

Personal Data in the Social Security Institute

Exploratory analysis on some personal
data protection practices in the
social security system of the Paraguayan state.

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Summary

The Social Security Institute (IPS, for its acronym in Spanish) of Paraguay is the most important public social insurance system in the country. In the absence of regulations, competent authority, supervision and systematic sanctions for the protection of personal data, along with almost non-existent litigation in this area, this results in concerns around privacy, confidentiality in health data. The evidence gathered in this investigation indicates that the storage of sensitive data - biometric - of the insured persons does not have a regulation for the protection of public databases.

As expected, in countries where social welfare is at risk, like the paraguayan case, patients prioritize access to care at any price, even over other rights, for example by providing their biometric data. In turn, they are less likely to oppose and protest in case of violation of their rights of privacy and confidentiality. **This is due to a common reality of countries in the region with long dictatorships that normalized surveillance, as well as the registration of large amounts of sensitive information in the state's database. In Paraguay, the storage of these communications and citizen information during the authoritarian regime was called "Archivo del Terror"**¹

On the other hand, the research shows significant evidence about who and for what purpose the medical examinations of the workers are taken. It is possible that the access to the medical history of the workers is in the hands of the administrative personnel of the companies; and that in some cases they are not delivered by default to the workers, but only when they request it. At the same time it is possible to access sensitive health data beyond what is allowed by current labor regulations, and that, as a consequence, this leads to discriminatory measures in the workplace.

In the absence of a protocol of occupational medicine to determine the fitness of the workers, it is possible that the clinics that perform the medical examinations request more sensitive information and that this exceeds the nature of each job assignment. This has a direct impact on the costs of medical examinations that economically affect the applicant companies.

This research shows a series of discretionary practices, some that protect the rights of people and others that violate them, so standardization is necessary for all the actors involved in the system. The most genuine way to achieve this is through a comprehensive act for the protection of personal data in accordance with the highest international standards of protection.

Keywords: Privacy, personal data, sensitive data, biometrics, health data, social security, protection and security of health data.

¹ Jacinto Flecha, Víctor. The discovery of the Archive of Terror in 1992. Ministry of Culture. May 28, 2011. "Database of: records of detainees, controlled and delayed; investigatory statements; reports on people, social activities, students and trade unions, controls on people, entry and exit of people through border points, collection of photos and detainees, meetings, fingerprints, etc. Available at: <http://www.cultura.gov.py/lang/es-es/2011/05/el-descubrimiento-del-archivo-del-terror-en-1992/> [Date of consultation: December 2, 2018].

Introduction

With regard to health, Paraguay - and Latin America in general - requires an integral approach from different disciplines and approaches. Even more, the weak Paraguayan institutional character causes an increase in the risk of bad administrative management, mainly in the field of health.

For example, only one example is enough: it was recently published through the press a scandalous case in which some 10 tons of medications of different nature were expired². According to statements by the Minister of Health for the newspaper ABC Color in his note "Tons of Irregularities" (ABC Color, 2018):

We currently have approximately 10 tons of expired medications and supplies in our health system, which corresponds to almost one million items.

We found fictitious plans, because they are based on untruthful data; we also found decisions that are difficult to explain, priorities that do not meet the most critical health needs.

However, the problems and challenges are not only administrative, but there are structural problems and cross-cutting to all administrations, which the country has been suffering since the advent of democracy, and which are still far from being solved.

Only in regard to coverage and access, the country is in high debt to its citizens. As established by the study *Financing Universal Health Coverage in Paraguay*³ (Gaete, 2017):

In terms of horizontal coverage (how many people have coverage), Paraguay still has 60% of its population excluded from basic health services, that is, population without primary health care coverage through the Units of Family Health (UFH). It is estimated that the 801 UFH that currently exist cover only 40% of the total population of the country.

To understand the different actors that make the health ecosystem in Paraguay, it is important to point out that in the country there is a segmentation related to its service providers, and that it is determined to a large extent by the purchasing power of each group (Gaete, 2017):

The health system in Paraguay is highly segmented and includes a public subsector constituted by the Ministry of Public Health and Social Welfare (MSPBS, for its Spanish acronym), a subsector of social security constituted by the Social Security Institute (IPS, for its Spanish acronym) and a private subsector constituted by institutions for profit (hospitals, sanatoriums, clinics and private practices). It also includes prepaid and non-profit medicine companies (private universities with their hospitals and NGOs that provide health services).

A public actor of national importance emerges here and will be extensively analyzed in the framework of the present research: the Social Security Institute (IPS) and specifically the rules that

² The diseases that these medications could cure or mitigate ranged from pneumonia, cancer and so on. More information in: <https://twitter.com/elsurti/status/1039830743181127681>

³ Universal Health Coverage implies that the organization and financing mechanisms are sufficient to cover the entire population.

regulate it. This is a relevant actor in terms of the health and well-being of Paraguayan citizens, as it is one of the three main subsectors that provide coverage to Paraguayan society.

By analyzing coverage by segments according to health subsectors, 21.5% of the total population is covered by the IPS (Gaete, 2017). This percentage acquires even greater significance by pointing out that the economically active population of the country is estimated at 62.6% (Ministry of Health, 2017). This reveals an important dependence of the economically active population towards the Social Security Institute.

The Social Security Institute is one of the main entities linked to the concept of social protection in Paraguay. The essay "Guidelines for the construction of social protection policy" (Verónica Serafini, 2017) defines *social protection* as:

A set of government and private policies and programs with which societies respond to various contingencies in order to compensate for the lack or substantial reduction of income from work, to provide assistance to families with children and to provide medical care and housing to the population.

For its part, the IPS defines its institutional vision as follows: "To be the reference Institution for Social Security recognized for its efficiency, transparency and human warmth that provides services with technical quality to the insured population" (IPS, 2018).

In Paraguay, only a quarter of the Paraguayan population is within a social security or retirement system (Verónica Serafini, 2017) which shows the high degree of vulnerability in which most of the population is, since by not having this type of benefits associated with decent work, they depend on the health services of the state, which in comparative terms has much less resources to invest per citizen. As Gaete (2017) points out:

In terms of financial coverage or health financing, the segmentation also reflects a large difference in the annual per capita expenditure on health according to the subsectors. Thus, it is estimated Gs 825,479 for the public subsector (Ministry of Health) and Gs 1,636,005 for the social security subsector (IPS). The private sector would represent a proportionally much higher figure, especially considering that 54.1% of total health expenditure is private and only 8.6% of the population has private insurance.

As evidenced, there is a high degree of vulnerability of the population in terms of access and health coverage. In a context and reality such as the one indicated above, the public and private sectors have enormous challenges and responsibilities that must be confronted and mitigated with efficient public policies, but that, above all, are in line with human rights, an obligation and guarantee assumed by the states before the international community. Paraguay should move in this direction.

Thus, the present research takes as a point of analysis the crisis situation of the Paraguayan national health system to focus later on the handling of the personal data of the workers that are collected by different actors and with different purposes.

Background

There is a historical need to reform and update the current legislation on the protection of personal data in Paraguay⁴. There is currently a gap between the progress of the information society, with the management of personal data by authorities and institutions, both in the public and private sectors.

In that sense, there are diverse fields and disciplines that still need to be analyzed in depth, in order to understand the risks and opportunities, as well as current practices associated with institutions of different nature that produce and collect data for various purposes.

As regards the health field in its broad sense, there are still several fronts that need to be explored from a personal data protection approach and linked to the ethical limits demarcated by the legal regulations, the practice or exercise of medical secrecy, as well as international standards established and accepted by the global community.

The present research arose from the complaint of an anonymous worker who came to the TEDIC organization to inform about contrary and invasive practices to the privacy of the workers, within the framework of the application of the admission and annual medical examination that all workers of the country must take. According to his testimony:

They left the form on the desk of each staff member, and each one filled in and then by group they went to a private laboratory so they could take the samples.

The company that asked for the medical examinations was the one that distributed the forms. It was a well-known clinical laboratory.

Specifically, this form included a series of highly invasive questions and the reasons why they were made were not entirely clear. It should be remembered that occupational medical examinations only seek to determine the fitness of a worker with respect to the assignment he or she already performs or will perform.

Furthermore, in the case of working women, there was a specific section with gynecological questions and included very specific questions⁵. These questions aimed at collecting data that had nothing to do with the proper exercise of a job responsibility, for example, if a worker had, at some point in her life, had a clinical abortion:

Questions for women only:

Has had breast swelling Yes- No

Suppuration or blood in the nipple Yes- No

Breast surgery Yes- No

⁴ Act N° 1628/01 is currently in force in the country and regulates private information and its amendment, Act N° 1969/02. More information in: https://www.tedic.org/wp-content/uploads/sites/4/2017/09/La-protecci%C3%B3n-de-Bases-de-Datos-en-Paraguay_Documento-Final.pdf

⁵ A capture of the complete form can be found in Annex I of the present research. For the purposes of this research and the objectives it seeks, the logo of the laboratory that made such questions was deleted.

Pain during menstruation Yes-No

Hot Flashes Yes-No

Spontaneous pregnancy loss Yes-No

Pregnancy loss (clinical reason) Yes-No

Date of last menstruation

Thus arises the concern regarding the discretion and freedom with which the questions of this form were prepared and subsequently applied to workers in their places of work.

According to the worker interviewed, this questionnaire was applied in at least one more company which performs similar functions as his. In the case of the company in which he worked, the workers refused to fill in this form:

The form was an invasion of privacy and an exercise in resistance was done.

On the other hand, there is the regulation of fingerprint collection of insured persons of IPS, which was approved in 2015 and applies to people from 2 years old on. This resolution arises from **complaints of corruption** in the state social insurance by companies and insured persons and to prevent the theft of medications in such institution.

The resolution only talks about the importance of the implementation of the system as a tool for digitalization and optimization of the institutional management but without an analysis of the impact of the collection of sensitive data of the insured persons.

In all the above, risks and abuses are identified by various actors involved in the process of collection and systematization of personal data that needs to be explored from different approaches. In this way, it is sought to understand not only the reasons that lead to this collection, but also to identify potential practices that would put at risk the human rights of workers, which could end up in situations of discrimination, violation of privacy and abuse of power. In many cases, these violations occur without the victims understanding or perceiving such problems, which makes the situation more complex and aggravating.

Objectives of the Research

The objective of this research is to describe the legal situation regarding the management of personal databases in the Paraguayan public health system.

This research seeks to generate a *policy paper* that serves as a roadmap for the academic community and political actors to address issues related to technology and regulations for the protection of sensitive health data. The creation of analytical tools to expand the knowledge repository in this area is key. So far, no studies have been found that analyze at a local level the challenges that require the protection of sensitive information from the Social Security Institute (IPS) of Paraguay.

In order to comply with the objectives of the study, the local context is identified about the uses, management and procedures, as well as current national legal regulations that define the implementation of the storage of sensitive health information in the Social Security Institute. On the other hand, interviews are held with those in charge of the storage system for health sensitive information of IPS to investigate which principles, protocols and standards they use for the protection of health data.

Methodological strategy

The research has an exploratory approach, given that at a local level there are few academic works that address the protection of sensitive health data in Paraguay's public health system.

In addition, an analysis of substantive and procedural law that is closely related to the use of information technologies will be conducted. It is intended to know the current status and the challenges for the implementation of regulations that regulate the storage of sensitive information on health issues, as well as the compliance or not of standards of personal data protection and other human rights.

In carrying out the research, **2 methodological tools** will be used: first, the **legal analysis** of the current regulations of the Social Security Institute that will serve to make a diagnosis for the process of their implementation. It will be contemplated with the development of a conceptual framework of personal data to measure the current legal application. In the second part of the research, semi-structured interviews will be conducted to determine the status of implementation of regulations for the storage of sensitive health data. The sampling frame was constructed by selecting actors from the private sector (companies), as well as people insured in IPS and a responsible person involved in the storage of sensitive health data in IPS.

These interviews seek to inquire about the quality and the status of application of IPS regulations and public international law in matters of health, privacy and confidentiality of health data. Using this approach will serve as a tool to strengthen the normative framework, as well as to identify its limitations and challenges of the IPS health system.

The duration of the interviews was between 30 minutes and 1 hour and they were nominal or anonymous, depending on the decision of the person interviewed.

Sampling frame

The interviews are built on the theoretical sampling frame containing the following descriptions: a person representative and involved in the storage of sensitive information of IPS, a person insured in IPS, two responsible for the business sector that insure their employees in IPS, an intermediary company that is in charge of the compulsory procedures of the private sector in IPS.

As the interviews progressed and from the difficulties and possibilities of contacting the interviewees, the number of institutions was reduced to 7, which are 4 from the private sector, 2 representatives from the public sector and 1 worker as a qualified informant. On this last point, 4 interviews were held with heads of the business and academic sectors in charge of insuring their employees in IPS. With this group, the sample was considered saturated for the objectives set in the research.

On the other hand, the public sector agreed to the interview, but did not respond to the consultation made through the access to public information website.⁶

Analysis categories

From the development of a question guide, the set of questions adapted to the function of each profile is created: private sector, insured person in IPS and representative of IPS. Then, it is enriched and improved in the analysis procedure (available in Annex A.1).

Case study

The national social insurance institution IPS is studied, which is part of the administration of the Executive Branch and stores sensitive information of citizens through the use of technology.

Previously, the regulations for the storage of sensitive information in force for IPS are analyzed, as well as the international treaties related to data protection, the data protection regulations in force in Paraguay, the security protocols of the databases and biometric data and other points of the research that store sensitive information in the registration process that citizens have to do to access the national social security system of Paraguay.

The private sector is also studied on the basis of a diagnosis of the handling of sensitive data by its employees, research specified in the section on the findings of the interviews.

⁶ Access to Public Information Website: www.informacionpublica.paraguay.gov.py/portal

Conceptual framework

To achieve an adequate understanding of the research topic, it is necessary to specify the concepts and discuss the different theoretical approaches. The precise definitions will give theoretical strength to this research, as well as allow a better understanding of the scope and challenges that this topic represents.

Personal data

"Personal data" refers to all information about an identified or identifiable natural person (the interested party). The regulation of the European Union defines the subject of the data as:

"any information relating to an identified or identifiable natural person (the data subject); an identifiable natural person shall mean any person whose identity can be determined, directly or indirectly, in particular by reference to an identifier, for example a name, an identification number, location data, an online identifier or one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of such person" Article 2/1 (European Parliament, 2016 & TEDIC, 2017).

On the other hand, it should be remembered that the right to data protection has constitutional recognition in Paraguay: Article 135 of the National Constitution establishes the guarantee of habeas data, which provides the following:

"All people can access the information and data about themselves or about their properties, which are found in private or official records of public nature, as well as to know the use made of them and their purpose". (Constituent Assembly, 1992)

In addition, people may require the update, rectification or destruction of personal data which are erroneous or that illegitimately affect their rights before competent authorities. It is done before a judge from a court of first instance⁷.

It should be noted that the **protection of personal data** is not an absolute right, but must be considered in relation to its role in society (European Parliament, 2016).

Sensitive personal data

The Paraguayan law contemplates the definition of **sensitive data**, adapting to the international doctrine and jurisprudence that seek to prevail the right of privacy and respect for sensitive data (Article 4). These are:

"Racial or ethnic affiliation, political preferences, individual health status, religious, philosophical or moral convictions; sexual intimacy and, in general, those which promote prejudice and discrimination, or affect the dignity, privacy, domestic privacy and private image of individuals or families" (National Congress, 2001).

⁷ Idem. Jazmin Acuña, Luis Alonzo Fulchi, & Maricarmen Sequera, 2017

Regarding sensitive data, its publication or disclosure is prohibited, but no sanctions are observed in case of abuse by any public or private entity. Therefore, the defense action against an abuse is exclusively in the hands of the affected person⁸.

Sensitive data refers to information linked to prejudice, intolerance, fanaticism, etc., which historically has led to various types of discrimination: racial or ethnic origin, political opinions, religious convictions, data related to health or sexual life, etc. Within the concept of "sensitive data" are included all those data that in some way may cause discrimination, even in a potential way, because the norm adopts a **preventive guardianship** criterion. Then, what characterizes a sensitive data as such, is its potential to generate discriminatory attitudes towards its subject.

Health facilities, whether public or private, and professionals related to the health sciences are authorized to collect and process personal data related to the physical or mental health of patients who go to them or who are or have been under treatment with them, protecting the treatment of personal data in the guarantee of professional secrecy that must be respected by the intervening physicians.

Biometric data

Biometric data are automated methods that allow an individual to be recognized accurately, based on physical or behavioral characteristics. The technology used in biometrics includes the recognition of fingerprints, palmar prints, facial, vein patterns, iris, voice and other exposures of the body including DNA or the sequence of keystroke, among others. That is, biometrics refers to the measurement of physical signs, biological and behavioral characteristics used for the identity of people ("Biometrics", 2017).

For the processing of biometric data, a normative regulation of data protection must be considered, something that Paraguay has not done so far. A **biometric data** is considered a sensitive data by the new regulation of the European Union Directive, since it implies special characteristics. It establishes the prohibition of its treatment except for some exceptions contemplated in the same norm, for example, when the interested party gives an explicit consent or when dealing with specific needs. Particularly, when the treatment is carried out within the framework of legitimate activities by certain associations or foundations whose objective is to allow the exercise of fundamental freedoms.

It is worth asking if in the Paraguayan jurisdiction the biometric data is a sensitive data. Act 1682/2001 defines **sensitive data**, adapting to international doctrine and jurisprudence that seek to prevail the right of privacy and respect for sensitive information (Article 4) as:

"Racial or ethnic affiliation, political preferences, individual health status, religious, philosophical or moral convictions; sexual intimacy and, in general, those which promote prejudice and discrimination, or affect the dignity, privacy, domestic privacy and private image of individuals or families"

This research will focus only on one type of biometric data: the storage of fingerprints in **IPS databases**.

⁸ Idem. Jazmin Acuña, Luis Alonzo Fulchi, & Maricarmen Sequera, 2017

Databases

Due to the ambiguities presented by the act on "private data" in Paraguay, it is worth analyzing a definition of **database** and in particular those that are held by state institutions:

"[...] an organized set of data which are managed or processed, electronic or not, regardless of the type of formation, storage, organization or access, whose owner is a legal person of public nature"

From this definition, we observe that an organized set of data stored in physical folders, in drawers of a public institution, is also a database. But the object of interest of this research are those that are digitized.

Confidentiality and privacy of personal health data

There is a wide bibliography on health and bioethics legislation, on the importance of the right to confidentiality of medical and genetic data, which is considered a fundamental right of the patient and is enshrined in the legislations of several countries. This right is also one of the main data protection rights.

It is important to highlight that **medical and genetic data** are considered exceptionally confidential data according to the current data protection laws, which is a special status that requires extra protection measures of security and confidentiality. The reason for this special status is that it is considered that medical and genetic data belong to the "private" sphere of the person (data subject), in relation to the most intimate personal areas. Therefore, an unauthorized disclosure of these data may be intended to cause discrimination and stigmatization in the domains of the personal, professional or social life of the data subject. At the same time, the privacy of health data is also a very important tool in public health policies.

The EU Regulation maintains the concept that "health-related data" and "genetic data" should be considered as "confidential data", and as such require more guarantees of data protection.

Confidentiality of sensitive data and public interest

Understanding the tension between the right to duty of confidentiality and the public interest should also be informed by a more detailed analysis of the different definitions of the latter.

The **public interest** is an open concept and constantly evolving. Experts argue that it does not matter to what extent the concept evolves and transforms, the public interest should never be allowed to be confused with curiosity or voyeurism and that the exaggerated expansion of some definitions of public interest will end up emptying the notion of private information by turning it into trivia, and defeating the purpose of recognizing a right to confidentiality with balanced limits.

On the other hand, others argue that we are moving towards a broad notion of public interest that, in most cases, would favor the dissemination of information. According to this notion, the alternative public interest related to the protection of trust is increasingly similar to a private interest. No matter on which side we take this argument, it is important to balance the public interest with confidentiality and identify and discuss the relevant factors that lead to a possible fading or transmutation of the latter (Faria & Cordeiro, 2014).

Privacy by design in health information systems

The defense of the rights of privacy and confidentiality of health data depends essentially on the existence of very objective security measures in health information technologies (IT). As an example to follow is the definition of "**privacy by design**" in article 23 of the regulation of the European Union, section "Protection of data by design and by default" (European Parliament, 2016).

This regulation aims to strengthen individual rights and address the challenges of globalization and new technologies with a special focus on the Internet, by adapting the general principles that were considered valid for these challenges, while maintaining the technological neutrality of the legal framework.

The obligation to incorporate "*privacy by design*" for the processing of health data or bio-banks⁹ will be key for managers of health information systems and will allow managing the risks associated with data processing, even in extreme cases such as "zero day"¹⁰, allowing to know what and how the data was exposed. However, the costs and technical implications of these measures can be dissuasive, especially if the sanctions for non-compliance with these protective measures are not strong enough or if the control by the competent authorities is non-existent. For example, in Paraguay, a complete and official health data platform¹¹ has been launched without really informing the public about issues of privacy and health confidentiality.

⁹ Gene Banks (DNA) of people

¹⁰ A zero-day vulnerability (also known as 0 days) is an unknown computer software vulnerability for those who are interested in mitigating the vulnerability (including the destination software provider). Until vulnerability is mitigated, malicious computer scientists can exploit it to negatively affect software, data, additional computers or a network. An exploit aimed at a zero day is called a zero-day exploit, or zero-day attack. Wikipedia. Accessed September 4, 2018.

¹¹ Online IPS services: <https://portal.ips.gov.py/sistemas/ipsportal/contenido.php?e=14>

Legal Framework

What follows is a legal description of the current national regulations that protect the private lives of people and that are directly related to our object of study, which are personal health data, considered sensitive.

National Constitution

In the constitutional reform of the year 1992, the following figures are incorporated into the National Constitution (NC) (Constituent Assembly, 1992):

Article 28 - Right to be informed (final paragraph): "(...) Every person affected by the disclosure of a false, distorted or ambiguous information has the right to demand its rectification or clarification by the same means and under the same conditions as it has been disclosed, without prejudice to other compensatory rights".

Article 33 - On right to Privacy - "Personal and family privacy, as well as the respect for private life, are inviolable. The behavior of people, as long as it does not affect the public order established in the law or the rights of third parties, is exempt from public authority. The right to protection of privacy, dignity and public image of people are guaranteed".

Article 86 - Of the right to work - "All the inhabitants of the Republic have the right to a licit, freely chosen work and to be carried out in decent and fair conditions.

The law will protect work in all its forms and the rights that it grants to the worker are inalienable."

Article 88 - Non-discrimination - "No discrimination shall be allowed between workers on ethnic grounds, sex, age, religion, social status and political or union preferences.

The work of people with physical or mental limitations or disabilities will be specially protected."

Article 102 - Of the labor rights of civil servants - "Civil servants and public employees enjoy the rights established in this Constitution in the section on labor rights, in a uniform regime for the different careers within the limits established by law and with protection of acquired rights."

Acts, resolutions and national public policies

Act N° 213/93- Labor Code

Article 275 - In particular, the employer shall: a. Have the medical, admission and periodic examination of each worker, covering the cost. The regulations will determine the time and manner in which periodic medical examinations should be taken, which will be relevant to the hazards involved in the worker's assignments.

General Technical Regulation of Safety, Hygiene and Medicine in the Work- Decree 14.390/92- Section IV.

Of the Compulsory Admission and Periodic Medical Examinations:

Art 262 °: The admission medical examination will include, for all workers:

1. Clinical examination (sight, hearing, skin, extremities, etc.).

2. Chest x-ray
3. Complete hemogram
4. Investigation of VDRL- Syphilis. Cholesterol
5. Glycemia
6. Immunofluorescence (Chagas disease)
7. Blood typing (blood groups and RH factor)
8. Routine examination (urine)
9. Parasitological faeces examination

Resolution 730/2009 "By which the error sheet of the general technical regulation of safety, hygiene and medicine in the work, approved by decree 14390/92 is relieved. In which it is stated that the admission medical examination, Elisa test, is mandatory. Likewise, regulations concerning the Elisa test in the workplace are regulated, observing the practical recommendations of the ILO, and the UNGASS 2001 Declaration of Commitment (Ministry of Labor, 2009).

The National Cyber security Plan (Executive Branch, 2017), directed by the Cyber Incident Response Center (CERT), was prepared during 2016, in consultation with academia, the private sector, civil society and State institutions, in which IPS also participated (CERT, 2016). This plan has the objective of accompanying public policies on digital security in the general population and is also focused on the protection of public and private sector databases. However, its implementation is still in the initial stage, so it is **not having an impact** on the new regulations and nor on the management that public institutions carry out on the personal data they collect. That is to say, there is not a comprehensive human rights perspective on the digitalization of services.

Another problem that is observed in the plan is the absence of digital security concepts for the protection of personal data and databases. That is, it does not adjust to the international standards for safeguarding them, to avoid fraudulent abuses that may put the privacy and confidentiality of the citizens' personal data at risk.

Compliance with the cyber security plan depends essentially on the existence of very objective security measures in health information technology. The concept of "**privacy by design**" proposed by the EU data protection reform is a measure that is in the implementation phase for health units and may be the key to avoid confidentiality violations "from scratch". However, the costs and technical implications of these measures can be dissuasive, especially if the sanctions for non-compliance with health data protection measures are not strong enough or if control by the competent authorities is non-existent.

On the other hand, as regards the storage of personal health data, it is important to emphasize that traceability and access to them are often independent of privacy and confidentiality criteria. The CERT advises that the storage of health data have its own servers and are located in national territory: this criterion has a political component referring to the sovereignty of the population's data. Furthermore, for the specific case of this research, it is essential to protect the right to confidentiality of health units, that is, the technological systems that store patients' data. Although confidentiality became expensive to protect and, as such, it can come to be seen as a "luxury", for the management of health it is an **essential necessity**.

Regulatory Framework of the Social Security Institute

The institution or figure of social insurance is a right and obligation present in most countries of the world. The International Labor Organization (ILO), in its document "Concrete Facts on Social Security" (ILO, 2018) defines it as:

"Social security is the protection that a society provides to individuals and households to ensure access to medical care and guarantee income security, particularly in case of old age, unemployment, illness, disability, work accidents, maternity or loss of the breadwinner"

Also, in Article 22, the Universal Declaration of Human Rights of the United Nations (UN, 1948), establishes social security as a right to say that:

Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

In Paraguay, social security is regulated in Article 95 of the National Constitution (Constituent Assembly, 1992). It determines that:

The mandatory and comprehensive Social Security System for the dependent worker and his family will be established by law. Its extension will be promoted to all sectors of the population. The services of the Social Security system may be public, private or mixed, and in all cases they will be supervised by the State. The financial resources of social insurance will not be diverted from their specific purposes and will be available for this purpose, without prejudice to lucrative investments that may increase their assets.

However, the National Constitution dates back to 1992. The institution of social security in Paraguay, as well as the legal and administrative institution that supports it - the Social Security Institute - has an even greater longevity.

Although the mention of social security in the maximum legal document of the Republic is positive, it is also important to highlight that it is a commitment of the Paraguayan state even before the current Magna Carta. Therefore, a correct implementation and strengthening of it is a high priority.

The Social Security Institute was formally created by Decree Act No. 17.071/43. It recognizes a series of classic obligations of a welfare State, by establishing in its letter of exhibitions (Presidency of the Republic, 1943, p. 0)

That it is the proper function of the State to assure the citizen the means to protect him from the hazards of life, in regard to sickness, maternity, disability, accidents at work, etc.

That the accidents at work and the occupational diseases suffered by the employees leave these victims or their families in an economically distressing situation, which the community should tend to mitigate by introducing social insurance, whose contributions are paid by the respective employers.

The Decree Act formally established the first social security system in Paraguay, called the Insurance of Diseases, Maternity, Disability and Occupational Accidents (Presidency of the Republic, 1943) which replaced the previous Decree-Law No. 4490 of Compulsory Savings for Employees of a permanent nature, because it only focused on the prevention of old age and disability (Presidency of the Republic, 1943).

It is in the same Decree-Act No. 17.071/43 that the agency responsible for overseeing and managing the social security system in Paraguay is established and is baptized with the name that still holds to this day. Article 13 provides that:

Create an autonomous body, responsible for the management and control of all matters relating to the purposes of this Decree-Law, with the name of "Social Security Institute"

Subsequently, through Decree Act 1860/50 - and later approved by Act 375/56¹² - a reflection exercise is carried out after 7 years of functioning and a series of limitations are recognized in the initial approach, establishing the nature, objectives, functions and the legal and financial profile that IPS has to date.

Article 1° indicates the type of support that will be granted to insured persons and reaffirms the Social Security Institute as the body in charge of administering and managing the Social Security institution in Paraguay (Presidency of the Republic, 1950):

Social Security will cover, in accordance with the terms of this Act, the hazards of non-professional illness, maternity, occupational accidents and occupational diseases, disability, old age and death of salaried workers of the Republic.

The Social Security Institute, an autonomous body with legal status that created Decree-Act No. 17.071 of February 18, 1943, will continue to direct and manage Social Security.

For the purposes of this Act, Social Security will be named as Insurance and Social Security Institute as Institute.

In order to understand the scope of social insurance, Article 2 delimits the beneficiaries of it, and clarifies in turn those figures that are excluded from it (Presidency of the Republic, 1950):

It is compulsory to insure in the Institute all salaried workers who provide services or perform a work under a work contract, written or verbal whatever their age or the amount of remuneration they receive, as well as apprentices who do not receive salary.

The following are excepted from the present provision:

- a. Officials and employees of public administration*
- b. Freelance workers*

¹² By which Decree-Law No. 1860 of December 1, 1950, is approved, which modifies Decree-Law No. 17071 dated February 18, 1943, of the creation of the Social Security Institute. Available in: <https://informacionpublica.paraguay.gov.py/portal/#!/ciudadano/solicitud/13894>

c. Employees and workers of the Central Railroad of Paraguay, until it is resolved by law to unify this Fund with the Institute of Social Security.

The staff of the autarkic entities of the State or Joint Ventures in charge of an economic exploitation or a public service, as a general rule will be included in the social insurance, except when special provisions, legal or administrative, oppose it.

The institute may accept, as voluntary insured, employees not included in the first paragraph of this article in accordance with the respective regulations.

However, different provisions established throughout the institutional life of the IPS have expanded and revised the scope of who should be insured under the social insurance scheme.

For example, Act No. 4.933/13 authorizes the voluntary incorporation of independent employees, employers, housewives and domestic workers into Social Security - Pension and Retirement Fund of the Social Security Institute. The same act clarifies that access to health services provided by the pension system is excluded from said provision (National Congress, 2013).

According to the Insured's Manual of the IPS (IPS, 2017) and based on current regulations, the following are currently insured owners and are required to be enrolled in the Pension Fund:

Salaried employees dependent on the private sector and their families.

Employees of decentralized entities and mixed economy companies

The employees of the municipalities

Officials, employees, workers and relatives of the National Electricity Administration (ANDE)

Apprentices who work in these companies

Teachers of Private Sector

The same Manual defines that the insured holder is the one who quotes or pays monthly contributions to the Social Insurance of IPS and who is registered in the pension fund (IPS, 2017).

On the other hand, and in order to establish the compulsory nature of employers when registering their employees, article 3 of Decree-Law 1860/50 establishes the mechanisms to do so:

Employees must be enrolled in the Institute by their employers in forms that the Institute will have available to them. The forms will contain all the data that in the opinion of the Institute are necessary for the identification of the insured persons and for statistical purposes.

Registration must be made in urban areas within three business days from the beginning of the service of the employee.

In rural areas the Institute will set the period according to the particular conditions of them.

The employee will be considered duly registered when in possession of the supporting document that the institute will provide when authorizing the registration. In these cases, the employer is exempt from the obligation to enroll him/her, but must correctly record the

number assigned to the employee in said document whenever doing any procedure before the Insurance that relates to the respective insured.

It is noteworthy in this section the fact that within the Decree-Act it is clarified that the registration will be subject to forms with content to be defined by the IPS and according to data that said institution considers necessary for access to benefits insured by the same.

On the other hand, Article 4 of Decree-Law 1860/50 is central in the sense of explicitly establishing the autarchy of the Social Security Institute by stating that:

The Institute will be an autarchic entity with legal status and its own patrimony governed by the provisions of this Decree-Act, the other pertinent acts, the Decrees of the Executive Branch in matters authorized by law, and the regulations issued by the institution itself.

With regard to the management of IPS, it is under the direction and administration of a Board of Directors supervised by the State, and whose members are appointed by the Executive Branch (IPS, 2017). Such Board of Directors is composed of 1 (one) President and 5 (five) members representing:

- Ministry of Labor, Employment and Social Security
- Ministry of Public Health and Social Welfare
- Employers
- Insured employees
- Retired and pensioners of IPS

Likewise, and to understand the purpose of the IPS and to frame its functioning, the institutional website¹³ of the Social Security Institute establishes that:

The main purpose of the IPS is to provide its insured and family members with a set of services that protect them in case of illness, occupational accidents and occupational diseases. In the case of the worker holding the General Scheme, a retirement or a pension is granted upon completion of the age and seniority requirements established in the law or upon retirement due to incapacity for work.

Thus, within the framework of its responsibilities, and as has already been stated above in many articles and provisions, **IPS has the power to collect documents and forms** within the framework of its functions and to fulfill its purpose of protecting workers who are within its reach.

It is also noteworthy the independent nature of it. Established and guaranteed by law, such autarchy is central in the sense of ensuring the protection of the patrimony in charge of the Institute, and that can only be used to guarantee the provision of the services that it is obliged to provide.

International standards of workers' rights and personal data of workers.

The International Labor Organization (ILO), in its search "to establish labor standards, formulate policies and develop programs promoting the decent work of all, women and men" («About the ILO»,

¹³ Historical Review of the Social Security Institute. Available in:
<https://portal.ips.gov.py/sistemas/ipsportal/contenido.php?sm=1>

2018) has a series of provisions, recommendations and regulations regarding the protection of personal data of workers of their Member States.

In this regard, it is important to highlight that the ILO, in its capacity as a specialized agency of the United Nations with regard to work, produces a series of documents that, to varying degrees, commit or oblige States to recognize the best standards and practices emanating from said body. The **Conventions** are international treaties of a mandatory nature, while the **Recommendations** are not mandatory, but they entail certain obligations in terms of procedures (Beres, 1997).

Finally, the repertoire of recommendations, also without being mandatory, is limited to making recommendations and laying the groundwork for employers and workers to determine certain rules and standards. They are used to elaborate acts, regulations, collective agreements, directives and labor policies, as well as practical rulings at the company level (Beres, 1997).

In relation to the specific topic of the present research, the international standards produced by the ILO are diverse and even relate to other provisions that do not have a direct relationship or explicit mention of the protection of personal health data of workers. As an example of this, Convention 111 concerning Discrimination in Employment and Occupation (General Conference of the ILO, 1958) defines discrimination in its Article 1 as:

- (a) *any distinction, exclusion or preference made on the basis of race, color, sex, religion, political opinion, national extraction or social origin, which has the effect of nullifying or impairing equality of opportunity or treatment in employment or occupation;*
- (b) *such other distinction, exclusion or preference which has the effect of nullifying or impairing equality of opportunity or treatment in employment or occupation as may be determined by the Member concerned after consultation with representative employers' and workers' organizations, where such exist, and with other appropriate bodies.*

As it can be observed, these distinctions or exclusions can occur in various contexts, and even more in situations of full access to certain private data of workers.

Measures to protect people's private lives directly influence the application or assurance of **equal opportunities and equal treatment in employment** and are necessary in the protection against discrimination to access decent work. Unfavorable scenarios towards certain collectives or minorities historically relegated and that traditionally end in discrimination -both in the workplace and outside of it- can occur in the face of potential abuses in the type of data collected, related to the health of workers or future workers.

The main regulations mentioned in relation to workers' health - and which are directly related to data protection - are Convention 161 (General Conference of the ILO, 1985a) on occupational health services¹⁴ and Recommendation 171 (General Conference of the ILO, 1985b) on occupational

¹⁴ Convention 161 defines health services in its article 1 as services entrusted with essentially preventive functions and responsible for advising the employer, the workers and their authorized personas about:

- (i) the requirements for establishing and maintaining a safe and healthy working environment which will facilitate optimal physical and mental health in relation to work;
- (ii) the adaptation of work to the capabilities of workers in the light of their state of physical and mental health;

health services. It is precisely in this Recommendation where the main delimitations, approaches and recommendations regarding the management, limits and storage of personal health data of workers are found.

As it is mentioned in the preamble, regarding the protection of workers against diseases and occupational accidents, the mandate of the ILO describes a series of issues concerning the handling of health data files, the permits to access to certain types of documents, as well as the ways in which the files and medical results of the workers must be consigned and delivered to the employers, to the extent that it is necessary and contemplated in the law.

In Article 14, Recommendation 171 (General Conference of the ILO, 1985b) states that:

(1) Occupational health services should record data on workers' health in personal confidential health files. These files should also contain information on jobs held by the workers, on exposure to occupational hazards involved in their work, and on the results of any assessments of workers' exposure to these hazards.

(2) The personnel providing occupational health services should have access to personal health files only to the extent that the information contained in the files is relevant to the performance of their duties. Where the files contain personal information covered by medical confidentiality this access should be restricted to medical personnel.

(3) Personal data relating to health assessments may be communicated to others only with the informed consent of the worker concerned.

It is thus observed the importance given to the confidentiality of sensitive data that could be in a specific file, limiting the type of person and professional profile with access to this type of highly sensitive documentation. It also reinforces the idea that in the specific case of containing data of a medical nature, access should be strictly limited to medical personnel.

Also, this document highlights the need for the competent authority – if any - to establish the **rules of the game** in matters such as the time that such personal health records are kept, the manner in which they are informed and communicated, as well as the measures that are adopted to maintain the confidentiality nature and with special attention to those situations in which such data are in a computer (ILO General Conference, 1985b).

On the other hand, when communicating and transferring the medical results of a particular worker so that the employer can determine and verify the fitness of the worker for a job, or to clarify what is the type of assignment that a worker can perform, Recommendation 171 (General Conference of the ILO, 1985b) is very clear in pointing out in its article 16 that:

(1) On completing a prescribed medical examination for the purpose of determining fitness for work involving exposure to a particular hazard, the physician who has carried out the examination should communicate his conclusions in writing to both the worker and the employer.

(2) These conclusions should contain no information of a medical nature; they might, as appropriate, indicate fitness for the proposed assignment or specify the kinds of jobs and the conditions of work which are medically contra-indicated, either temporarily or permanently.

In this way, Recommendation 171 ensures worker confidentiality and protection by default and sets the guidelines concerning personal health data, which are collected by employers in a specific hiring process. The above also applies to subsequent examinations that may be performed and applied in the course or natural development of the employee in a certain company.

The ILO code of practice also goes into a series of issues related to the protection of personal health data of workers.

It is important to recognize the different reasons that make the collection of personal data of workers by their employers. The repertoire of recommendations (Beres, 1997) begins by giving an overview of these motives, stating that:

The data that employers collect about workers and candidates for a job serve several purposes: to comply with the legislation; support the selection of candidates, training and promotion of personnel; safeguard personal and work safety, quality control, the service provided to clients and the protection of assets. There are new ways of collecting and processing data that imply new risks for workers. Although several national laws and international standards have established mandatory procedures for the processing of personal data, there is a need to improve the provisions specifically aimed at the use of workers personal data.

Subsequently, the repertoire divides the standards and recommendations into sections that organize stages or time around the protection of personal data and which are arranged in titles such as general principles, data collection, individual and collective rights and others. For the purposes of the present research and the purposes pursued, only some of the sub-points included in each of the sections will be addressed.

Regarding the General Principles, an emphasis is again made in the **confidentiality** for the access of the workers personal data, since it indicates that all those who have access permits, such as employers, representatives of the workers, placement agencies and workers themselves, should be governed by confidentiality (Beres, 1997).

This section is interesting in the sense that it invites employers to make evaluations about the methods of data processing they have in order to reduce as much as possible the type of data they collect, as well as to improve security standards to protect the private life of their workers.

With regard to personal data of a medical nature, paragraph 6.7 (Beres, 1997) of the same code establishes that they should only be collected in accordance with national legislation, respect for medical secrecy and general health principles, and safety at work, and only when necessary in order to:

- a. determine if the worker can occupy a specific job assignment;*
- b. comply with the requirements regarding health and safety at work;*
- c. determine the right to social benefits and their enjoyment.*

It is also important to point out that in the repertoire of recommendations, there is again an emphasis on the ways in which the medical information of the workers to their respective places of

employment should be informed. Subsections 10.8 and 10.9 (Beres, 1997) clearly establish that in relation to the communication of personal data:

10.8 In the case of medical examinations, only conclusions that are relevant to the decision in question concerning employment should be communicated to the employer.

10.9 These conclusions should not contain information of a medical nature; they could, when appropriate, indicate fitness to perform the proposed assignment, or specify the types and conditions of work that, temporarily or permanently, are contra-indicated.

As noted, the detailed medical information **never reaches the hands of the employer**, since such results are only and exclusively available to the data subject, in this case, the worker.

Traditional topics such as the consent of workers when collecting personal data - of a medical or other nature - are also contemplated within the framework of such repertoire.

However, a reality that must be taken into account when collecting personal data is related to the real significance of the consent as a reflection of the real willingness of workers to deliver sensitive data. The relative repertoire of recommendations in paragraphs 6.5 and 6.9 (Beres, 1997) points this out:

Although the participation of workers is very important, there should not be an exaggerated concept of their impact on informative work. In general, the fact that workers are in a situation of dependence in the workplace will induce them to meet the wishes of the employer, and their participation will be limited to a mere formality. That is why most national courts try to prevent, especially in the case of questionnaires, the collection of particularly sensitive personal data. Something similar is done in many data protection acts, as well as the 1981 Convention of the European Council and in the proposals of the EU Personal Data Directive. These sensitive data include those related to the sex life of the personnel, their union status, their racial origins, their political opinions, their religious beliefs and their criminal record.

Unlike a self-regulation where corporate interests are generally imposed, a clear regulation and according to international standards becomes essential.

Consent, often, can occur in **situations of power** and real need by the worker, and in the dynamic of dependency that is generated in the employee-employer contract. Having the guarantee of a present State that looks after the interests of both parties taking into account the particular situations, becomes central to ensure a healthy and fair environment, in which the collection of personal data - and especially those related to health- are given in the best conditions.

Resolutions of the Social Security Institute - IPS

Biometric data for access to state social insurance

With the argument of “you are looking for patient comfort and general security” when collecting medications, medical imaging and analysis, the Board of the Social Security Institute (IPS) approved in 2015 the biometric registration of all its insured persons, from 2 years of age. In 2016, the

resolution of the Board of Directors of IPS No. 003-050/16 came into force, which obliges patients and patients' authorized persons to register their fingerprints in order to withdraw high-cost cancer medications. The Central Hospital pharmacy together with the Customer Service Center (CAU) implemented this mandatory procedure for the collection of medications, gradually extending to all IPS insured.

During the first months of 2016, fingerprints of 1,000 patients were registered for collections in external pharmacy. Gladys Coronel, head of the department of Pharmacies, said that the goal for that year was to reach the 7,000 registered insured and 21,000 authorized persons (ABC Color, 2016).

In 2017, the IPS newsletter highlights the importance of enrollment to access the IPS health service (Communication Office of the Social Security Institute, 2017):

"Enrolling means that at some point, instead of using the identity card, the fingerprint is used, when the patient puts their fingerprint, all their data is released, if he/she is up to date, if he/she is insured, which insurance corresponds, if prosthesis is applicable or not, etc. We seek for the patients comfort and general safety, there is a certain process that now has to be done, checking the rights, going from one office to another, searching the computer system etc. All that will disappear by using just the fingerprint" says Dr. Manuel García, medical director of the Central Hospital.

The implementation of the IPS biometric system is not regulated in the Paraguayan national legislation. Although the right to privacy is recognized in the National Constitution of Paraguay (Art. 33), in practice there are not enough measures to guarantee compliance with this right, as evidenced by the processing of personal data in public and private databases (TEDIC, 2017).

Act 1682/2001 that regulates certain aspects of data processing in our country is far from complying with minimum standards of personal data protection, such as the self-determination of the data subject, the requirement of purpose of the collection, the storage time of the data, proportionality, data quality control, scope of application, accountability, among other principles. In addition, a great absence in this administrative resolution are the administrative sanctions in case of abuses in the treatment of sensitive data and databases, by any public or private entity.

A research of ADC Digital on Biometrics and protection of personal data contemplates a case investigated by the University of North Carolina:

"A research that has found significant differences between fingerprints belonging to people of African descent and people of European descent. Although researchers themselves state that a larger sample of people and a more diverse analysis of ethnic groups are necessary to obtain a definitive conclusion, the first scientific results indicate a high possibility that the fingerprints reflect specific patterns of a specific ethnic group" (Eduardo Ferreyra, 2017).

As a result, the storage of fingerprints in Paraguay meets the conditions required to be classified as sensitive data. The resolution of the Administrative Board of IPS **does not include a previous analysis** to justify the implementation of this type of system. According to data processing standards, an impact evaluation is mandatory for the collection of **biometric data** based on the

principle of the need to use this type of systems. Nor does it justify why the current identity card - issued by the State itself to identify citizens - does not serve as an identification tool to carry out the legal act before IPS. This mechanism would be less invasive than the collection of fingerprints, and therefore, the risk of violation of fundamental rights would be greatly reduced.

According to the newsletter that is mentioned at the beginning of this section, it is sought to avoid bad intentions of people when using the identity of third parties for criminal purposes. But to justify the collection of biometric data, which are sensitive data, it must be analyzed if there is no alternative way that affects to a lesser extent the rights of the people and, at the same time, can achieve the objectives that are pursued (EFF, 2016). This measure, that seeks to be preventive to avoid any type of crime, not only reflects a disproportion in terms of the aim pursued, but also leaves aside the ideal of a minimal intervention by the punitive apparatus of the State, typical of what is called "minimal criminal law".

The design of the system for the prevention and prosecution of crimes must take into account that it cannot end the criminal chain that it seeks to fight on its own. There are some alternatives that can be more effective and less invasive for people, such as the voluntary identity implantation report, the cooperation between operators, or the tracking and capture of criminal gangs dedicated to this illegal activity.

The former Special Rapporteur on the promotion and protection of the right to freedom of opinion and expression (UN), Frank La Rue (Human Rights Council, 2013) and the High Commissioner for Human Rights (UN), Navi Pillay ("UN rights chief urges protection for individuals revealing human rights violations", 2013) have expressed concern about violations of the right to privacy due to the lack of effective protection measures in the use of biometric technologies.

For his part, the former Special Rapporteur on the promotion and protection of human rights and fundamental freedoms in the fight against terrorism of the UN, Martin Scheinin, determined in his report published in 2009 that, although the use of biometrics is presented in certain circumstances as a legitimate tool for the identification of suspects in cases of terrorism, there is a special concern about:

"The cases in which biometrics is not stored in an identity document, but in a centralized database, increasing the risks for the security of the information and leaving individuals vulnerable. As biometric information increases, error rates can increase significantly" (Leandro Ucciferri, 2017).

The increase in error rates can lead to the illegal criminalization of individuals or social exclusion. At the same time, the Rapporteur highlights an aspect that was mentioned earlier, the irrevocability of biometric data:

"(...) Once copied and/or fraudulently used by a malicious actor, it is not possible to issue an individual a new biometric signature [identity]."

It also highlights that biometric data present obstacles of privacy and confidentiality that at first glance seem to be overcome if the concept of confidentiality is redefined and readjusted: moving

from an information confidentiality model based on trust, to an anonymous data model. That is, anonymization should be a basic requirement to build a biobank.

However, some authors (Faria & Cordeiro, 2014) consider that there are doubtful areas in the validity of this "guarantee". On one hand, they claim that the anonymization of data "often hides situations in which, in fact, there is still the possibility of re-identifying data, and therefore, that anonymity is not real or complete" (...). On the other hand, the strongest doubt is that the anonymity is used as a "rhetorical strategy to deny the existence of any subjective interest in human biological materials (HBM) and, consequently, to affirm its free availability for those who can do an interesting use of them, such as the medical and biotechnology industry".

Admission medical examination of IPS

The resolutions of the Board of Directors of IPS, No. 099-022/16 "Approving the regulation that establishes the presentation of the Administrative Medical Examination of Act No. 430173, in its Article 46", establishes that: "Employers are obliged to provide the Institute's authorities with all the reports that are required regarding the situation of the affiliated to the Benefit"; the "Admission medical examination of the workers in charge of the employers." Resolution No. 024-009-17-Validity Admission Examination "By which the article 2 of the RCA N° 099-022/16, dated November 24, 2016 is modified, "Which approves the regulation that establishes the presentation of the Admission Medical Examination of the workers in charge of the employers". Resolution No. 035-007/17 "Approving the compulsory use of the form of admission exam by employers and entrusting the Legal Department to proceed to analyze the feasibility of sharing the costs of the Admission Exam, between the Social Security Institute and the Employers". Resolution C.A N ° 090-022/17 which modifies Article 3 of Resolution No. 035-007/17, dated May 25, 2017, approving the compulsory use of the form of admission exam by employers and entrusting the Legal Department to proceed to analyze the feasibility of sharing the costs of the Admission Exam, between the Social Security Institute and the Employers.

These resolutions are in line with the legal obligation of the Labor Code - Act No. 213/93, Art 275, which establishes the submission of workers to periodic examinations established by the employer, with no costs for the workers. Through this norm, IPS can request each employer the examinations of each worker in case of suspicion of insurance fraud¹⁵ or at the moment of registration in IPS.

Likewise, what is stated in Annex 1 - Admission medical examination of resolution C.A N° 099-022/16, numeral 7:

Requirements. The medical-labor board may require the Employer to submit other laboratory analyzes, imaging and medical examinations.

It is important to highlight that the rights interconnected to privacy and confidentiality with respect to medical information and medical history have been widely discussed in the fields of bioethics and health act. These have been the object of consensual and challenging ideas. It is indisputable that medical secrecy remains a key to medical work: even without this criterion most patients would not

¹⁵ Specifically affiliations of people with preexisting serious diseases, which therefore simulate a labor relationship for the sole purpose of accessing medical treatment, medication, hospitalization and other benefits financed with the Sickness - Maternity Fund. Resolution C.A No. 099-022/16 IPS.

disclose part of their intimate medical history. It is therefore important to emphasize the notion that the right to confidentiality in health not only serves to preserve a significant element of trust, but also to prevent stigmatization and defense against discrimination. Therefore, measures to protect confidentiality are key to public health.

Analysis of interviews

To understand the scenario surrounding the implementation of Resolution CA No. 099-022/16 of IPS, of the Board of Directors of IPS No. 003-050/16 on biometrics and other related topics¹⁶, a series of interviews were conducted with State civil servants linked to such regulations and representatives of the private sector in different areas and linked to the management of personnel within the companies. The IPS Economic Performance Manager was interviewed from the public sector, under whose management is the Occupational Hazards and Subsidies Department, a unit within the IPS directly linked to the implementation of Resolution No. 099-022/16. The Director of the Department of Inspection and Supervision of the Ministry of Labor was also interviewed, a body that controls the documentation of the workers in the framework of the annual periodic examination.

In relation to the private sector, 4 companies of different categories were identified and with a minimum average of 150 employees. For all cases, both the admission and annual medical examination is an obligation that must be complied.

It should be noted that in order to improve the authenticity of responses, interviews were conducted with anonymity agreement, both with respect to the person and the company in which he/she works. An approximation and accurate understanding of the phenomenon addressed by the present research is sought.

To order the most significant information given by each of the sectors interviewed, there will be a differentiated disaggregation of the testimonies, starting the analysis of the interviews conducted with IPS and the Ministry of Labor, by the different nature of the questions asked to said entities of the State, to then go on to analyze the interviews to the different companies that agreed to the interviews.

Interviews with IPS authorities

In relation to the Social Security Institute (IPS) and the consultations of different nature and scope that were conducted, they show that the necessary and sufficient regulations that justify the collection of health data of workers in the framework of the Admission Medical Examination, are article 275 of the Labor Code and Resolution C.A N° 099-022/13. The interviewees mentioned that, since 1993, admission-type examinations for workers were taken through consultations, but because of the institution's own capacity, this was very complex, so the current regulations that are more direct and easier to sustain were opted by IPS.

Regarding the safeguard criteria carried out by the Labor Registry and Subsidy Department, as well as the processes of loading and systematizing said information, the interviewee mentions that

¹⁶ Management of data bases in general and the collection of biometric data for access to medicines by the Social Security Institute.

initially the organism had planned to receive the medical examinations, but this was subsequently modified by resolution, thus safeguarding the confidentiality of patients:

First, the admission exam was to be presented to IPS, but that was subsequently modified by resolution and became an Affidavit. What is informed to me? Worker X took the admission exam and is fit for work. If the doctor refers on the certificate, he/she can write: the patient has mild diabetes, congenital heart disease, and the doctor's information is included in the certificate. We do not receive medical examinations or anything. That is also why the confidentiality of patients is guaranteed. The information we receive is also allowed only to our medical professional personnel. Obviously, those who do face-to-face deliver the document in a window and an administrative officer uploads it online. But the REI¹⁷ system is direct, not even we, the IPS administrative staff, see it. We are interested in knowing whether the person is fit or not, if refers X pathology or not. The issue of HIV was removed and is not part of the Admission Medical Examination. Tripartite meetings were held with HIV prevention organizations, the Ministry of Labor and we even issued joint statements. Because that was used to discriminate. People were detected and got fired.

On the other hand, as regards the deletion of old data, and rectification mechanisms thereof, there is evidence of a lack of differentiation of the types of data that can be deleted without obstructing the nature and functioning of IPS in safeguarding the interest of workers. There are also no constant data update processes:

In general, IPS does not delete information. Because it is linked to very long-term benefits. If in 15 years I have to give disability retirement due to illness to a person, I am interested in knowing that person's medical history, what pathology he/she had when started to work, so I cannot delete anything, I have to have that information, that remains in the Hospital Information System, a database from which information is extracted.

As regards the update, it is updated to the extent that the worker comes to get his check-ups.

Likewise, in relation to access to said data bases, the interviewees clarify that only the data subject is the one who can have access to his/her medical studies: workers themselves are the ones who request information regarding the data contained and stored in IPS. On the other hand, only physicians have permission to access the health data of workers referred to both the admission medical examination and others that have to do with the proper functioning of an institution such as IPS that provides health services to its insured persons.

In the framework of the protocols that companies must follow to store health data - be it annual medical examinations or the affidavits delivered to IPS - IPS employees affirm that it is not part of their responsibility to fulfill the inspection role over said internal processes of companies:

¹⁷ The REI System is a new data processing system via Internet, called Electronic Information Registry through which you can make all movement operations of employees, print the liquidation and then pay cash or directly through the payment system of the adherent banks. More information in: <https://portal.ips.gov.py/sistemas/ipsportal/contenido.php?c=119>

What happens is that you have to differentiate two things. I am a provider of short and long-term health services. The governing body of the Labor Code is the Ministry of Labor and they have a department for this. They have their inspectors who are responsible for this safeguard.

Beyond the list offered by Decree 14.390/92 on the type of medical examination that should be done to workers, the interviewee from IPS states that this is not limiting and that for this reason it is vital that companies consult an occupational physician to study each particular assignment that a worker must do within the framework of his/her duties:

This Decree references, but it is not absolute and essential. It is important for companies to hire an occupational physician to define their jobs and inherent hazards.

In relation to the general management of the databases that the IPS has, with respect to the national, internal and international regulations that sustain the management of such, the interviewee states that:

In case, by priority, it is the national law. They are data, they are medical reports. So they have the necessary precautions. We, for example, if a company asks us what illness a certain patient has, only by court order we can inform about it. In fact, IPS cannot give individualized data, medical data, salaries, nothing. Only for statistical purposes some information can be shared with the Ministry of Finance, Civil Registry, etc. and for the purpose of attacking tax evasion and so on. Information can only be given to the data subject, upon request.

The interviewee also clarifies that the data collected by IPS are not used for purposes other than those for which they were collected for, and as regards the question about infrastructure incidents of some kind, they do not remember having suffered any in particular. In any case, he states that they have protection mechanisms and protocols in case there is some type of attack.

Another question for the interviewee was about the location of the IPS servers that store all the information that the institution collects in the framework of its functions. The interviewee pointed out that everything is stored in the country. There is a main server located in the IPS's headquarters and then a mirror in another part of the city (he did not specify where, for security reasons) that protects the data in case of a disaster.

Finally, regarding the obligation of the insured and authorized persons of a patient to register their fingerprints for the collection of medicines granted by IPS, it is identified that there are not enough regulations that refer to the definition and implication of the biometric data collection by IPS. The only regulations that the interviewees mention for the collection of said data are Resolution No. 003-050/16, which requires the collection of the fingerprints of IPS insured persons.

Regarding the reasons for accessing such biometric database, as well as the permissions and accesses of each employee who can consult it, they state that:

All our databases that are here have a confidentiality agreement. I have a username and a password that is confidential to me. If I access and take some information out, it will be registered in the system.

Tomorrow, if there is a problem of data disclosure we can know from what computer and what user it was made. We already had cases in the media with salaries of managers, etc.

Health data, the Hospital System is only available to doctors, and it is also confidential.

The reasons for accessing the database are for access to medication (an ID is presented and then the pharmacy employee can give it to the patient, and that's where the fingerprint is used and it is only for that purpose). All this is stored in the electronic medical database (medical consultations made, how many times medications were collected, how many times was the patient in the emergency room).

On the risks identified in the biometric databases, he points out that:

We have a specific area of security that identifies the risks and makes the recommendations.

Regarding the enrollment process for the registration of all IPS insured persons to the biometric database, it is still an ongoing process, since although they mention that all retirees have already been registered, the rest of the insured persons are still in the process of registering their fingerprint. The interviewees could not provide an exact number of registered people.

Finally, when asked about potential situations of discretion of IPS employees to sell information to companies and private clinics, they indicate that:

Yes, everywhere. As in any organization there are dangers: medical and administrative. There is corruption everywhere, and profit with information. But there is also a strong fight, whoever is caught doing that, is immediately fired.

When the same question is asked but to the private sector and more in the sense of potential situations of discrimination according to the type of degree of health or illness identified to a certain worker, they indicate that:

We already have experiences of complaints. This issue of the Admission Medical Examination was very distorted. We do not seek to limit access. But a lot of things were said.

In fact, if we go to the conception itself, the Admission Examination serves as a filter. Because, if for example the three of you apply for a job here and one of you has a disease that is proven that can generate several rest days, obviously I will not hire you. That is why it is called admission.

The issue of HIV that is so taboo, we have complaints from organizations that said that there is discrimination.

Interviews with employees of the Ministry of Labor

For the purposes of the present research, and in view of the decision to expand the object of the research to also analyze the annual periodic examination required by the Ministry of Labor, an interview was conducted with the Department of Inspection and Supervision of the Ministry of

Labor. This seeks to better understand the process of control to companies in the context of the application of this examination.

Specifically with regard to the type of examinations that workers must take, the employee interviewed makes reference to Decree 14.390/92 as the basic standard, but clarifies that each case is also specific, depending on the hazard:

The examinations vary according to each case (Back to Art. 260, 261, and 262 and 263 of Decree 1490 of 1992 establishes what should be taken, as well as the periodicity). They are defined by the Labor Code, and therefore required by the Ministry.

The Ministry demands that those who work in situations of hazards such as, for example, heights, take an examination done by an occupational doctor. The company has the obligation according to each case in particular. And ideally, with an occupational doctor, and not clinical one, but we accept it because there are usually not many.

Also, about risky or unhealthy jobs, refers that the examinations should not be taken every year, but semiannually, to be able to better accompany the evolution and welfare of workers.

On the other hand, and within the framework of whether there is an inspection process to evaluate the safety standards that companies have for the protection of the health data of their workers, he refers that with regard to the obligation of the Ministry of the Labor and its attributions:

That is up to the doctor. There are companies that do have and there are others that do not. Those are the ones that are fined, and the fines are very high because they are made according to the number of workers. The Ministry does not have a standard of review or care of medical examination data because it does not correspond to it, and it is the full responsibility of the doctor.

Whether or not the medical examination was taken and if the worker is fit or not are the criteria that only the inspector has. These are the main requirements. For more issues, the labor code would have to be modified, and since currently it is not included in it, it is not the inspector's competence, but the doctor's.

There is no contemplated fine or penalty from the Ministry of Labor. It would be necessary to look for a mechanism, perhaps coming from the Ministry of Health. It does not really matter to us.

The interviewee points out that all the protection and access of the data to an inspector are also under the responsibility of the doctor:

The company doctor is responsible and can only provide the information to the inspector who requests it. In companies with more than 150 employees, there must be a health department that is responsible for collecting this data. When there are less than 150 employees, there is not a doctor in the company, but there are outsourced doctors who go from time to time. In that case and according to the regulations, it is that doctor who must safeguard the medical personal data of the workers. The main responsibility of the Ministry is to see if the employee is fit to perform the job assigned to him/her. Everything is corroborated on the basis of the National Constitution, the Labor Code and Convention 81, and Act 5115/13, on the creation of the Ministry of Labor and the functioning of the General Department of Inspection.

Likewise, he points out that the Ministry does not collect workers' health data, but is only responsible for monitoring compliance with the regulations in force through its supervisors:

The Ministry is not the entity that collects these data. The doctors must store the examinations and the data of the workers while they work there. The Ministry does not collect any type of data in this regard.

Finally, as regards the degree of employers' compliance with the annual periodic examinations, like the Admission Medical Examination, the large companies are the ones that mostly comply with the resolution, as opposed to the medium and small ones, they do not do it in a large number.

Interview with private sector companies

Both for the Admission Medical Examination and for the annual one, some similar practices are identified and others are different in what refers to compliance with current regulations for the collection of medical data of workers by companies. Four companies from different sectors were interviewed: academia, media, services sector and pharmaceutical sector.

The 4 companies are currently complying with the current regulations related to the admission medical examination and also in relation to the annual examination. Some, like that of the "media" sector, already had mechanisms for medical check-ups of new workers and others have just begun to implement these examinations after the IPS regulation.

In the interviews, there are similarities and coincidences identified regarding the process of collecting medical examinations, in the sense that most of the companies outsource the health data collection service:

[In the media sector]: The admission examinations are carried out by a hired company, an outsourced service. This company receives the data that are sent by the people.

[In the service sector]: The service is outsourced, we do not do it, we do not collect anything.

[In the pharmaceutical sector]: It takes place during the onboarding process of the worker to the company. It is done by an outsourced service: a private clinic.

On the other hand, the academic sector is in a kind of gray area, in the sense that it is not the company that collects the data, but uses a hospital associated with one of the careers that it offers:

We have our own hospital that provides this service to the university community and also for urgencies when IPS cannot help us. The doctors who are working in the hospital send us the reports (professional medical statement).

A particular situation referred by one of the companies interviewed has to do with the criteria of outsourced clinics when making health examinations to workers, as well as certain irregularities that some doctors perform for profit:

The outsourced clinics, contracted by the employer to perform the worker's medical examinations during the onboarding process, usually perform a complete examination of the

workers. Their criterion has the purpose of charging more to the company; instead of an examination of 60 thousand guaraníes, they charged 250 thousand guaraníes per person, so it is convenient for them to make a complete examination.

In 2015 we suspended the clinic for requesting health information beyond what was requested by us. I think this was not to sell more information to others necessarily, but to charge us more.

Another problem that we found is that doctors usually give you the medical certificate without performing the examinations, it is a little more expensive but they certify the company for faster registration to IPS. We do not accept it, but it is something that exists in the market.

On the other hand, it is noteworthy that in all the cases referred to the access of health data collected - whether affidavits or the medical examinations themselves - only human resources personnel have access to such files. In all cases, workers also have full access to their data, upon request:

[In the services sector]: Only the Human Resources personnel who are two people. And we give a copy of those results to the workers, in fact they ask you because they never take any type of check-ups and it is the only time in their life that they get a complete medical check-up.

[In the media sector]: Only the Human Resources department and the worker. A copy can be given to the worker upon request. In this department there are only 4 people, and all of them handle this information.

[In the academia sector]: we do not see the results of the examinations because it is a matter of patient-doctor. The university does not receive any electrocardiogram, tomography, clinical analysis or doctor's opinion. There is only one sheet that technically the Personnel Department usually gives the professor and that is the sheet that the doctor signs saying the person is fit or not for the particular assignment.

[In the pharmaceutical sector]: The area of human resources of the company has access to it. The original results are given to the workers.

On the other hand, for all cases, companies receive and handle affidavits and medical results in printed format. Only the academia sector claims not to store medical results that are delivered only to workers. In the case of the other 3 companies:

[In the services sector]: Only printed, nothing digital. They send you the pre-established form with the patient's questions and answers plus the examinations that were performed to them and they send you everything on paper, and we file it, keep it in a folder that is specific to the medical examinations and is managed by a human resources person and there is no other person with access to that, because it is under lock and key.

[In the media sector]: Printed, they keep it in the file of the people in the Human Resources department.

[In the pharmaceutical sector]: We only have documents in printed format. We only have a medical certificate. The doctor who makes the certificate has the data of the worker's examinations, and all that is stored in the file of each worker under lock and key.

The original results are given to the workers, we keep a copy, and then we see if it is necessary to follow up on any disease that needs to be treated.

All the companies interviewed affirm that all workers have access to their files and medical records upon request. On the other hand, another coincidence found in 2 of the companies interviewed has to do with the fact that they do not destroy the health data they collect about their workers:

[In the media sector]: We do not delete the databases.

[In academia sector]: We really leave that in the file, which was the indication given to us. We cannot suddenly throw it away because anything can happen if you do it, unless you incinerate it but then that is an environmental matter and is another problem. So it is kept in the file.

Of the other two companies interviewed one adduces reasons that have to do with the fact that they have been applying the law for a short time. According to the interviewee, documentation has not yet been destroyed due to the Accounting Act that requires the storage of legal and fiscal documents for 5 years, and they use this same criterion for personal data. The other company uses the same criteria also when destroying documentation:

[In the services sector]: No, because the law requires you to keep all types of documents for 5 years. After 5 years, we will for sure burn and throw everything away. Since it is something new, we do not have a 15-year database of these issues. But we will destroy everything after 5 years as we do it with other documents.

[In the pharmaceutical sector]: Yes, every 5 years. We do not have any written protocol, it's just verbal.

Also, in the cases of the sectors of services, pharmacy and academia, they are dedicated to studying the particular role of each assignment, to determine what type of examinations should be applied to an incoming worker. In the case of the media sector, they are governed only by Decree 14390/92 on Hygiene and Health:

We are guided by what is required by the Act established by the Ministry according to its regulations.

Finally, on the consultation of the possibility of discretion of IPS employees for the sale of health data to clinical and pharmaceutical companies, none of the interviewees make assertions about it, varying the arguments of why:

[In the service sector]: I do not know, neither is it ... when you send the data, they ask you for very basic things, they do not ask for diseases: they ask if the person is fit or not, if the person has some health problems, more or less, it is just a matter of yes or no.

They ask for the doctor's name and registration. It's only for IPS to make sure that the company did the admission medical examination and shield themselves from the favor insurance. Really, with the information asked for in the website, there is not much they can do.

[In the media sector]: I do not think so, IPS carries out this for the insurance of favor, and I do not believe that there can be a particular interest of the people of IPS given the fact that the admission examinations are requirements for all the companies.

[In the academia sector]: The insurance of favor is a problem and this whole issue of the admission exam can palliate it. However, there needs to be a special care with the data management information that is essential, because they are rights of third parties.

[In the pharmaceutical sector]: No, IPS takes too long for basic blood tests, therefore it is done with another company for registration to IPS.

Conclusions and recommendations

The challenges mentioned clearly illustrate how the field of technology, health, rights of privacy and confidentiality of personal data, become a very complex field, both from the legal point of view and the integrity and dignity of the people. This calls for more attention from the Paraguayan State, as well as it should be a focus of interest of the academy, in the field of health.

The trivialization of the collection and exchange of sensitive health data and fingerprints require greater attention by the competent authorities to control the amount of health data that are currently being collected by public and private sectors. For this, the development of technologies that allow the implementation of standards for the protection of privacy and confidentiality with respect to personal health and biometric data, in order to avoid carelessness by health administrators, will be indispensable.

On the admission examination and the annual examination

When dealing with medical examinations required by IPS and the Ministry of Labor, it is necessary to recognize that **guarantees are needed to ensure that the mechanisms are adequate**. That is, that each mechanism is specifically applied to the working conditions that the person will be assigned to and avoid putting their environment at risk. It seeks to generate a healthier work ecosystem where there is protection for the worker, coworkers and the employer itself.

The challenges that technologies propose for the right to privacy and confidentiality are many. Society has evolved in ways that seem to contradict the importance of these rights in the past. However, the evidence that emerges from this research makes it possible to ensure that the protection of rights with respect to personal health data remains a priority for patients and physicians.

Beyond the annual medical examination that has been obligatory for years, **most of the interviewees mention that the obligation of these examinations is very recent**. The admission medical examination is of recent implementation, which is why it is in a phase of application on the part of the employers who are registered in IPS. Because of this, successive resolutions of the Board of Directors of IPS have postponed the application of fines for those who do not comply with the regulations in this regard. **However, it is assumed that progressively more employers will have to comply with said regulations.**

On the side of those companies that are currently in compliance with these regulations, the findings show that the norm is **the discretion or intuition of the employers and managers in charge of the management of human resources**. That is, they do not have practices or standards related to the management of workers' health data.

With regard to the collection and systematization of health data of workers by third parties (outsourcing), common practices were found. However, one of the people interviewed pointed out that it is common to request more examinations than necessary by some clinics. **With this, they charge more money and it becomes worrisome, as well as a violation of workers' rights, leaving them in a situation of potential vulnerability.**

The fact that all the companies assure that access to health files is the exclusive right of each worker, that is, the data subject, stands out as positive. In the case of companies that keep medical examinations, the same thing happens.

Of the companies interviewed, there are some with greater care when analyzing which health data they need to keep, avoiding the unnecessary storage of data. Only one of the companies interviewed said that they only keep the affidavit form required by IPS, as well as the fitness certificate of the workers. The rest of the companies interviewed keep even the results of medical examinations, and although they deliver the original document to the workers, they keep a copy for the company's archive, without there being any real justification for it. **In all cases, the companies keep this data in printed form and under lock and key.**

Another worrisome fact related to the previous point is that both the Ministry of Labor and IPS do not actively assume the role of control over the way in which the documentation required by their own regulations and provisions is protected. No convincing criterion or argument is identified that exempts the responsibility of these institutions in relation to their role in controlling that companies manage the health files of their workers in a proper manner. **Based on the interviews conducted, a worrying gap is identified when a public entity or body guarantees that the security measures of the companies' health files are stored according to the appropriate standards.**

Another worrisome identified trend is the lack of a general protocol that contemplates the destruction of sensitive health data - and data in general - of workers, once the purpose for which they were collected was accomplished. The majority of the companies and public entities interviewed keep the databases for an indeterminate period of time, or for longer than necessary. **It is a reality that must be corrected with regulations in accordance with the highest standards of personal data protection.**

On the other hand, both IPS and the Ministry of Labor pointed out that the majority of the large companies comply with these regulations, while small and medium-sized companies are in a high degree of non-compliance. It is necessary to study this phenomenon in greater depth in order to understand why the legal requirements in this sector are not being met and therefore the maximum welfare and protection for workers is not being ensured.

Regarding the definition of the **type of medical examinations** that can and should be performed to workers by companies, some define them with the advice of doctors, but there could be potential situations in which companies ask for more medical examinations than necessary, which can lead to situations of discrimination. There have been complaints about requesting HIV studies during the onboarding process, which is in clear violation of current legislation. Although IPS has taken measures, clarifying that it is not necessary to request this kind of information, a commitment must be identified by the authorities so that these violations of rights do not happen again.

Regarding the collection of health data of the insured person in IPS, the principles that govern the collection of personal data in general are applicable. In this case, the standards expressly established for the treatment of sensitive data must be taken into account.

The principle of **data quality** must be respected, that is to say that the data collected must be adequate, relevant and not excessive in relation to the scope and purpose for which they were

collected. Also, its collection cannot be done by unfair, fraudulent means or in a manner contrary to the legal provisions, nor can the data be used for purposes that are different or incompatible with those that led to its collection.

Thus, and with particular reference to the admission and annual medical examination, **it is necessary to reiterate the urgent need for an comprehensive act for the protection of personal data** that has the attributions and competent authority necessary to balance and clarify the practices and standards related to the collection, storage and communication of personal health data of workers. This applies not only to companies and employers, but also to public entities that require the collection and store this type of data.

On the biometric data stored in IPS

It is necessary that there is greater speed in the adaptation of certain practices, since the continuous transformations in society constantly bring new facts that impact on privacy and confidentiality, such as patients' rights. This applies both to medical research or medical care environments, and to the storage of fingerprints of people insured in IPS. More and more people adhere to the free information and are ignorant or reluctant to the principles of data protection, until they suffer considerable consequences.

The collection of biometric data (fingerprints) was implemented without an adequate legal framework. Without one, the treatment of such data cannot be guaranteed in a proper manner by the State or the private sector. In case of abuses or filtering of biometric data, the State does not have a competent authority to ensure the protection thereof.

The biometric data are sensitive data, which requires greater safeguard mechanisms that this draft law does not contemplate. In the resolution of the IPS Administrative Council, the challenges to guarantee the care of the data in the face of discriminatory practices, biases in the development and implementation of the biometric data collection software are not taken into account. It is also important to clarify that with mere consent, it is not a sufficient legal argument to deal with biometric data.

The technology and mechanisms that will be used for the collection, analysis and storage of the biometric data, as well as the scope of this policy, are unknown. Who will have access to the biometric data? Will they be shared and transferred between different public or private organizations? Which State institutions will access these data and can it be guaranteed that the request for biometric data is made through a prior judicial order in cases of criminal investigations? Are safeguards provided to prevent manipulation and adulteration of stored fingerprint copies? Will there be sanctions in case of abuses by those responsible for the databases or the authorities? These are just some questions that arise in the analysis.

The collection of biometric data is disproportionate. Fingerprints can be a more control mechanism that could aggravate surveillance practices and harassment of minorities, ethnic groups, immigrants, and so on. The failure of the State to take care of citizens' private information makes these records even more problematic and with a high risk of being filtered.

There is no impact evaluation of the use of biometric data systems. A previous impact analysis was not conducted to evaluate the importance of the implementation of a biometric data collection system. Any interference by the State must be based on solid foundations, based on data and serious and independent diagnoses, in order to meet the conditions of necessity and proportionality required for the legitimacy of any measure that seeks to limit fundamental rights.

Finally, it should be emphasized that the only defense against the risks of abuse by public authorities and private corporations is to strengthen the regulations around privacy and confidentiality as well as data protection rights in health care.

In the research carried out on databases in the public sector (Acuña, Alonzo, & Sequera, 2017), published together with Privacy International, the systematized problems and recommendations highlight **the strong necessity of an integral personal data protection law in Paraguay.**

In the current legislation, health data are still considered particularly sensitive and vulnerable in relation to fundamental rights or privacy, but they deserve specific protection. The future regulations must take into account not only the defense based on human rights, but the creation and defense of more inclusive and reliable economic models in the online environment.

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Annexes

Annex A: interviews

A.1 Interview for the Social Security Institute.

Main regulations consulted for the questions

- Resolution of the Board of Directors N ° 099-022 / 16 "By which the regulation that establishes the presentation of the Admission Medical Examination of the workers in charge of the employers is approved".
- Resolution No. 035-007/17 "Approving the compulsory use of the admission exam form by employers and entrusting the Legal Department to analyze the feasibility of sharing the costs of the Admission Examination, between the Social Security Institute and the Employers".

1. What are the regulations that justify the collection of the Admission Examination Forms?
2. What are the criteria for safeguarding the documents of health examinations of workers by the Department of Occupational Hazards and Subsidies? Are these documents digitized? What are the procedures? Example: photos, uploading of the manual form
3. How often are the data contained in such database deleted? In case of having erroneous data, how are they updated?
4. Can workers access their own medical examinations contained in said database?
5. Who has access to such data within IPS? Are there special permits required for this purpose?

Decree N° 14.390 "By which the general technical regulation of occupational safety, hygiene and medicine is approved" in its article 266 it establishes that "The result of the medical examinations of different kinds must be registered in proper registers, which must be kept for reference purposes"

1. What are the appropriate records to which the results of the Admission Medical Examination should be registered?
2. What are the proper conditions in which companies must keep the results of the Admission Medical Examination?
3. Does the Social Security Institute control that these documents are duly stored and protected by the companies, taking into account the requirements to store them?
4. Decree 14.390/92 establishes a series of medical examinations to be performed to all workers. Can companies leave this predetermined list of medical examinations within the framework of Resolution 099-022/13?
5. Why was a specific memo released on the need not to apply HIV diagnostic tests for the admission exam?

6. How should all the examinations indicated and contained in Decree 14.390/92 be detailed and delivered?

Resolution C.A No. 035-007/17

1. The Admission Examination Form can be submitted in both electronic and physical formats. In what format is presented with the highest percentage?
2. The Admission Examination Form is valid for one year. Should workers repeat the examinations every year?

Databases

“[...] an organized set of data which are managed or processed, electronic or not, regardless of the type of formation, storage, organization or access, whose owner is a legal person of public nature”

1. What regulations apply to the protection of personal data? Internal regulations of the institution? National regulations taken into account?
2. Are these data used for purposes other than the original purposes (archival purposes, scientific studies, etc.) Are they disseminated, shared or published beyond the original purposes of the collection (principle of limitation in use)?
3. Are these data modified if they are erroneous? How? (are they rectified, deleted?) (principle of quality, principle of individual participation, accuracy)

Infrastructure of databases

1. Do you remember an incident where data security was compromised? How did you respond to the situation?

Biometrics

The Board of Directors of IPS N° 003-050/16 ruled a resolution that obliges the insured persons (from two years of age) and authorized of the patients to register their fingerprints for the collection of high-cost cancer medications. The Central Hospital pharmacy together with the Customer Service Center (CAU) implemented this mandatory procedure for the collection of medications, gradually extending to all IPS insured. Is it like that?

A.2 Interview for the Ministry of Labor- Department of Inspection and Supervision

1. What is the legal regulation that justifies the application and collection of the annual medical examination by the workers?
2. What is the specific Department responsible for collecting and safeguarding the medical personal data of workers within the Ministry of Labor?
3. What are the medical examinations that should be performed to workers? Are they defined by the employer or by the Ministry of Labor itself?

4. How long are the workers' medical data stored in the Ministry of Labor's databases? Are there rectification mechanisms in case of an error?
5. Are there mechanisms for the deletion of personal data of workers provided once they have fulfilled their assignment or every certain period of time?
6. Do workers have access to their personal data stored in the Ministry of Labor? What are the access protocols?
7. Do the employers comply with the obligation to submit the annual medical examination of their workers? In what approximate percentage?
8. What are the safety standards that companies must follow to store workers' medical examinations in the framework of the annual examination?
9. What is the audit process of the Ministry of Labor to verify these safety standards? In case of non-compliance, what is the sanction?

A.3 Interviews for workers

1. Do you know the provision that requires the collection of health data by employers when a worker is hired for a job?
2. Did you take this medical examination when you were hired for your current job?
3. What kind of examinations were you requested to take? How was the process?
4. Do you know in which department of the company where you work is this information stored?
5. Do you have access to such health data? What is the process to access it?
6. Do you think it is possible for IPS's administrative staff to access patients' clinical records to sell this information to pharmaceutical companies and private clinics? Do you have a suspicion? Or is there any evidence?
7. Are you aware that the private sector, as an employer, has access to sensitive health data of their employees -data subjects- beyond what is permitted by current labor regulations, and which results in discriminatory measures in the labor sphere?

A.4 Interviews for the private sector- Private companies

1. Do you know the current regulations that justify the collection of health data of workers by the Social Security Institute?
2. What is the health data collection process that applies to your workers? Is it done by someone from your company or is it an outsourced service?
3. Once the results of the medical examinations are delivered to the company, who has access to them?

4. Are the medical results that your company manages in digital or printed format? What are the storage protocols for these results?
5. What is the criterion that applies to performing the medical examinations to your employees? Do you have the advice of an occupational physician to define the types of medical examinations according to each particular assignment that an employee fulfills?
6. Do workers have access to their medical examinations results by default, and do they request it after the delivery and systematization of them in the company's database?
7. How often are these workers' health data updated?
8. Are the databases that contain the medical examinations of your employees deleted at some point? Is there a protocol for this process?
9. Do you think it is possible for IPS's administrative staff to access patients' medical records to sell this information to pharmaceutical companies and private clinics? Do you have a suspicion? Or is there any evidence?

Annex B: forms

Form requested by IPS, and below there is a form version requested by a private company-clinic

<i>IPS Logo</i>		<i>Government Logo</i>
FORM – ADMISSION EXAM		
The Medical Certificate and/or the auxiliary diagnosis examinations used for this affidavit may be required by IPS at any time after the Worker's Entrance		
ID	DATE OF BIRTH	
NAME AND LAST NAME		
DATE OF IPS ENTRANCE	REGISTRY No.	
EMPLOYER		
ACTIVITY OF THE COMPANY		
MEDICAL CERTIFICATE (Specify sex, age, current health condition and if any, existent pathologies) (In case of different abilities, specify which)		
IDENTIFICATION OF THE DOCTOR (Name and last name, professional registry and contact number)		
WORK ACTIVITY (Task assigned to the employer; working place and time)		
SIGNATURE AND STAMP OF THE EMPLOYER LEGAL REPRESENTATIVE REGISTERED IN IPS OR OWNER IN CASE OF SINGLE-SHAREHOLDER		
Received by (signature and stamp)	Verified by (signature and stamp)	Filed by (signature and stamp)

**GENERAL TECHNICAL REGULATION 14390/92
Ministry of Labor, Employment and Social Security**

Art. 263 The annual medical examination of 12 (twelve) in 12 (twelve) months, shall maximum include:

- | | |
|-------------------------|-----------------------------|
| 1. Clinical examination | 5. Electroencephalogram |
| 2. Chest X-RAY | 6. Psychological test |
| 3. Complete blood count | 7. Gynecological test (PAP) |
| 4. Clinical urine tests | |

This questionnaire must be filled in by the interested party and has an **affidavit** nature

- | | |
|----------------------|--------------------|
| - Name and last name | - Company |
| - Age | - Marital Status |
| - Date of birth | - ID |
| - Address | - Telephone number |

Assignment to be performed:

WORK SURVEY

Without omitting answers or manifesting reticence, mark the corresponding box

- | | | | |
|--|-----|----|---------------------|
| - Have you carried out an unhealthy job? | Yes | No | Which one? |
| - Have you had to quit a job due to health reasons? | Yes | No | Why? |
| - Have you had or is it pending a compensation for an occupational accident or sickness? | Yes | No | Reason |
| - Have you been excepted from military service? | Yes | No | Why? |
| - Has a life insurance ever been rejected to you? | Yes | No | Reasons |
| - Has a job ever been rejected to you due to health reasons? | Yes | No | Reason |
| - Have you had any surgeries? | Yes | No | Indicate which ones |

Hospital where you were admitted (different from the one mentioned due to surgery)

How many hours do you sleep a day?

How many hours do you work?

Do you smoke? How many per day?

What beverages do you drink? How many per day?

Do you practice any sports? Which ones?

What medications do you take?

Since when?

Has any of your relatives ever had:

- | | | |
|----------------|--------------------|-----------------------|
| - Tuberculosis | - Hemophilia | - High blood pressure |
| - Cancer | - Epilepsy | - Heart disease |
| - Asthma | - Rheumatism | |
| - Diabetes | - Mental illnesses | |

- Name and last name
- Age
- Date of birth
- Address
- Company
- Marital Status
- ID
- Telephone number

Assignment to be performed:

MEDICAL EXAMINATION

- Skin and mucous membrane
- Eye
- Ear
- Cardiovascular
- Respiratory
- Urogenital
- Digestive
- Locomotive
- Nervous system

ANTHROPOMETRY

- Weight
- T.A.
- Height
- FC(R) FC(PE)

ADDITIONAL EXAMINATIONS

CLINICAL EXAMINATIONS

- Hemogram
- Erythro sedimentation
- VDRL
- Cholesterol
- Glycemia
- Chagas
- Tification
- Urine
- Dregs

Others

- Chest X-RAY
- Visual acuity
- Toxicology
- Audiometry

PERSONAL BACKGROUND

Mark the right answer

- | | | | |
|----------------------------------|--------|--|--------|
| - Frequent headache | Yes/No | - Vesicular colic | Yes/No |
| - Hepatitis | Yes/No | - Stomachache | Yes/No |
| - Frequent cold | Yes/No | - Had vomited blood | Yes/No |
| - Sinusitis | Yes/No | - Had blood in the urine | Yes/No |
| - Frequent sore throat | Yes/No | - Had defecated in black color | Yes/No |
| - Ear buzz | Yes/No | - Has frequent diarrheas | Yes/No |
| - Frequent nosebleed | Yes/No | - Difficulty when urinating | |
| Yes/No | | | |
| - Deafness | Yes/No | - Had sediment in urine | Yes/No |
| - Bleeding gums | Yes/No | - Has swollen eyelids | Yes/No |
| - Dental problems | Yes/No | - Renal colic | Yes/No |
| - Well colors differentiation | Yes/No | - Venereal disease | Yes/No |
| - Wears glasses/contacts lenses | Yes/No | - Pain in the legs | |
| Yes/No | | | |
| - See spots in front of the eyes | Yes/No | - Consider yourself nervous | Yes/No |
| - Eye pain | Yes/No | - Usually feel weak | Yes/No |
| - Dizziness | Yes/No | - Easily irritated | Yes/No |
| - Fainting | Yes/No | - Has seen a doctor due to nervousness | Yes/No |
| - Balance loss | Yes/No | | |
| - Had lung problems | Yes/No | | |
| - Pneumonia | Yes/No | | |
| - Asthma | Yes/No | | |
| - Chronic cough | Yes/No | | |
| - Blood spit | Yes/No | | |
| Yes/No | | | |
| - Wheezing | Yes/No | | |
| - Convulsive cough | Yes/No | | |
| Yes/No | | | |
| - Had a chest X-ray | Yes/No | | |
| - High pressure | Yes/No | | |
| - Chest pain | Yes/No | | |
| Yes/No | | | |
| - Swollen ankles | Yes/No | | |
| ----- | | | |
| - Palpitations | Yes/No | | |
| - Trouble with heat/cold | Yes/No | | |

FOR WOMEN ONLY

- | | |
|--------------------------------------|--------|
| - Had swelling in the breasts | Yes/No |
| - Suppuration or blood in the nipple | |
| - Breast surgery | Yes/No |
| - Pain during menstruation | |
| - Hot flashes | Yes/No |
| - Spontaneous pregnancy loss | Yes/No |
| - Pregnancy loss (clinical reasons) | |
| - Date of last menstruation | |

Signature of Applicant

Signature of Doctor

Date

"I don't want to live in a world where everything that I say, everything I do, everyone I talk to, every expression of creativity, or love, or friendship is recorded" Edward Snowden

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