hansen.app: Simplified Neurological Assessment Form Application for Data Collection to Support Hansen's disease Treatment

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Abstract. *This study addresses the challenge of improving Hansen's disease understating and monitoring in Brazil's public healthcare system (SUS) through the development of a digital record system rooted in Soft Systems Methodology (SSM). The proposed solution, the hansen.app, integrates participatory cycles with real stakeholders to adapt and digitize the Simplified Neurological Assessment (from Portuguese ANS) form, ensuring data fidelity and enhanced usability for healthcare professionals and patients. Hence, data modeling and the prototype aim to reduce the complexity of Hansen's disease care and monitoring by delivering more essential data to improve the knowledge capacity of the healthcare system.*

1. Context

Hansen's disease is part of the group of Neglected Tropical Diseases (NTDs), which is predominant in tropical and subtropical regions and mainly affects vulnerable and marginalized populations [World Health Organization 2022]. In 2023, 24,773 cases were recorded in the Americas, of which 91.92% occurred in Brazil [Ministério da Saúde 2023]. Brazil occupies one of the top positions in the world in terms of the number of cases of Hansen's disease, behind only India [World Health Organization 2023].

Hansen's disease is a disease caused by the bacterium *Mycobacterium leprae*, which causes dermatological and neurological symptoms and can cause physical disabilities in patients [World Health Organization 2021]. Transmission occurs through the respiratory tract, through the inhalation of droplets expelled through the mouth or nose of an infected person. Prolonged contact is necessary to infection and the bacterium has a long incubation period, which can vary from 2 to 14 years [Kowalska and Kowalik 2012].The diagnosis is established through dermatological and neurological examinations aimed at detecting lesions or areas with altered sensitivity. In addition to peripheral nerve involvement, Hansen's disease can cause sensory, motor, and/or autonomic alterations [Ministério da Saúde 2024].

This paper proposes the hansen.app that aims to mitigate the impact of Hansen's disease in the Brazilian public healthcare system (SUS) by providing more data to improve the knowledge capacity of the healthcare system. This perspective is based on challenge #4 of the "Grand Research Challenges in Information Systems in Brazil 2016 - 2026" [Boscarioli et al. 2017]: Strengthening of the Sociotechnical Approach in Information Systems Research. The SUS is a complex and multifaceted system that cannot be understood without considering a sociotechnical approach. Given the inherent complexity, this study employs the Soft Systems Methodology (SSM) as a post-Cartesian approach to effectively address these challenges.

2. Related Works

In the works[Fadel et al. 2006], [Vigolo et al. 2008], and [Matos et al. 2022], the authors develop a mobile or web-based electronic health record system for record notification data and monitor patients with Hansen's disease. The work of [Souza and et al. 2021] proposed a multi-platform application for Hansen's disease screening and classfication based on artificial intelligence techniques. .[Ministério da Saúde nd] developed a knowledge repository application to assist healthcare professionals in diagnosing and managing patients with Hansen's disease or suspected cases, as well as their contacts.

Our work differs from related studies by specifically focusing on the development of an application designed to digitize the SUS' Simplified Neurological Assessment form(Portuguese: *Formulario de Avaliação Neurológica Simplificada*, ANS) , which is currently registered on paper. The ANS serves as the primary document for Hansen's disease classification; however, the data collected remains restricted to the healthcare facility that conducted the assessment. Digitization of the ANS aims to improve evaluation speed, accuracy, data efficiency, and data portability, while also enabling the generation of reports and facilitating targeted analytical processes based directly on the primary ANS data.

3. Methodology

Complex problems, such as Hansen's disease healthcare, require approaches that go beyond technical aspects, considering the interactions between various actors and processes within a social and organizational system. The Soft Systems Methodology (SSM), developed by Checkland [Wheeler et al. 2000], is designed to address these ill-defined situations. Unlike traditional methodologies that seek rigid, single solutions, SSM acknowledges the multifaceted nature of these problems, where multiple worldviews coexist, and objectives may be ambiguous or even conflicting.

Rather than imposing predetermined solutions, SSM fosters a process of continuous and participatory learning, engaging all stakeholders in exploring and defining the problem, as well as identifying desirable and feasible changes within the specific context. This approach allows for dynamic adaptations to the particularities of each system, promoting sustainable and culturally acceptable transformations within each organization.

This study is conducted with the collaboration of actual stakeholders from a public reference health facility in Pernambuco, Brazil, alongside healthcare researchers. Each cycle of SSM allows healthcare professionals and managers to validate and participate in progressive changes to the system until a more efficient model, aligned with the real needs of users, is achieved. The involvement of stakeholders occurs specially during the initial and secondary phases (problem definition) as well as during the fifth and sixth stages (validation) of the SSM cycle. This dynamic approach facilitates a gradual and participatory transition, reducing resistance to the proposed changes.

A fundamental stage of SSM is the creation of the rich picture, which aims to capture a representation of the complexity of the socio system in an clear and comprehensible way for all involved. Initially, it represents the current situation, but it can be continuously updated to reflect changes and adjustments perceived during iterative cycles. The Figure 1 represents the current representation of the application domain.

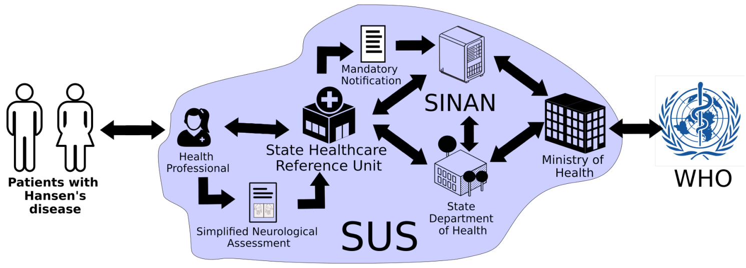


Figure 1. Rich picture of the considered Hansen's disease healthcare domain in Brazilian SUS.

One significant relationship depicted in Figure 1 is the state's control over the healthcare reference unit. This specific configuration within the SUS shapes policies and practices. The reference unit serves numerous patients from municipalities outside Recife, resulting in a diverse patient population and a wide range of healthcare procedures. Another important aspect is that the ANS forms are physically stored at the healthcare reference unit. This limits the State Department of Health's ability to investigate specific complications of Hansen's disease, such as blindness. The lack of accessible information hinders policymakers from improving existing policies to enhance patient care.

The CATWOE analysis is another key element in SSM, structuring the problem from different stakeholder perspectives[Checkland and Poulter 2020]. The elements were agreed with stakeholders as follows:

- **Customers (C)**: Patients and healthcare professionals who need an agile system to record and access information.
- **Actors (A)**:Health professionals responsible for filling out the ANS form and patients, to keep record of their assessment;
- **Transformation Process (T)**: Systematization of information to communicate ANS data.
- **Worldview (W)**: Improve the collection and distribution of ANS data without requiring changes to forms and processes.
- **Process Owner (O)**: The more desirable is the Ministry of health, but the most feasible one is the State Department of Health. At this moment, we consider the State Department of Health.
- **Environmental Constraints (E)**: The rules and standards set by the Ministry of Health alongside the existing technological infrastructure in healthcare facilities.

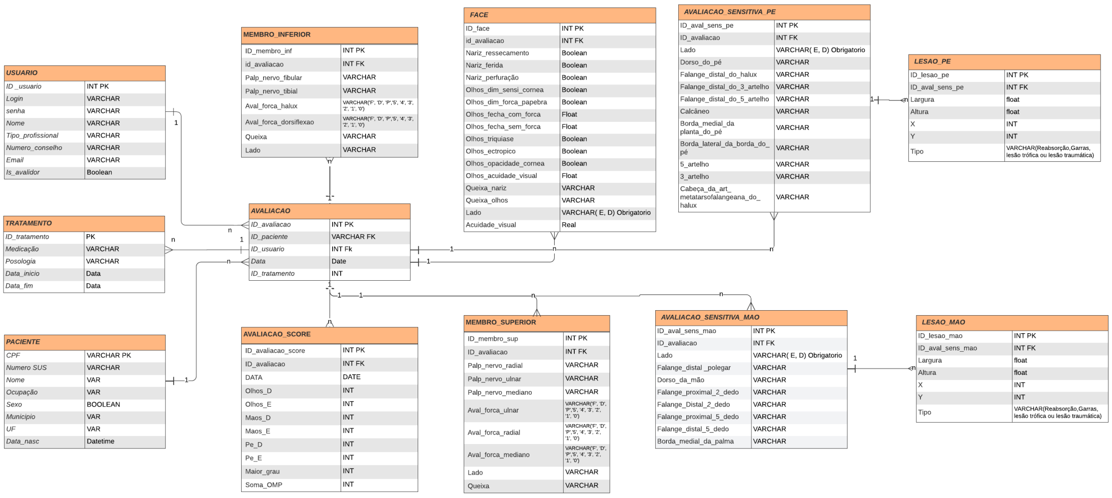
With those guiding elements of the domain, we start iterate over the Checkland's learning cycles[Checkland 1999]. As a work in progress, this paper presents two initial cycles.

4. Development learning cycles

4.1. First Cycle

In the first cycle, the challenge lies in adapting all information obtained through the ANS form into a digital system. The first root definition agreed with stakeholders was: *"create a data representation that supports all elements from the Simplified Neurological Assessment form"*. This definition aims to ensure that the same data are represented both in the digital system and the paper form without losing any information. It may appear straightforward; however the ANS contains visual and unstructured elements that are challenging to capture.

The model of ANS form data is presented as an ER diagram in Figure 2. This model structured the data in a systematic manner within the system, segmenting it into small, interrelated entities for improved organization and coherence.



USUARIO	
ID _usuario	INT PK
Login	VARCHAR
senha	VARCHAR
Nome	VARCHAR
Tipo_profissional	VARCHAR
Numero_conselho	VARCHAR
Email	VARCHAR
Is_avalidor	Boolean

MEMBRO_INFERIOR	
ID_membro_inf	INT PK
id_avaliacao	INT FK
Palp_nervo_fibular	VARCHAR
Palp_nervo_tibial	VARCHAR
Aval_forca_halux	VARCHAR('F', 'D', 'P','5', '4', '3', '2', '1', '0')
Aval_forca_dorsiflexao	VARCHAR('F', 'D', 'P','5', '4', '3', '2', '1', '0')
Queixa	VARCHAR
Lado	VARCHAR

FACE	
ID_face	INT PK
id_avaliacao	INT FK
Nariz_ressecamento	Boolean
Nariz_ferida	Boolean
Nariz_perfuração	Boolean
Olhos_dim_sensi_cornea	Boolean
Olhos_dim_forca_papebra	Boolean
Olhos_fecha_com_forca	Float
Olhos_fecha_sem_forca	Float
Olhos_triquiase	Boolean
Olhos_ectropico	Boolean
Olhos_opacidade_cornea	Boolean
Olhos_acuidade_visual	Float
Queixa_nariz	VARCHAR
Queixa_olhos	VARCHAR
Lado	VARCHAR(E, D) Obrigatorio
Acuidade_visual	Real

AVALIACAO_SENSITIVA_PE	
ID_aval_sens_pe	INT PK
ID_avaliacao	INT FK
Lado	VARCHAR(E, D) Obrigatorio
Dorso_do_pé	VARCHAR
Falange_distal_do_halux	VARCHAR
Falange_distal_do_3_artelho	VARCHAR
Falange_distal_do_5_artelho	VARCHAR
Calcâneo	VARCHAR
Borda_medial_da planta_do_pé	VARCHAR
Borda_lateral_da_borda_do_pé	VARCHAR
5_artelho	VARCHAR
3_artelho	VARCHAR
Cabeça_da_art_metatarsofalangeana_do_halux	VARCHAR

LESAO_PE	
ID_lesao_pe	INT PK
ID_aval_sens_pe	INT FK
Largura	float
Altura	float
X	INT
Y	INT
Tipo	VARCHAR(Reabsorção,Garras, lesão trófica ou lesão traumática)

TRATAMENTO	
ID_tratamento	PK
Medicação	VARCHAR
Posologia	VARCHAR
Data_inicio	Data
Data_fim	Data

AVALIACAO	
ID_avaliacao	INT PK
ID_paciente	VARCHAR FK
ID_usuario	INT Fk
Data	Date
ID_tratamento	INT

PACIENTE	
CPF	VARCHAR PK
Numero SUS	VARCHAR
Nome	VAR
Ocupação	VAR
Sexo	BOOLEAN
Municipio	VAR
UF	VAR
Data_nasc	Datetime

AVALIACAO_SCORE	
ID_avaliacao_score	INT PK
ID_avaliacao	INT FK
DATA	DATE
Olhos_D	INT
Olhos_E	INT
Maos_D	INT
Maos_E	INT
Pe_D	INT
Pe_E	INT
Maior_grau	INT
Soma_OMP	INT

MEMBRO_SUPERIOR	
ID_membro_sup	INT PK
ID_avaliacao	INT FK
Palp_nervo_radial	VARCHAR
Palp_nervo_ulnar	VARCHAR
Palp_nervo_mediano	VARCHAR
Aval_forca_ulnar	VARCHAR('F', 'D', 'P','5', '4', '3', '2', '1', '0')
Aval_forca_radial	VARCHAR('F', 'D', 'P','5', '4', '3', '2', '1', '0')
Aval_forca_mediano	VARCHAR('F', 'D', 'P','5', '4', '3', '2', '1', '0')
Lado	VARCHAR
Queixa	VARCHAR

AVALIACAO_SENSITIVA_MAO	
ID_aval_sens_mao	INT PK
ID_avaliacao	INT FK
Lado	VARCHAR(E, D) Obrigatorio
Falange_distal _polegar	VARCHAR
Dorso_da_mão	VARCHAR
Falange_proximal_2_dedo	VARCHAR
Falange_Distal_2_dedo	VARCHAR
Falange_proximal_5_dedo	VARCHAR
Falange_distal_5_dedo	VARCHAR
Borda_medial_da_palma	VARCHAR

LESAO_MAO	
ID_lesao_mao	INT PK
ID_aval_sens_mao	INT FK
Largura	float
Altura	float
X	INT
Y	INT
Tipo	VARCHAR(Reabsorção,Garras, lesão trófica ou lesão traumática)

Figure 2. ER diagram of the ANS form data representation.

Before the final version of the diagram presented in Figure 2, the stakeholders reviewed the data modeling and validated it. The primary contribution of the evaluation was a refinement of the technical terminology specific to healthcare domain, including the names of neurological assessment points for the hands and feet. At last, insertion tests were carried out using real ANS data to confirm the consistency of the constructed data model, thus completing the first cycle.

4.2. Second Cycle

The second cycle of the project is characterized by the digital representation of the ANS. The agreed Root Definition was *"create a visual user interface to simplifying and adapt fully the elements of the ANS"*. The team reached a consensus on creating a mid-fidelity prototype that incorporates all the fields included in the original ANS form.

In addition to the data model, an use case diagram was created to describe the main interactions between the actors (patients and health professionals) and the application. Figure 3 illustrates functionalities such as authentication/login to the system, registering and modifying patients records, conducting evaluations, and sharing information. For the patient, the most crucial aspect is the ability to maintain personal health records for future reference. Given that the SUS is a complex and decentralized healthcare system, the location of care can vary due to numerous factors. By utilizing the application, patients can securely store their records and present them to any healthcare professional involved in their care. Additionally, the hansen.app prototype aims to deliver an ANS digital format for both patients and healthcare professionals, ensuring greater accessibility and convenience.

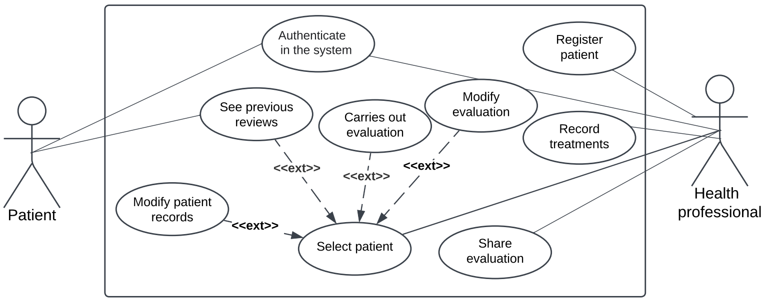


Figure 3. Use case diagram for represent the actors interaction

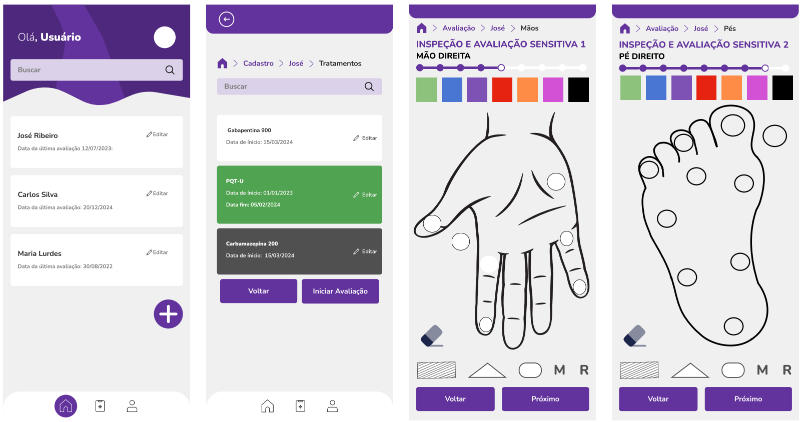
The prototype sections were organized based on the ANS information areas. Due to its complexity and scale, certain sections — such as those related to inspections and evaluations — were divided across multiple screens. The overall navigation of the proposed model is presented here [HansenIA 2025].

The ANS form is based on the assessment and treatment of the patient. In the stakeholder's routine, there are some patients that do not fit the structure of the ANS. When a patient has a Hansen's disease reaction, healthcare professionals use the same ANS form to record the patient neural evaluation. However, the ANS does not include a field for documenting new procedures or treatments beyond the PQT-U. In contrast to the physical version of the ANS, our digital prototype incorporates a new section dedicated to patient treatments and medication administration records, present in Figure 4. This functionality, absent in the original ANS form, enhances patients records and adapts the ANS form to real context of healthcare professionals.

Another context-specific awareness of the model is the chance of the patient change the point of attendance in the health system. If, by any chance, the patient changes city or healthcare facility, all ANS related data is lost.

Figure 4 shows the first version of the mid-fidelity prototype, which was validated with stakeholders to evaluate its functionality. This process ensured that the features implemented align with the expectations of healthcare professionals.

Figure 4 presents four screens of the prototype, illustrating the functionalities that aim to digitize and organize the ANS form data. The first screen, Figure 4.a, displays a patient list and a search field, seeking to facilitate record identification and access. The second screen, Figure 4.b, proposes a space for detailed treatment documentation, allowing for the recording of medications and interventions. The last two screens, Figure 4.c and Figure 4.d, show the interfaces for hand and foot sensory inspection and evaluation, respectively, attempting to incorporate visual elements to support the documentation of potential neurological changes. Together, these screens represent an effort to integrate information in a way that meets healthcare professionals' needs, contributing to potentially more efficient clinical data management.


Olá, Usuário

José Ribeiro
Data da última avaliação 12/07/2023:

Carlos Silva
Data da última avaliação: 20/12/2024

Maria Lurdes
Data da última avaliação: 30/08/2022

Gabapentina 900
Data de início: 15/03/2024

PQT-U
Data de início: 01/01/2023
Data fim: 05/02/2024

Carbamazepina 200
Data de início: 15/03/2024

INSPEÇÃO E AVALIAÇÃO SENSITIVA 1
MÃO DIREITA

INSPEÇÃO E AVALIAÇÃO SENSITIVA 2
PÉ DIREITO

(a) (b) (c) (d)

Figure 4. Mid-fidelity hansen.app prototype close-up.

The general feedback from the stakeholders was positive, highlighting certain learning aspects in the assessment of the location of the assessment. They emphasized the importance of a more managerial interface for collecting and analyzing ANS form data at a local and regional level. As a result, the second development cycle of the application was completed with new inputs for the next cycles.

5. Conclusions and next steps

This work presents the preliminary results of the development of the hansen.app. This application uses the Soft System methodology [Checkland and Poulter 2020] to address the Brazilian Unified Health System (SUS) domain.The SUS is a complex and multifaceted system that demands a sociotechnical perspective for a comprehensive understanding.

The development cycles were structured to align the expectations of real domain stakeholders and researchers, creating a convergent project with a common goal. Both data modeling and the prototype contribute to mitigate the complexity of the Hansen's disease healthcare and monitor in Brazil with more data.

In the next steps, we plan to develop both mobile and desktop applications for the hansen.app. The data regarding their assessment must be share with the patient and with the management level of the SUS. In addition, the data stored in the application will serve as a basis for other research in the areas of computing and health. We consider a repository with an API a relevant future feature, especially to be used by AI models to predict or classify Hansen's disease cases. If widely used in the SUS, the proposed system can help healthcare professionals with more information to better allocate resources to Hansen's disease healthcare in the SUS.

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