan on Child Mortality in Argentina"). Facultad de Ciencias Económicas. Buenos Aires, Argentina. Universidad Nacional de La Plata.
- Ganguly, S., and S. Bakhshi. 2021. "Teleconsultations and Shared Care in Pediatric Oncology during COVID-19." *Indian Journal of Pediatrics* 88 (1): 1–2. <https://doi.org/10.1007/s12098-020-03499-2>.
- García Molina, M., L. A. Chicaíza-Becerra, H. Quitian-Reyes, A. Linares, and O. Ramírez. 2017. "Costo efectividad de las pruebas para estratificar riesgo en el tratamiento de la leucemia mieloide aguda (LMA) en población pediátrica" ("Cost-Effectiveness of Tests to Stratify the Risk in the Treatment of Acute Myeloid Leukemia"). Bogotá, Colombia. Revista de Salud Pública, Universidad Nacional de Colombia. <https://doi.org/10.15446/rsap.v19n5.56508>.
- Grynszpanchoc, E., Pinto, V., Ayoroa, A., García, L., Armesto, A., & Dran, G. 2019. "Frecuencia y determinantes del retraso en el diagnóstico de cáncer infantil en Argentina" ("Frequency and Determinants of the Delay in Childhood Cancer Diagnosis in Argentina"). *Medicina* (Buenos Aires) [online] 79 (5): 349–57. ISSN 0025-7680.
- Gupta, S., S. Howard, S.C., Hunger, S.P., Antillon, F.G., Metzger, M.L., Israels, T., Harif, M., Rodriguez-Galindo, C. 2015. "Treating Childhood Cancers in Low- and Middle-Income Countries." In *Disease Control Priorities* (3rd ed.): Vol. 3, Cancer, edited by H. Gelband, P. Jha, R. Sankaranarayanan, and S. Horton. Washington, DC: World Bank.
- Guzman Cruz, P. C., M. A. Cordoba, N. Godoy, A. Castaño, K. B. Ribeiro, F. Moreno, and E. de Vries. 2021. "Childhood Cancer in Latin America: From Detection to Palliative Care and Survivorship." *Cancer Epidemiology* 71 (Part B): 101837. <https://doi.org/10.1016/j.canep.2020.101837>.

- Health Ministry (Ministerio de Salud). 2009. “ACTA 06/09 de la VI Reunión Ordinaria del Consejo Federal de Salud (CoFeSa), ver Anexo 3: Aspectos distintivos de la incorporación de módulos de CC al Plan Nacer.” (Minutes 06/09 of the Regular Meeting of the Federal Health Council (CoFeSa), See Annex 3: Distinctive Aspects of the Introduction of CC Modules to Nacer Plan). Ciudad de Iguazú, December.
- . 2010. “Salud y redes. Módulo 9.” Posgrado en Salud Social y Comunitaria (“Health and Networks. Module 9.” Postgraduate Program on Social and Community Health). Buenos Aires.
- . 2013a. “Evaluación de la incorporación del Plan Nacer al Programa Nacional de Cardiopatías Congénitas (PNCC)” (“Review of the Introduction of Plan Nacer to the National Congenital Heart Defects Program”). Buenos Aires.
- . 2013b. “Redes, otra manera de pensar la salud. Primeros logros de los proyectos provinciales” (“Redes, Another Way of Approaching Health. First Achievements of Province Projects”). Buenos Aires.
- . 2015. “Evaluar para seguir adelante: Resultados del Programa Redes” (“Evaluating for Moving Forward. Results of the Redes Program”). Buenos Aires.
- . 2016. “Redes, otra manera de pensar la salud. De procesos a resultados” (“Redes, Another Way of Approaching Health. From Processes to Results”). Buenos Aires. https://bancos.salud.gob.ar/sites/default/files/2018-10/0000000903cnt-anuario_2015_actualizado_2016.pdf.
- . 2019. “Monitoreo de procesos de Red en el primer nivel de atención: La Experiencia del Programa Redes” (“Monitoring of Network Processes at the First Level of Care: The Experience of Redes Program”). Buenos Aires.
- . 2021a. “Monitoreo de procesos de redes integradas de servicios de salud: Resultados del relevamiento de medio término” (“Monitoring of Integrated Health Service Network Processes: Results of the Mid-Term Survey”). Buenos Aires.
- . 2021b. “Reporte breve sobre monitoreo de facturación de prestaciones N°12—‘Prestaciones de oncopediatria’” (“Brief Report on the Monitoring of Service Invoicing for Nbr 12—Oncopediatric Services”). Buenos Aires.
- Health Ministry (Ministerio de Salud), Secretaría de Coberturas y Recursos de Salud. Subsecretaría de Coberturas Públicas Sanitarias. 2021. “Reportes de cantidad de prestaciones financiadas por el Programa Sumar y su monto, desagregado por jurisdicción para el año 2019” (Secretariat of Health Coverage and Resources. Undersecretary of Public Health Coverage. 2021. “Reports on Number of Services Funded by Sumar Program and Amount Broken Down by Jurisdiction for 2019”). Datos Abiertos del Ministerio de Salud (Health Ministry Open Data): <http://datos.salud.gob.ar/dataset/cantidad-de-prestaciones-financiadas-por-el-programa-sumar-y-su-monto-desagregado-por-jurisdiccion>.
- Health Ministry and INC (Ministerio de Salud e Instituto Nacional del Cáncer). 2019. “Plan Nacional de Control del Cáncer 2018–2022” (“National Cancer Control Plan: 2018–2020”). Buenos Aires.
- Health Ministry (Ministerio de Salud) and SUMAR. 2016. “5 años de implementación del Programa de Nacional de Cardiopatías Congénitas integrado en el modelo de gestión del Programa SUMAR: Recorridos y aprendizajes de una política de articulación nacional” (“5 Years of

- Implementation of the National Congenital Heart Defects Program, Integrated into the Sumar Program Management Model. Journey and Lessons from a National Articulation Policy”). Buenos Aires. (<http://iah.salud.gob.ar/doc/Documento145.pdf>).
- Health Ministry of Chile (Ministerio de Salud de Chile), and L. Vargas. 2010. “Manual Detección cáncer infantil en centros de salud primaria: ‘¿Cómo y cuándo sospechar cáncer en el niño?’” (“Manual of Childhood Cancer Detection in Primary Healthcare Centers: ‘How and When to Suspect Cancer in Children?’”). <https://bancos.salud.gob.ar/sites/default/files/2020-11/Acta-06-09.pdf>.
- Heirs, M., S. Suekarran, R. Slack, K. Light, F. Gibson, A. Glaser, M. Hawkins, et al. 2013. “A Systematic Review of Models of Care for the Follow-Up of Childhood Cancer Survivors.” *Pediatric Blood and Cancer* 60 (3): 351–56. <https://doi.org/10.1002/pbc.24253>.
- Handayani, K., M. N. Sitaresmi, E. Supriyadi, P. H. Widjajanto, D. Susilawati, F. Njuguna, P. M. van de Ven, et al. 2016. “Delays in Diagnosis and Treatment of Childhood Cancer in Indonesia.” *Pediatric Blood and Cancer* 63 (12): 2189–96. <https://doi.org/10.1002/pbc.26174>.
- INC (Instituto Nacional del Cáncer). 2010. “Registro Oncopediátrico Hospitalario Argentino. Resultados” (“Argentine Hospital Oncopediatric Registry, Results”) Buenos Aires: Instituto Nacional del Cáncer y Ministerio de Salud de la Nación (National Cancer Institute and National Health Ministry).
- . 2012. “Registro Oncopediátrico Hospitalario Argentino. Resultados 2000–2007.” (“Argentine Hospital Oncopediatric Registry, 2000–2007 Results”) Buenos Aires: Instituto Nacional del Cáncer y Ministerio de Salud de la Nación (National Cancer Institute and National Health Ministry).
- . 2015. “Registro Oncopediátrico Hospitalario Argentino. Resultados 2000–2009” (“Argentine Hospital Oncopediatric Registry, 2000–2009 Results”). Buenos Aires: Instituto Nacional del Cáncer y Ministerio de Salud de la Nación (National Cancer Institute and National Health Ministry).
- . 2016. “Cuando sospechar del cáncer en el niño.” (When Should One Suspect Cancer in a Child?) Buenos Aires: Ministerio de Salud de la Nación (National Health Ministry). https://www.sap.org.ar/uploads/archivos/files_sospechar-cancer-infantil_1502151835.pdf.
- . 2018a. “¿Cuándo sospechar cáncer en el niño?” (“When Should One Suspect Cancer in a Child?”) Buenos Aires: Instituto Nacional del Cáncer y Ministerio Nacional de Salud (National Cancer Institute and National Health Ministry).
- . 2018b. “Registro Oncopediátrico Hospitalario Argentino. Resultados 2000–2013.” (“Argentine Hospital Oncopediatric Registry, 2000–2013 Results”) Buenos Aires: Instituto Nacional del Cáncer y Ministerio de Salud de la Nación (National Cancer Institute and National Health Ministry).
- . 2021. “Registro Oncopediátrico Hospitalario Argentino, Resultados 2000–2019” (“Argentine Hospital Oncopediatric Registry, 2000–2019 Results”). Buenos Aires: Ministerio de Salud de la Nación (Argentine Health Ministry). <https://bancos.salud.gob.ar/recurso/registro-oncopediatrico-argentino-resultados-2000-2019-20-anos>.
- INC and SAP (Instituto Nacional del Cáncer y Sociedad Argentina de Pediatría). 2019. “Diagnóstico oportuno del cáncer infantil. Guía de algoritmo diagnóstico.” (“Timely Diagnosis of

- Childhood Cancer. Diagnostic Algorithm Guide”). Buenos Aires. https://www.sap.org.ar/uploads/archivos/general/files_algoritmo-ca-infantil-11-19_1580335026.pdf).
- ICCI-LA (Integrated Cancer Control Initiative in Latin America). 2020. “Cómo enfrentar la creciente carga del cáncer en Argentina: Desafíos y oportunidades” (“How to Face the Growing Burden of Cancer in Argentina: Challenges and Opportunities”). <https://www.uicc.org/resources/c%C3%B3mo-enfrentar-la-creciente-carga-del-c%C3%A1ncer-en-argentina-desaf%C3%ADos-y-oportunidades#>.
- Joseph, J. M., A. M. Farron, R. Renella, and C. Gapany. 2014. “Can Smaller-Scale Comprehensive Cancer Centers Provide Outstanding Care in Abdominal and Thoracic Pediatric Solid Tumor Surgery? Results of a 14-Year Retrospective Single-Center Analysis.” *Annals of Surgical Oncology* 21 (5): 1726–31.
- Kalbfleisch, J. D., and R. L. Prentice. 2002. “The Statistical Analysis of Failure Time Data (2nd ed.).” Hoboken, NJ: Wiley-Interscience.
- Lam, C. G., S. C. Howard, E. Bouffet, and K. Pritchard-Jones. 2019. “Science and Health for All Children with Cancer.” *Science* (New York), 363 (6432): 1182–86. <https://doi.org/10.1126/science.aaw4892>.
- López Puig, P., I. Morales Suarez, S. Manchaca, N. Martínez Trujillo, S. Lau López, and S. Soler Cárdenas. 2009. “Las Redes integradas de servicios de salud desde la realidad cubana” (“Integrated Health Services Networks from the Cuban Reality”). *Revista Cubana de Salud Pública* 35 (4).
- Lupo, P. J., and L. Spector. 2020. “Cancer Progress and Priorities: Childhood Cancer.” *AACR Journals* 29 (6).
- Maceira, D. 2006. “Descentralización y equidad en el sistema de salud argentino. <https://repositorio.cedes.org/>. Maceira, D. 2014. “Capacidad Resolutiva y Desempeño de Redes Hospitalarias en Líneas de Cuidado Prevalentes” (“Resolution Capacity and Performance of Hospital Networks in Prevalent Lines of Care”). Buenos Aires: CEDES Documento interno (Propuesta de programa) (Program proposal).
- . 2018. “Cobertura de Enfermedades de Alto Costo, y el accionar del Sistema Único de Reintegros en Argentina. Pautas para un análisis de equidad distributiva” (“High-Cost Illness Coverage and the Performance of the Single Reimbursement System in Argentina”). Buenos Aires: CEDES.
- . 2021a. “El Sistema de salud argentino en imágenes” (“The Argentine Health System in Images”). Buenos Aires: Fundar. <https://www.fundar.org/publicacion/el-sistema-de-salud-argentino-en-imagenes/>.
- . 2021b. “El Sistema de salud como construcción colectiva. Notas para un debate” (“The Healthcare System as a Collective Construction. Notes for a Debate”). Buenos Aires: Fundar. <https://www.fundar.org>.
- Maceira, D., and C. Cejas. 2010. “Actores, Contratos y Mecanismos de Pago: El Caso del Sistema de Salud de Salta” (“Actors, Contracts and Payment Mechanisms: The Case of the Health System of Salta”). *Estudios Económicos* XXVII, no. 54 (January–June).

- Maceira, D., and P. Kremer. 2012. "Fortalecimiento de las redes de servicios de salud en el tercer nivel. Lecciones del caso argentino" ("Strengthening of Third-Level Health Service Networks. Lessons of the Argentine Case"). *Medicina y Sociedad* 32, no. 3 (September).
- Maceira D., and A. Palacios. 2012. "Estructura, Gestión y Desempeño de Cabeceras de Red Hospitalarias Perinatales. Dos estudios de caso en la Provincia de Buenos Aires."
- Maceira, D., A. Palacios, and M. Urrutia. 2014. "Desempeño de Cabeceras de Redes Perinatales en la Provincia de Salta" ("Performance of Perinatal Network Head Hospitals"). Buenos Aires: CEDES.
- Maceira, D., and A. Reynoso. 2013. "Contratos, Mecanismos de Pago y Poder de Negociación. El Caso del Sistema de Salud de Córdoba" ("Contracts, Payment Mechanisms and Negotiation Power. The Case of Cordoba Health System"). *Universidad Nacional de Córdoba, Revista de Salud Pública* XVII (4): 21–30.
- Maceira, D., and M. Urrutia. 2013. "Actores, contratos y mecanismos de pago: el caso del sistema de salud de Neuquén" ("Actors, Contracts and Payment Mechanisms: The Case of Neuquen Health System"). *Estudios Económicos* XXX (N.S.), no. 60 (January–June): 3–35.
- Manrique Díaz, M., C. E. Narvárez Gordillo, P. C. Guzmán Cruz, and M. Pedraza Gálviz. 2011. "Estudio de supervivencia en pacientes pediátricos con cáncer atendidos en el Centro Javeriano de Oncología" ("Study of Survival in Childhood Cancer Patients Treated at the Centro Javeriano de Oncología"). Colombia: Pontificia Universidad Javeriana.
- Mendes, E. V. 2013. "Las Redes de Atención en Salud" ("Healthcare Networks"). Washington, DC: Pan American Health Organization (PAHO).
- Moreno, F., W. Cacciavillano, M. Cipolla, M. Coirini, P. Streitenberger, J. López Martí, M. Palladino, et al. 2017. "Childhood Osteosarcoma: Incidence and Survival in Argentina. Report from the National Childhood Cancer Registry, ROHA Network 2000–2013." *Pediatric Blood and Cancer* 64 (10): 10.1002/pbc.26533. <https://doi.org/10.1002/pbc.26533>.
- Moreno, F., V. Dussel, L. Orellana, and ROHA Network. 2015. "Childhood Cancer in Argentina: Survival 2000–2007." *Cancer Epidemiology* 39 (4): 505–10. <https://doi.org/10.1016/j.canep.2015.04.010>.
- Moreno, F., D. Loria, G. Abriata, B. Terracini, and ROHA Network. 2013. "Childhood Cancer: Incidence and Early Deaths in Argentina, 2000–2008." *European Journal of Cancer* 49 (2): 465–73. <https://doi.org/10.1016/j.ejca.2012.08.001>.
- Moreno, F., A. Rose, M. A. Chaplin, M. C., Cipolla, M. García Lombardi, M. Nana, G. Cervio, et al. 2020. "Childhood Liver Tumors in Argentina: Incidence Trend and Survival by Treatment Center. A Report from the National Childhood Cancer Registry, ROHA Network 2000–2015." *Pediatric Blood and Cancer* 67 (11): e28583. <https://doi.org/10.1002/pbc.28583>.
- Nagel, K., M. Eves, L. Waterhouse, C. Alyman, S. Posgate, J. Jamieson, and M. Wright. 2002. "The Development of an Off-Therapy Needs Questionnaire and Protocol for Survivors of Childhood Cancer." *Journal of Pediatric Oncology Nursing* 19 (6): 229–33.
- Office of the President (Presidencia de la Nación). 2021a. "Reporte de Monitoreo de Sumar 1º trimestre 2021" ("SUMAR Monitoring Report 4th Quarter 2021"). https://www.argentina.gob.ar/sites/default/files/informe_sumar_1t_2021_final.pdf.

- . 2021b. “Reporte de Monitoreo de Sumar 4º trimestre 2019” (“SUMAR Monitoring Report 4th Quarter 2019”). https://www.argentina.gob.ar/sites/default/files/informes_sumar_4t_2019_vf_c_indice.pdf.
- PAHO (Pan American Health Organization). 2005. “Consulta regional sobre la renovación de la atención primaria de la salud en las Américas” (“Regional Consultation on Primary Healthcare Renewal in the Americas”). Montevideo, Uruguay.
- . 2007. *Agenda de Salud para las Américas 2008–2017*. (Health Agenda for the Americas 2008-2017) Ciudad de Panamá, June.
- . 2010. “Serie ‘La renovación de la atención primaria de salud en las Américas.’ Redes Integradas de Servicios de Salud” (“Series ‘Renewal of Primary Health Care in the Americas,’ Integrated Health Services Networks”). Washington, D.C: OPS, -1, 2010.
- . 2010. “Redes Integradas de Servicios de Salud: Conceptos, Opciones de Política Y Hoja de Ruta Para Su Implementación En Las Américas.” Washington, D.C: OPS, -1, 2010. <https://iris.paho.org/handle/10665.2/31323>
- . 2011. “Serie ‘La renovación de la Atención Primaria de Salud en las Américas N°4.’ Redes Integradas de Servicios de Salud. Conceptos, Opciones de Política y Hoja de Ruta para su Implementación en las Américas” (“Series ‘Renewal of Primary Health Care in the Americas N°4.’ Integrated Health Services Networks. Concepts, Policy Options and Roadmap for implementation in the Americas”). Washington, D.C: OPS, -1, 2011.
- . 2014a. “Diagnóstico temprano del cáncer en la niñez” (“Early Diagnosis of Childhood Cancer”). Washington, DC.
- . 2014b. “Estrategia para el acceso universal a la salud y la cobertura universal de salud” (“Strategy for Universal Access to Health and Universal Health Coverage”). <https://www.paho.org/es/documentos/estrategia-para-acceso-universal-salud-cobertura-universal-salud>.
- Pautasso F., T. Camargo Lobo C. Dias Flores and R. Aquino Caregnato. 2020. “Enfermero navegador: Desarrollo de un programa para Brasil” (“Patient Navigation: Development of a Program for Brazil”). *Rev. Latino-Am. Enfermagem*.
- Pereira, J. S., and W. C. A. Machado. 2016. “Referência e contrarreferência entre os serviços de reabilitação física da pessoa com deficiência: A (Des)articulação na microrregião Centro-Sul Fluminense.” *Physis Revista de Saúde Coletiva*. Rio de Janeiro. <https://doi.org/10.1590/S0103-73312016000300016>.
- Peters, D.H. 2014. “The application of systems thinking in health: why use systems thinking?”. *Health Research Policy and System* 12, 51. <https://doi.org/10.1186/1478-4505-12-51>
- PNUD (Programa de las Naciones Unidas para el Desarrollo). 2011. “El Sistema de salud argentino y su trayectoria de largo plazo: Logros alcanzados y desafíos futuros / 1a ed.” (“The Argentine Health System and Its Long-Term Trajectory: Achievement and Future Challenges / First Edition.” Buenos Aires.
- Pritchard-Jones, K., R. Pieters, G. H. Reaman, L. Hjorth, P. Downie, G. Calaminus, M. C. Naafs-Wilstra, et al. 2013. “Sustaining Innovation and Improvement in the Treatment of Childhood Cancer: Lessons from High-Income Countries.” *Lancet Oncology* 14 (3): e95–e103. [https://doi.org/10.1016/S1470-2045\(13\)70010-X](https://doi.org/10.1016/S1470-2045(13)70010-X).

- Protasio, A.P.L., Silva, P.B., Lima, E.C., Gomes, L.B., Machado, L.S., Valença, A.M.G. 2014. "Evaluation of the reference and counter-reference system based on the responses of the Primary Care professionals in the first External Evaluation cycle of PMAQ-AB in the state of Paraíba". *Saúde Debate* [online], 38: 209–20. ISSN 0103-1104. <https://doi.org/10.5935/0103-1104.2014S016>.
- Pujola, C. J. A., C. L. Bertone, and L. D. Acosta. 2014. "Morbimortalidad por cáncer infantil en la República Argentina: 2006–2008" ("Childhood Cancer Morbimortality in the Argentine Republic"). *Archivos argentinos de pediatría* 112 (1): 50–54. <https://dx.doi.org/10.5546/aap.2014.50>.
- Ramos, S., C. Straw, M. Viniegra, C. Almada, M. Schneider, V. Pesce, L. Mignini, G., Tabares, N. Robles, I., Romero, & V. Moretto. 2018. "Barreras y facilitadores en las trayectorias de mujeres con cáncer de mama usuarias de hospitales públicos" ("Barriers and Facilitators in the Journey of Women with Breast Cancer as Users of Public Hospitals"). *Rev Argent Salud Pública* 9 (36): 14–21.
- Rasmusen, E. 1987. "Moral Hazard in Risk-Averse Teams." *The RAND Journal of Economics* 18 (3): 428–35. <https://doi.org/10.2307/255560>.
- Rosen, R., and C. Ham. 2008. "Integrated Care: Lessons from Evidence and Experience." Birmingham, UK: Nuffield Trust.
- Russell, H. V., J. Panchal, H. Vonville, L. Franzini, and J. M. Swint. 2013. "Economic Evaluation of Childhood Cancer Treatment: A Systematic Literature Review." *Pediatrics* 131 (1): e273–e287. <https://doi.org/10.1542/peds.2012-0912>.
- Sada, Y. H., R. L. Street Jr., H. Singh, R. E. Shada, and A. D. Naik. 2011. "Primary Care and Communication in Shared Cancer Care: A Qualitative Study." *The American Journal of Managed Care* 17 (4): 25965.
- SAP and UNICEF (Sociedad Argentina de Pediatría and United Nations Children's Fund). 2013. "Salud materno-infanto-juvenil en cifras 2013" ("Maternal, Newborn, Child and Adolescent Health in Numbers for 2013"). Buenos Aires. <https://www.sap.org.ar/docs/profesionales/SapUnicef2013.pdf>.
- Serra, C. G. and P. H. Rodrigues. 2010. "Avaliação da referência e contrarreferência no Programa Saúde da Família na Região Metropolitana do Rio de Janeiro (RJ, Brasil)" [Evaluation of Reference and Counter-Reference in the Family Health Program at the Metropolitan Region of Rio de Janeiro (RJ, Brazil)]. *Cien Saude Colet*, Nov. 15 Suppl 3: 3579–86. Portuguese. doi: 10.1590/s1413-81232010000900033. PMID: 21120346.
- Shaked, A., and J. Sutton. 1987. "Product Differentiation and Industrial Structure." *The Journal of Industrial Economics* 36 (2).
- SIOPE (Société Internationale d'Oncologie Pédiatrique). 2009. "Estándares Europeos de Atención a Niños con Cáncer" ("European Standards for Childhood Cancer Care"). Warsaw, October 14.
- Sirohi, B., K. Chalkidou, C. S. Pramesh, B. O. Anderson, P. Loeher, O. El Dewachi, O. Shamieh, et al. 2018. "Developing Institutions for Cancer Care in Low-Income and Middle-Income Countries: From Cancer Units to Comprehensive Cancer Centres." *Lancet. Oncology* 19 (8): e395–e406. [https://doi.org/10.1016/S1470-2045\(18\)30342-5](https://doi.org/10.1016/S1470-2045(18)30342-5).

- Steliarova-Foucher, E., M. Colombet, L. Ries, F. Moreno, A. Dolya, F. Bray, P. Hesselting, et al. 2017. "International Incidence of Childhood Cancer, 2001–10: A Population-Based Registry Study." *Lancet. Oncology* 18 (6): 719–31. [https://doi.org/10.1016/S1470-2045\(17\)30186-9](https://doi.org/10.1016/S1470-2045(17)30186-9).
- Steliarova-Foucher, E., C. Stiller, B. Lacour, and P. Kaatsch. 2005. "International Classification of Childhood Cancer, Third Edition." *Cancer* 103 (7): 1457–67. <https://doi.org/10.1002/cncr.20910>.
- Sullivan, R., J. R. Kowalczyk, B. Agarwal, R. Ladenstein, E. Fitzgerald, R. Barr, E. Steliarova-Foucher, et al. 2013. "New Policies to Address the Global Burden of Childhood Cancers." *Lancet. Oncology* 14 (3): e125–e135. [https://doi.org/10.1016/S1470-2045\(13\)70007-X](https://doi.org/10.1016/S1470-2045(13)70007-X).
- Sussman, J., and L. M. Baldwin. 2010. "The Interface of Primary and Oncology Specialty Care: From Diagnosis through Primary Treatment." *Journal of the National Cancer Institute. Monographs* (40): 18–24. <https://doi.org/10.1093/jncimonographs/lgg007>.
- UN (United Nations). 2015. Sustainable Development Goals. New York. <https://www.un.org/sustainabledevelopment/es/health/>.
- UNICEF and SAP (United Nations Children’s Fund and Sociedad Argentina de Pediatría). 2019. "Salud materno-infanto-juvenil en cifras" (Maternal, Newborn, Child and Adolescent Health in Numbers"). Buenos Aires, Argentina.
- Van Goudoever, H. 2015. "Concentrating Childhood Cancer Treatment in the Netherlands." *Padiatrie und Padologie* 50 (Suppl 2): 38–41. <https://doi.org/10.1007/s00608-015-0282-3>.
- Vásquez, L., J. Montoya, C. Ugaz, L. Ríos, E. León, I. Maza, E. Maradiegue, et al. 2021. "ONCOPEDES: A Mobile Application to Improve Early Diagnosis and Timely Referral in Childhood Cancer in a Low- and Middle-Income Country—A Pilot Study." *Pediatric Blood and Cancer* 68 (4): e2890. <https://doi.org/10.1002/xbc.28908>.
- Warner, E. L., A. C. Kirchhoff, G. E. Nam, and M. Fluchel. 2015. "Financial Burden of Childhood Cancer for Patients and Their Families." *Journal of Oncology Practice* 11 (1): 12–18.
- Weller, D., P. Vedsted, G. Rubin, F. M. Walter, J. Emery, S. Scott, C. Campbell, et al. 2012. "The Aarhus Statement: Improving Design and Reporting of Studies on Early Cancer Diagnosis." *British Journal of Cancer* 106 (7): 1262–67. <https://doi.org/10.1038/bjc.2012.68>.
- WHO (World Health Organization). 2021. "CureAll Framework: WHO Global Initiative for Childhood Cancer: Increasing Access, Advancing Quality, Saving Lives." <https://apps.who.int/iris/handle/10665/347370>. Licence: CC BY-NC-SA 3.0 IGO.
- .2022. Global Health Expenditure database (<http://apps.who.int/nha/database>), published in the World Bank database. January.
- .2022. "Global Health Estimates 2020: Deaths by Cause, Age, Sex, by Country and by Region," 2000–2019. Geneva.
- .2022. International Agency for Research on Cancer (IARC), GLOBOCAN 2020: estimated number of new days in 2020, Latin America and the Caribbean, both sexes, ages 0–19.
- Word Bank. 2021. National Account data and Organization for Economic Co-operation and Development (OECD) national account data files.

———.2019. World Development Indicators (WDI).

Williamson, O. E. 1989. “Las Instituciones Económicas del Capitalismo, c.4.” *Fondo de Cultura Económica*.

Williamson, O. E. 1971. “The Vertical Integration of Production: Market Failure Considerations.” *The American Economic Review* 61 (2): 112–23. <http://www.jstor.org/stable/1816983>.

Zanetta C. 2020. “Case Study—Argentina. The Establishment of Argentina's Federal Network for the Care of Congenital Heart Defects under the Plan Nacer/SUMAR.” Geneva: World Health Organization.

Zhao, Y., A. Brettle, and L. Qiu. 2018. “The Effectiveness of Shared Care in Cancer Survivors—A Systematic Review.” *International Journal of Integrated Care* 18 (4): 2. <https://doi.org/10.5334/ijic.3954>.

The development of integrated health services networks is one of the main priorities set by the National Health Ministry of the Argentine Republic (Ministerio de Salud, MINSAL), considering that these networks are an effective strategy to overcome the inefficiencies and inequities that affect the health system. As a result, MINSAL requested the World Bank's financial support to design and implement a National Fund for High Complexity Diseases (NFHCD) by means of a new loan provided under a Program for Results scheme (PforR). As a first step toward the design of a National Fund for High Complexity Diseases, this paper, based on the study of childhood cancer in Argentina, seeks to investigate the key aspects that should be considered when planning an effective service network for such diseases. The selection of case studies was based on the characteristics of a high-complexity and low-incidence specialty, with a marked specificity in approach strategies. In addition, it is a high-cost network, taking into account the price of treatments—which may involve days, months, or years of hospitalization—and the cost of the drugs required to treat such cases. The evidence collected has allowed us to shed light on the critical pathways patients navigate in the current oncopediatric care structure. First, the family is the one that identifies the child's first symptoms and therefore approaches the health care system. Second, there is a poor understanding that both health care service providers and users have of the health network organized by levels of resolution. Another structural challenge is the fragmentation between subsystems—public, social security, and private health insurance companies—resulting in different approaches and qualities of care beyond the health need identified. A strong interplay between national public referral hospitals with patients with different health care coverage schemes could contribute to reducing access gaps.

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