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### PATIENT INFORMATION SYSTEM PROPOSAL

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All content in this magazine is licensed under a Creative Commons Attribution License. Attribution-Non-Commercial-Non-Derivatives 4.0 International (CC BY-NC-ND 4.0). Abstract: The article presents some concepts and examples in health information systems in Brazil, bringing the importance of information for health decision making. The systems currently existing in the Brazilian Unified Health System stand out as a reference for the importance of information to improve and develop public policies in this area. It also fulfills the role of bringing to light the importance of an information system for the patient as a protagonist in order to support the improvement and decision-making processes of health professionals in the care of patients and users of the system.

**Keywords:** Health. Management. Electronic Medical Record. Exams. Integrated Health System. Unified Health System (S.U.S).

#### INTRODUCTION

An information system (IS) aims to store, organize and distribute information within a context served by the IS. According to Cunha and Vargens (2017, p.72), "Data and information are terms that keep an intrinsic and formal relationship, however they are distinguished according to the field of study, source and use".

In administration, data, understood as a direct measure of physical phenomena and real transactions, is the raw material of information systems and a valuable resource for organizations. In this field, information is the processing record in which context and content are analyzed in order to add meaning to the data. (CUNHA; VARGENS, 2017, p.73).

In public health, data is understood as a record of observations and objective measurements of the characteristics of people and facts that make up a given health event or occurrence at a given time and place. Along these lines, the data adds meaning to health events. (CUNHA; VARGENS, 2017, p.73)

The stages of information production are: (a) data collection; (b) coding of the collected data; (c) processing the encoded data; and, (d) disclosure. According to these same authors (CUNHA; VARGENS, 2017, p.74), data collection is the first step in generating information, and it ends when the information is immediately recorded. Both a paper form and an electronic platform are acceptable forms of registration. It must be physically filed when recorded on paper, as it serves as a document demonstrating facts and events.

The usability of data for analysis, recommendations and judgments is impaired when it does not meet quality standards. The data quality standards are, according to Cunha and Vargens (2017, p.74): (a) **Reliability**: the data accurately reflects the reality of the event; (b) **Present news**: information is captured and made usable in a timely manner; (c) **Completeness**: all event features are covered by the data.

The collected and recorded data must be kept in a database that allows quick retrieval and is simple to use. Physical databases are those where information is recorded and filed on paper, while digital databases are those where information is saved electronically. (CUNHA; VARGENS, 2017, p.75)

In the production of information, data from two types of sources are used: (a) **primary** and (b) **secondary**.

Data from a primary source, therefore, is that collected by the service that produces the information and, therefore, is responsible for meeting the quality requirements. When information is produced from data collected by other services or other institutions, it is called secondary data. Thus, for example, demographic and socioeconomic data, which are used for health status diagnoses, can be primary or secondary. In the latter case, it is necessary to cite the source of the data, that is, the institution responsible for the production and quality of this data. (CUNHA; VARGENS, 2017, p. 76-7).

#### **INFORMATION SYSTEMS**

The definition of information system (IS) results from the combination of the concepts of "information" and system. (O'BRIEN, 2008, p. 7)

Turban, Rainer Jr. e Potter (2007, p.4) say that "An information system (SI) collects, processes, stores, analyzes and disseminates information for a specific purpose". According to them, "A computer-based information system (SIBC) is an information system that uses computer technology to accomplish some or all of its intended tasks".

Although you do not need a computer to have an information system, you usually use one to improve your ability to process information, increase performance in obtaining relevant information and optimize the search time for important information, among other advantages of the systems. computerized. Laudon and Laudon (2007, p.11) corroborate this question by saying that "An information system offers solutions to important problems or challenges [...]."

For O'Brien (2001, p.3), an important question regarding the importance of information systems concerns "Information technology is redefining the fundamentals of business". According to this author:

> Information technology can help all types of companies improve the efficiency and effectiveness of their business processes, managerial decision-making and workgroup collaboration, thereby strengthening their competitive positions in a rapidly changing market. (O'BRIEN, 2001, p.3)

In order to fulfill the diversity of objectives of any Structured System (Organization), a set of information systems is necessary for (a) Operations Support – assists in the execution of daily tasks and processes; (b) Management Support – subsidizes decisionmaking processes, and; (c) Strategic Support – provides information for the definition of strategies and policies.

Some information systems are developed to meet specific purposes, which require their own computational techniques: (a) Collaborative System – to support teams and work groups between institutions; (b) Expert System – aggregates specialized knowledge, providing support and diagnosis for specific situations, and; (c) Knowledge Management System – supports the creation, aggregation, organization and dissemination of knowledge among Structured System workers. (O'BRIEN, 2008, p.84-5)

However, not all available systems meet the need to obtain information, which forces users to look for the information they are looking for in other sources. The Ministry of Health has been aligning a proposal to restructure the Health Information Systems, so that it will guarantee quality in information management and consequently in serving the population, in order to integrate more comprehensive Health Information Systems (SIS), thus reducing the number of systems currently available.

### HEALTH INFORMATION SYSTEMS IN BRAZIL

In the health sector, information supports the decision-making process, as it helps in the knowledge about health conditions, mortality and morbidity, risk factors, demographic conditions, among others (ROUQUAYROL; ALMEIDA FILHO, 2006).

The World Health Organization (WHO) defines a health information system as:

"[...] a set of components that work in an integrated manner through mechanisms for collecting, processing, analyzing and transmitting the necessary and timely information to implement decision-making processes in the Health System. Its purpose is to select relevant data and transform it into information for those who plan, finance, provide and evaluate health services"

#### (WHO, 1981:42).).

"With the implementation of the Unified Health System, the decentralization of management and the definition of priorities for health services become prerogatives of the municipal sphere", emphasizes França (2001, p.21), and this way the decentralization of health services begins. information systems, making the access and manipulation of information somewhat bureaucratized.

The hallmark of the institutionalization of Health Information Systems (SIS) in Brazil was the standardization of the death certificate (DC) form and the corresponding data collection flow in the 1970s. (O'BRIEN, 2008, p.85)

Among the SIS in use in the SUS (Unified Health System), two represent the trunk of the structure, as all the others are connected to them; in a very simple way and that one can say that one identifies the "client" and the other the "service provider", we are talking about the SUS card of the citizen and the CNES (National Registry of Health Establishments).

The development, expansion and use of SIS, at the national level, accompany the regulation and organization definition, of the Unified Health System (SUS) in Health Care Networks enhanced by the accelerated development and incorporation of information and communication technologies. communication that have taken place in the country since the 1990s. The Pan American Health Organization (PAHO) defines a health information system as a set of components (administrative structures, health statistics department, health information units) that it works in an integrated manner with the aim of producing necessary and timely information to implement decision-making processes in the area (ORGANIZACION PANAMERICANA DE SALUD, 1984). In operational terms, what characterizes the SIS is the standardization of flow for collecting, recording, processing, storing and retrieving data in health services, aiming at the production of certain information. (O'BRIEN, 2008, p.86)

While health information systems aggregate data and information necessary for planning, evaluating and operationalizing health actions and services from the perspective of individual care and collective health, information and communication technologies allow access to data stored in different information systems. (O'BRIEN, 2008, p.86)

In Brazil, the Department of Informatics of the SUS (DATASUS) plays an extremely important role in the conduction of the information process, it maintains available all theSISinuse, manuals, download able programs, which can be accessed by professionals for planning the teams, whether local or not. It is possible to obtain information such as: Health Indicators; Health Care (hospitalization, outpatient production, immunization, family health, food and nutrition surveillance); Epidemiological (SUS and Morbidity hospital morbidity, notifiable diseases, nutritional status and other aggravations); Assistance Network (information from the National Registry of Health Establishments - CNES); Vital Statistics (birth, mortality, cancer); Demographics and Socioeconomics (population, education and sanitation), Surveys and surveys; Supplementary Health. It also provides financial information, systems and applications for data tabulation, such as TABNET and TABWIN.

According to França (2001, p.17 apud LAURENTI, 1985), "In 1975, the Mortality Information System (SIM) was implemented, being a pioneering system to employ a standardized document to collect information on death". The table below follows a summary of the systems created for health in Brazil.

Tasca, Greco and Villarosa (1995), "observed some basic characteristics in relation to health information systems in

Information system	Year
Mortality Information System (SIM)	1975
Epidemiological Surveillance System (SNVE)	1975
Hospital Information System (SIH)	1983
Integrated Health Actions (AIS)	1984
Unified and Decentralized Health Systems (SUDS)	1986
Mortality Information System (SIM)	
Information System on Live Births (SINASC)	
Information System on Notifiable Diseases (SINAN)	
Outpatient Information System of the Unified Health System (SIA/SUS)	
Hospital Information System (SIH/SUS)	

### Table 1 - Information Systems for Health Management in BrazilSource: author himself, adapted from França (2001)

Health Information Systems	Registration goal	Uses
Sinan – Notifiable Diseases Information System	Notifiable diseases and illnesses	Morbidity studies of diseases and diseases under notification.
SIM – Mortality Information System	Death	Mortality profile
SIH-SUS – SUS Hospital Information System	Hospitalizations financed by SUS (Unified Health System)	Profile of hospital morbidity and mortality in the SUS
Sinasc – Information System on Live Births	born alive	Profile of birth conditions
Sisab – Health Information System for Primary Care	Primary Care Actions and Procedures	Monitoring the living and health conditions of registered individuals and families
SI-PNI – National Immunization Program Information System	Assistance and administrative actions of the National Immunization Program	Monitoring of vaccine coverage and adverse events, stock control and distribution of inputs.
Sisvan – Food and Nutrition Surveillance System	Actions provided for in the National Food and Nutrition Policy	Monitoring of food profile and nutritional status.
Sisprenatal – Pregnancy Monitoring System.	Actions of the Prenatal Program	Monitoring of care for pregnant and postpartum women registered in the Program for Humanization in Prenatal and Birth (PHPN)
SIA-Apac – SUS Outpatient Information System and Authorization of High Complexity/Cost Outpatient Procedures	High-complexity or high-cost procedures.	Monitoring the number of high-cost and complex procedures

Table 2 - National SUS Information Systems

Source: DATASUS (2022a)

Brazil. They pointed out a high centralization of data with great limitation of access, making it difficult for the local user to have the information produced in a timely manner". In addition to this issue, they also point to "the long time between data processing at the central level and its dissemination at the local level, thus not meeting the needs of local health systems". The lack of community participation in the generation and use of information, the overload of tasks for the professionals responsible for the collection and, also, the failures in the analysis of the information are other highlighted points that harm the planning, monitoring and evaluation processes, highlights France (2001, p.20).

It is proper – and essential – for health services to collect, generate, store and manage information, including combining (considering) data from different systems. This process imposes ethical and technical responsibilities on workers and health services, especially regarding the privacy of the person in the handling, application and use of data stored in the SIS. (O'BRIEN, 2008, p.86)

Currently, the Ministry of Health has several systems for data collection. In the next paragraphs, these systems and their functionality within the SUS are presented. All information was taken from the Ministry of Health website. (DATASUS).

The system: **e-SUS Notifier** was released on March 27, 2020 to receive notifications of suspected and confirmed Influenza Syndrome (GS) of Covid-19 in Brazil. It is an online system with high performance infrastructure to ensure agility in the notification process. As it is online, it allows all levels of management, professionals and health units to have real-time access to the notifications made. (BRAZIL, 2021)

With the advance of the Covid-19 pandemic in Brazil, together with the significant increase

in the volume of data in the e-SUS Notifier and with the objective of helping to control the epidemic in the country, the system has been undergoing several modifications in favor of improvements and adjustments in the operationalization of the work process, including the creation of different modules, in addition to the first module, the 'Covid-19 Notification, such as: 'SUS Hospitalizations', 'AEPV Notifications', 'Vaccination Data' and 'e-SUS Notifier - 'Covid-19 Notification' Module'This module was implemented due to the Covid-19 pandemic to assist surveillance epidemiological in the identification and monitoring of cases in the territory, as well as other health authorities. In it, all mild cases of suspected or confirmed Covid-19 Influenza Syndrome (GS) must be recorded, in addition to the individual results of all laboratory tests with a positive or negative result for Covid-19.

In May 2021, the **'Contact Monitoring' module** was launched, in which it is possible to monitor individuals who had contact with a suspected or confirmed case of Covid-19, and who were previously registered in the 'Covid-19 Notification' module.

The module aims to track and monitor as many contacts as possible of people who had a suspected or confirmed case of Covid-19 during the period of transmissibility of the disease, even if they are still asymptomatic. In it, it is possible to record contact identification information such as name, CPF, telephone numbers, and above all, specify the type of relationship between the contact and the suspected or confirmed case and the date of the last contact, in order to make it possible to monitor the contacts during the period of transmissibility and tracking or triggering new investigations.

The **Public Health Events Registry** was developed with the objective of recording public health emergencies, considering that

surveillance actions related to these events need to be carried out urgently, thus allowing the consolidation, characterization and timely coping with the emergency. In 2015, in view of the change in the pattern of occurrence of microcephaly and/or changes in the central nervous system (CNS) associated with congenital Zika virus infection in Brazil, the Ministry of Health (MS) declared the situation a Public Health Emergency of National Importance (ESPIN), through Ordinance 1,813 of November 11, 2015. Due to the need to monitor the occurrence of microcephaly cases and CNS alterations, the Ministry of Health, in partnership with DATASUS, developed a form online in the RESP, called RESP-Microcephaly. (BRAZIL, 2021)

SISAB integrates the strategy of the Department of Family Health (DESF/SAPS/ MS) called e-SUS Primary Care (e-SUS APS), which proposes to increase information management, process automation, improve infrastructure and improving work processes. (BRAZIL, 2021)

The National Health Card (CNS) is the SUS user's identification document. This record contains information about individuals, such as: personal data (name, mother's name, date of birth, etc.), contacts (phone numbers, address, e-mails) and documents (Social security card, identity card, certificates, etc.). Currently, the CNS number is used in computerized health systems that require identification of individuals, whether users, operators or health professionals. This way, the CNS enables the creation of the service history of each citizen in the Unified Health System (SUS), through access to the Databases of the primary care systems, hospital system, drug dispensing system, etc. (BRAZIL, 2021)

**SIM – Mortality Information System:** created in the late 70's, the base document used is the Death Certificate containing 3 copies, allowing analysis of mortality rate, time, age, sex, areas, among other variables. (BRAZIL, 2021)

**SINASC- Live Birth Information System**: created in the 1990s, contains information on maternal and child health:

- live births (sex, birth weight)
- the mother (educational level, age)
- pregnancy (number of prenatal consultations, time of pregnancy)
- childbirth (type, place of occurrence) (BRAZIL, 2021)

SINAN – Injury and Notification Information System: fed by the notifications and investigations of diseases contained in the national list of diseases of compulsory notification, transmitting to the Health Information Systems (SIS) the National Epidemiological Surveillance System. States and municipalities may include other diseases in the list, according to their epidemiological profile and intervention profiles. (BRAZIL, 2021)

SIH/SUS – Hospital Information System: It has information from registration, hospitalization information (length of stay, patient profile) to payment of Hospital Admission Authorizations (AIH). (BRAZIL, 2021)

**SIA/SUS – Outpatient Information System:** It reports total outpatient procedures, medical consultations per inhabitant per year, among other indicators; consolidates outpatient production bulletins (BPA) and authorizations for highly complex procedures (APAC). (BRAZIL, 2021)

**SIAB – Primary Care Information System:** monitoring of the activities of the Family Health Strategy, including the registration of families and monitoring of risk groups, providing production indicators through the registration of specific sheets for data collection. (BRAZIL, 2022b)

**SIS/ HYPERDIA** – System for registration and monitoring of hypertensive and diabetic

#### patients. (BRAZIL, 2021)

**SISCOLO/SIS-BREAST** – Information control system for the collection and processing of clinical information about patients and reports of breast and uterine cancer prevention exams. (BRAZIL, 2021)

**SIS/PRE BIRTH**: monitoring system for pregnant women included in the Pre-Natal and Birth Humanization Program, from the beginning to the postpartum period. The woman must perform at least six prenatal consultations and one in the puerperium. (BRAZIL, 2021)

**CNES – National Register of Health Establishments**: contains managerial information from hospitals, outpatient clinics and health clinics. (BRAZIL, 2021)

**SISREG – National Regulatory System:** objective of managing requests and offers of services through the basic network of consultations, exams/procedures in medium and high complexity, as well as the regulation of hospital beds. (BRAZIL, 2021)

**DATASUS – Department of Informatics of Unified Health System (S.U.S.)**: provides information that can be used to support objective analyzes of the health situation, decision-making based on evidence, and the development of health action programs. (BRAZIL, 2022a)

A well-designed electronic health record system can provide future global technology advantage and application of up-to-date and consistent concepts as a health care model; enable connectivity and general coverage, allowing accessibility wherever the patient is; use technology that provides what the professional needs in terms of format, content and time; thus allowing the projection of the need for resources for the service, establishing metrics to evaluate the results obtained, the quality of the care provided, performance, disparities and the efficiency of the service, thus allowing progressive improvements. (BRAZIL, 2022a)

"The development of a computer information system that is able to coordinate and integrate all health information is essential and essential to guarantee the quality of care". (MARIN, 2010, p.23)

### PATIENT INFORMATION SYSTEM PROPOSAL

According Marin (2010,p.22), to "information is the essence of the profession. Health professionals need information to be able to exercise care, management and evaluation processes". Therefore, the author comments, "all health activities are related to the search and use of information". In this sense, he highlights, "the better the computerized systems are able to record, store and make this information available, the better the professional's act will be - better information, higher quality in decision making".

After pacifying the concept and importance of health information systems, it is questioned why so many systems collect information and this information is not the property of the patient, but of health institutions.

Following a very simple line of reasoning, today we see information systems in clinics and health plan operators in which exams are performed and posted on the patient's record, with electronic access via the Internet. The patient no longer receives a printed report, or prescription, or perhaps his exams. They are available in legacy information systems owned by the healthcare provider many times.

This logic needs to be reversed, because in case of recurrence, change of health plan or even exit from a health plan, the patient is helpless, loses his history, exams, reports and other information. At each consultation, there is a new battery of questions to retrieve, in the system that is used, information regarding the patient and their previous health, which leads to a loss of time, duplication of information and, often, inconsistency.

So, the question is: how to make the patient the protagonist of their health information and make it accessible on any device?

The integrated information system for the management of personal health information is an innovative proposal, with a broad market and in need of solutions that can assist in the treatment, monitoring and recovery of people's health information. In a web-based platform, which belongs to the citizen and not to the health system, the use of information becomes more effective, practical, inclusive and relevant.

The differential of this proposal in relation to what exists today in the market is the protagonism of the people in relation to their data, allowing their assistance in any health unit in the country and abroad through the solution that is envisioned.

Highlights Marin (2010, p.23) that "the future may, therefore, bring an electronic health record system designed to provide global advantage of technology and application of updated and consistent concepts".

Thus, the objective is to propose an integrated information system to generate people's health history, thus facilitating care in health units in the country and abroad.

What is sought is a SIS model where the protagonist is the patient, enabling connectivity and general coverage, with accessibility, responsive technology that provides the information that healthcare professionals need in terms of format, content and time. Addressing these main issues, it will be possible to provide a more agile service, with a projection of the need for resources for the service, improving patient care and the performance of professionals, reducing disparities and seeking efficiency in the service provided.

This way, the responsiveness of care will be increased, improving communications between the actors in the area, improving the care strategy and allowing health professionals to use information when necessary.

## ABSTRACT/DESIGN OF DEVELOPMENT

It began with a survey of the health market in Brazil, existing information systems and the applicability of the proposal. After that, a detailed literature search was carried out in the databases on the subject. The next step was the selection and review of studies with the application of inclusion and exclusion criteria. Then, a critical analysis of the selected materials was carried out.

The following development will be through seven steps: (a) initially, the research protocol will be prepared with the definition of criteria, and then open and closed questions will be formulated to health professionals from clinics, hospitals, laboratories and pharmacies in order to gather information for modeling the system's database; (b) the next step will include the elaboration of a field research form, selection and data collection; (c) the information modeling and structuring of the tool will be elaborated; (d) the technological project resources needed support to implementation will be detailed; (e) the system will be built using agile systems development methods; (f) the solution will be tested in the metropolitan region of Porto Alegre/RS; (g) the implementation of the system will be carried out by adding the studies already carried out in the area.

#### **EXPECTED RESULTS**

With the proposal implemented in a functional Internet system, easy to interact, transparent for users and at the national level, it is intended to make it easier for patients to access their information, bringing the possibility of greater protagonism in decisions regarding the management of Your health.



Figure 1. Proposed information integration scheme Source: authors

This condition allows patients to use their data in various care and attention settings.

The main barriers are the legacy systems that currently exist in the country and the loss of mastery of information by the agents involved. Another barrier will be the market itself adhering to this solution, but it is believed that with adequate marketing and aimed at those who have the right to information, it will be possible to transform the solution proposed here into an efficient solution.

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