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► **To cite this version:**

Al Hassim Diallo, Gaoussou Camara, Jean-Baptiste Lamy, Moussa Lo, Ibrahima Diagne, et al.. Towards an Information System for Sickle Cell Neonatal Screening in Senegal. STC, 2019, Hanover, Germany. 10.3233/978-1-61499-959-1-95 . hal-03479249

**HAL Id: hal-03479249**

**<https://hal.science/hal-03479249>**

Submitted on 14 Dec 2021

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# Towards an Information System for Sickle Cell Neonatal Screening in Senegal

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**Abstract.** Sickle cell disease is a major public health problem in Senegal. It is an inherited disease that affects about 300,000 births worldwide each year. There are 70 million people affected worldwide, 80% of whom live in sub-Saharan Africa. In Senegal, 1 in 10 people carries the sickle cell disease gene. This disease requires follow-up from birth and for life. The patient care requires the integration and the analysis of biological, clinical, social, economic data., etc. In this paper, we propose a health information system for data management of the blood sampling from the newborn at the maternity wards and the disease screening at the Center for Research and Ambulatory Care of the Sickle Cell Disease (CERPAD).

**Keywords.** health information system, sickle cell disease, neonatal screening

## 1. Introduction

Sickle cell disease is a major public health problem in Senegal [1] and in Africa in general [2]. Despite the fact that it affects mainly children and adolescents, the neonatal screening is not systematic [3]. Thus, the Center for Research and Ambulatory Care of the Sickle Cell Disease (CERPAD) has been created at Saint-Louis in Senegal to systematically screen newborns in the maternity wards of the region [4]. The center also ensures follow-up and care of positive-screened patients till 18 years old.

Electronic health records (EHR) plays an important role in the improvement of healthcare quality [5, 6]. The use of such a system in the process of neonatal screening [7, 8], follow-up and care of sickle cell patients is innovative in health practice in Senegal. EHR allows not only ensuring care continuity but also setting up a database for biomedical research and epidemiological studies on the disease.

We have initiated in Senegal a project for setting up a National Medical Information System (SIMENS) [9]. SIMENS is a modular application for EHR. It has been initially designed for public health facilities in level 3 of the sanitary pyramid system of Senegal [10]. The system provides generic modules for invoicing, outpatient clinic, hospitalization, biological analysis and radiology. It also provides specialized modules for surgical unit, emergency department, maternity ward and ENT service. All these

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modules are implemented and tested in collaboration with physicians from the Regional Hospital Center (CHRSL) and the Gaston Berger University of Saint-Louis.

This paper aims at presenting the module in SIMENS for the management of the sickle cell neonatal screening process. We present the global workflow for neonatal screening and the results obtained after 15 months.

## 2. Material and methods

Every newborns is proposed for inclusion in the neonatal screening program, with the consent of their parents. Parents were sensitized by midwives and gynecologists trained for this purpose. Materials collected include (a) for each newborn, a blood drop sample and an information sheet regarding the baby's medical data, the parent's marital status, contacts and socio-professional status, (b) for newborns suspected of having sickle cell disease or homozygous C after the initial screening, a second venous blood sample is collected for detailed analysis.

The initial blood sample is used to perform hemoglobin typing by isoelectrofocusing method. The second one is used for performing capillary electrophoresis of hemoglobin, to identify and confirm the sickle cell status. Newborns with a major sickle cell syndrome profile (SS, SC, SE, SD Punjab, SO Arab, S Lepore, S $\beta^0$  thalassemia, S $\beta^+$  thalassemia) or a CC status are considered as interned (*i.e.* followed by the center). They are followed monthly during systematic visits. They also receive emergency care during acute attacks or other complications related to the disease.

An application dedicated to sickle cell disease was designed for managing screening and follow-up data. It consists in a module integrated in SIMENS, with two main components: the laboratory and the medical services, corresponding to two patient trajectories in the CERPAD. The application was implemented using an Agile development process [11]. We worked with a medical and medico-technical team of doctors, nurses, laboratory technicians, biologists and administrative secretaries who were very involved in the design of the software. Regular meetings made it possible to clearly identify needs, discuss the requirements of the various user profiles, present intermediate results to gather opinions and suggestions, and define the following work, etc. To guide the design of new features and interfaces, workflow schemes and other essential information were regularly shared.

## 3. Results

Figure 1 shows the proposed workflow for sickle cell neonatal screening. This activity mainly involves biological tests done by the laboratory. The maternity wards intervene in the sampling phase, the secretary in the phase of creation of the patient's EHR and the nurse for filling the sample data. The laboratory tests also include, in addition to the screening test, all the other biological tests necessary for the healthcare of sickle cell patients. In this program, the sampling are made at birth at the maternity wards enrolled. Nevertheless, the nurse can take samples at the CERPAD center if necessary.

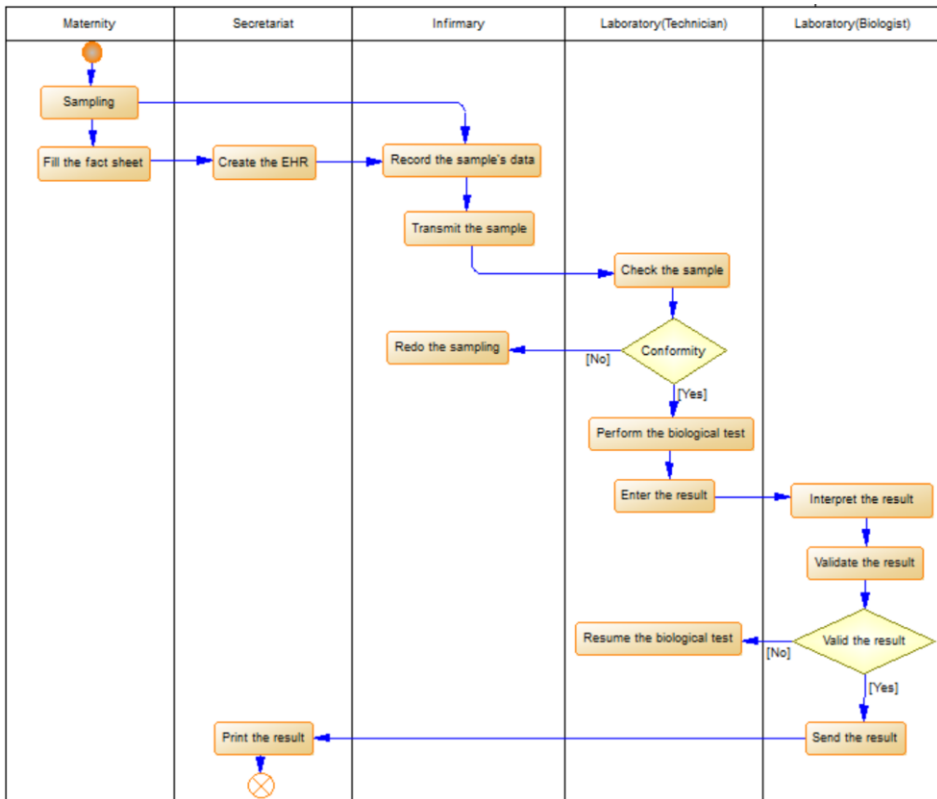


Figure 1. Neonatal screening workflow as a UML sequence diagram.

The screening process consists first of all, for the secretary, to create an EHR for the patient based on data in his information sheet from the maternity ward. The secretary is also responsible for recording requests for biological tests such as hemoglobin screening. Then, the nurse fills the data relating to the samples taken on the patient before sending them to the laboratory technician who performs the verification. Verification consists in checking the state of the samples, the conformity of the material used, etc. In the event of a problem, the technician can request through the SIMENS the resumption of the samples concerned. He is also responsible for recording the results of the biological tests. Finally, the biologist interprets and validates the results for printing and signature. The results are integrated into the patient's EHR. The secretary can access the results and print them for transmission to paediatricians and the newborn's parents.

The neonatal screening program started in April 2017 with a two-month experimental phase. This phase also made it possible to test and maintain the SIMENS screening module for sickle cell disease. Table 1 shows the evolution of the data over time and their distribution according to the various screened sickle cell profiles, covering a period of 15 months from June 2017 to August 2018. 3496 newborns were screened during this period. 3180 (green columns) of them were healthy and non-carriers. 316 (orange and red columns) are carriers of the gene Hemoglobin S. Among carriers, we distinguish healthy carriers (AS) and diseased patients (SS, SC, SE, SDPunjab, SOArabe, SLepore, Sβ<sup>0</sup>thalassemia, Sβ<sup>+</sup>thalassemia). In this first phase, we found 8 (red columns) diseased patients of SS profile.

**Table 1.** Summary of the screening program from June 2017 to August 2018

Period	AA	AC	AD	AS	CC	SC	SS	Total
2017-06	226	10	0	23	0	0	0	259
2017-07	236	5	1	22	0	0	2	266
2017-08	48	1	0	6	0	0	0	55
2017-09	146	4	0	13	0	0	0	163
2017-10	286	5	0	29	0	0	1	321
2017-11	245	2	0	29	0	0	0	276
2017-12	261	7	0	21	1	0	0	290
2018-01	308	6	0	26	0	0	0	340
2018-02	251	7	0	30	0	0	0	288
2018-03	216	6	0	31	0	0	1	254
2018-04	208	2	0	19	0	1	0	230
2018-05	174	6	0	16	0	0	0	196
2018-06	219	3	0	19	1	0	0	242
2018-07	241	5	0	23	0	1	2	272
2018-08	43	0	0	1	0	0	0	44
<b>Total</b>	<b>3108</b> (88.90%)	<b>69</b> (1.97%)	<b>1</b> (0.03%)	<b>308</b> (8.81%)	<b>2</b> (0.06%)	<b>2</b> (0.06%)	<b>6</b> (0.17%)	<b>3496</b>

#### 4. Discussion and conclusion

The workflow modeling allowed us to identify sets of tasks automatable from the sampling to the screening results. It also helped us to improve the CERPAD organization, the assignment of tasks to the actors and the coordination of the screening process. The system provides functionality to efficiently perform the tasks related to enrollment of patients, storage of screening data and compliance with best practice standards.

We observe a certain regularity in the number of children screened with a still low rate of positive screening. However, it should be noted that this phase involved only the main maternity ward (CHRSL) in the Saint-Louis region which performs about half of deliveries, out of 15 maternities. The 14 others are peripheric. All these maternity wards will have to be integrated. The reports on the screening data from the statistical module are designed to allow the CERPAD managers to have an overall view of the activities. This module provides reporting (a dashboard) and data export functionalities. For example, the dashboard allows real-time monitoring of the prevalence rate of sickle cell disease in the program's coverage area. Collected data can easily be used by researchers, with parental consent, to promote epidemiological studies and conduct clinical research [12] to improve treatment protocols and decision making.

The developed system is adapted to the needs of CERPAD and allows a good management of the screening data. The coherence between the system's architecture and the organization of the data flows has made it possible to improve the screening process by fostering easy data collection and access for all stakeholders. The system is designed in a generic way and according to the model of the health system of Senegal and all sub-Saharan countries [13]. Thus, it can be easily adapted for expanding the neonatal screening program of sickle cell disease at the national level or for other partner's centers in Burkina Faso and Mali.

As a future work, an Electronic Medical Record (EMR) for sickle cell disease is designed for the follow-up and healthcare of positive screened newborns. This EMR will be integrated with the lab within the CERPAD and the main SIMENS HIS already in use at different services of the Regional Hospital Center of Saint-Louis (CHRSL).

## Acknowledgement

This work is part of the SIMENS project which is supported by the Senegalese High Study and Research Ministry through the Scientific and Technic Research Impetus Funding (FIRST), the African Center of Excellence in Mathematics Computer Science and ICT (CEA-MITIC), and the Pierre Fabre Foundation.

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