



Challenges and perspectives in the management of patient records in Senegal

experiences from the SIMENS project

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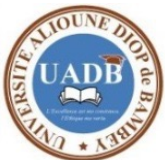
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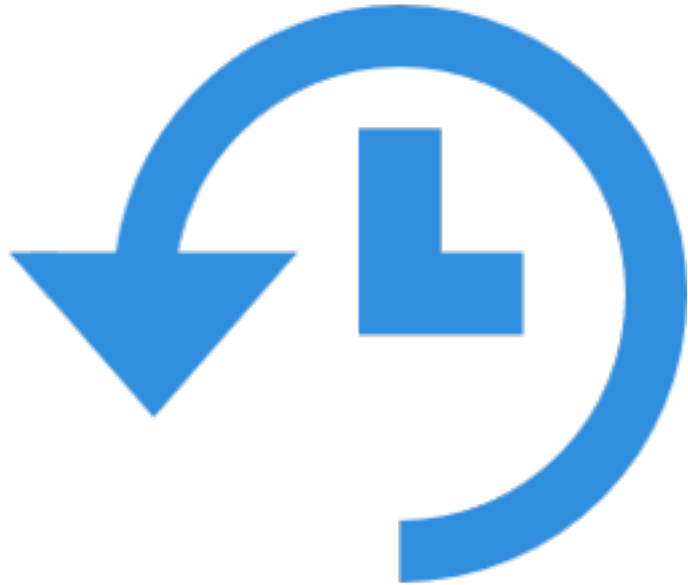
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SIMENS+





Problem statement in patient data management

Search



Diffusion

Reuse

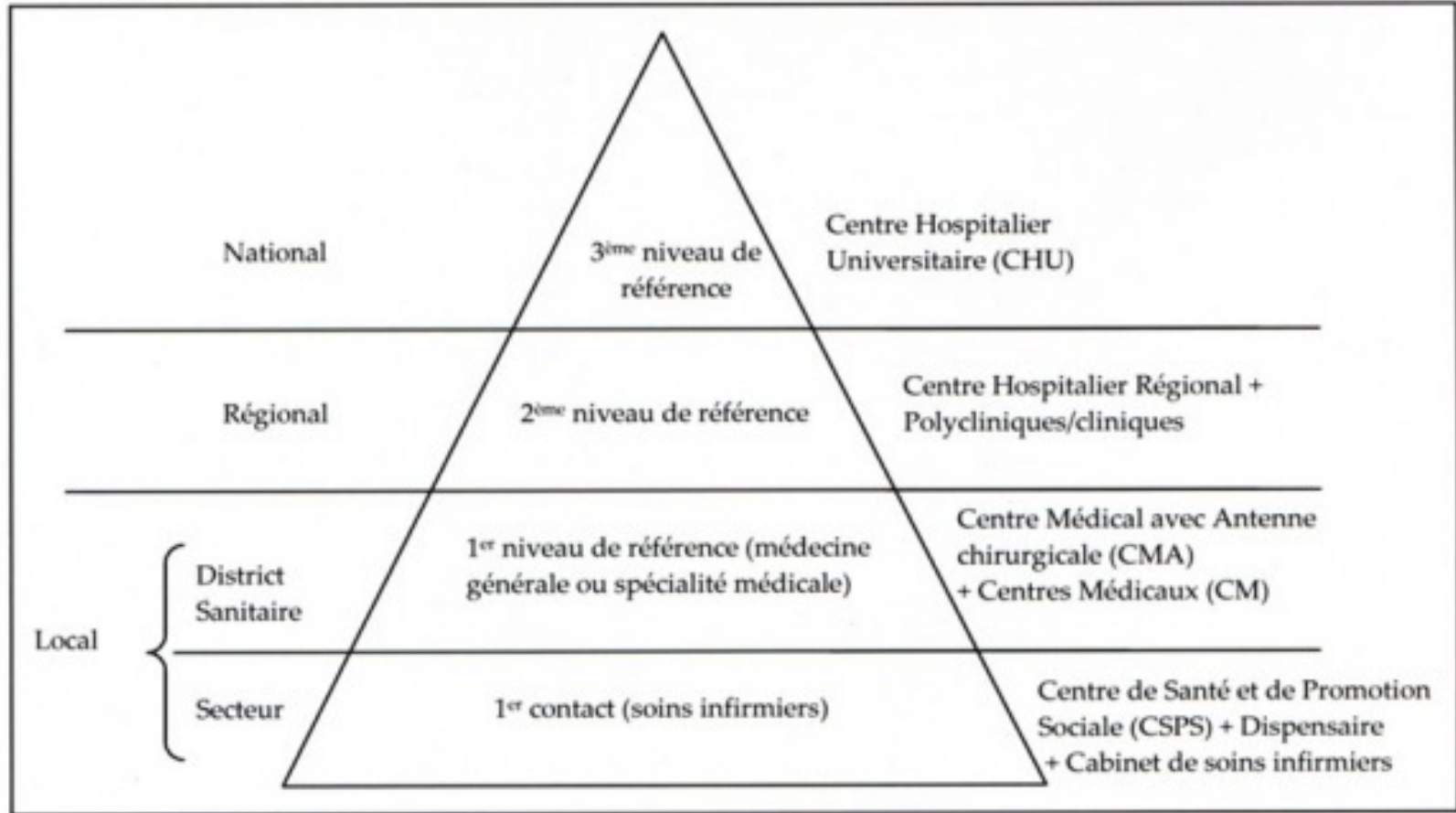
Cross

Existing efforts



Health system architecture of Senegal

Basée sur l'organisation du système de santé du Sénégal



Recommandations de la conférence de l'OMS à Harare en 1985.

Ministère de la Santé et de l'Action Sociale

- Cellule de Gestion de la Carte Sanitaire et sociale et de la Stratégie e-santé (CSeS) du MSAS
 - Unité de coordination de la stratégie e-Santé (UeS)
 - Encadrer et accompagner les projets de Télémédecine, de m-Santé, d'e-Learning, de système d'informations développés par des personnes morales et physiques ;
 - Administrer les solutions e-Santé développées par le Ministère en charge de la santé ;
 - Veiller au respect de la réglementation en matière de développement de la e-Santé ;
 - Développer des outils et des stratégies pour la gestion, le suivi et l'évaluation de la stratégie nationale e-Santé (plan stratégique, plan de mise en œuvre, etc.)

Feedback from the SIMENS project

Purpose of the SIMENS project

"Système d'Information MEdical National pour le Sénégal"@fr
"National Health Information System for Senegal"@en



Electronic patient record



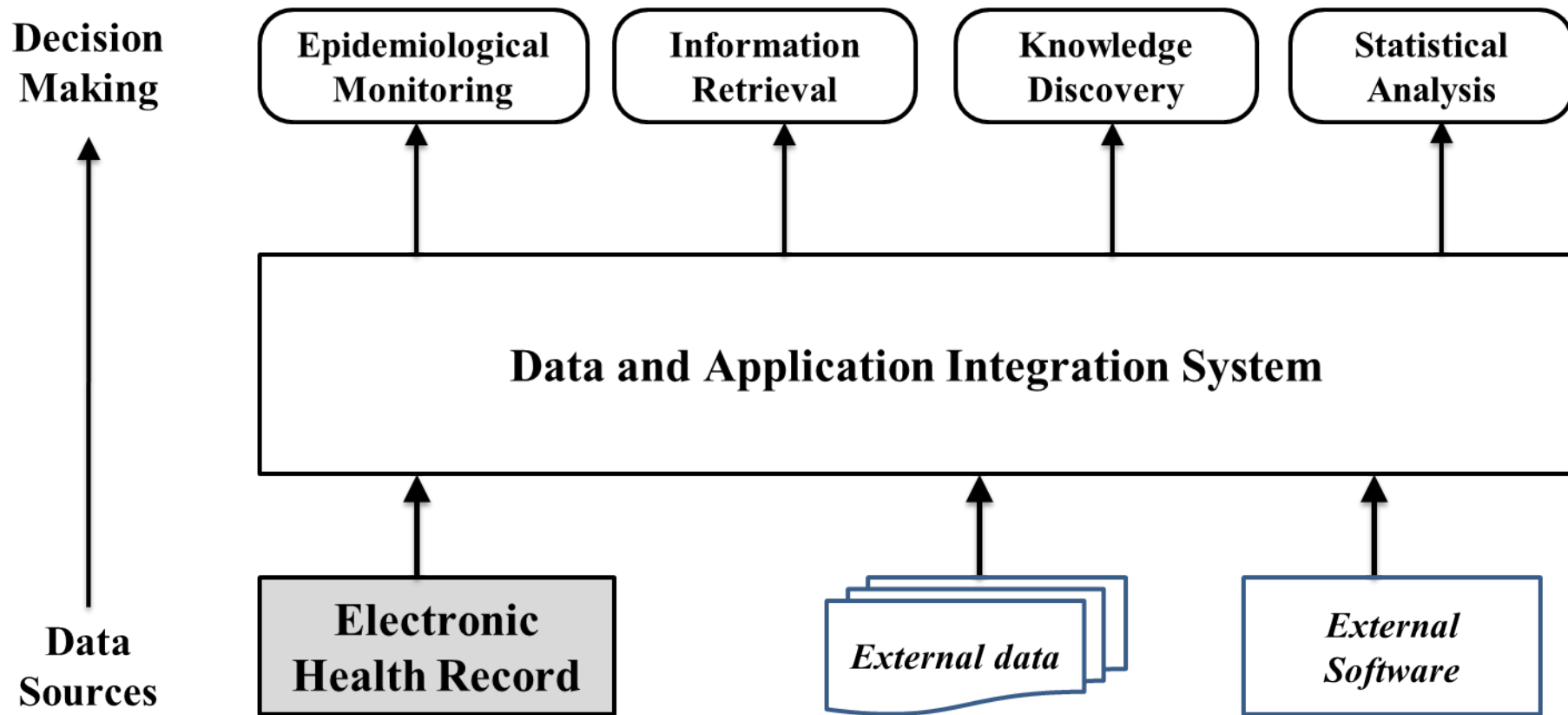
Unique identification of patients



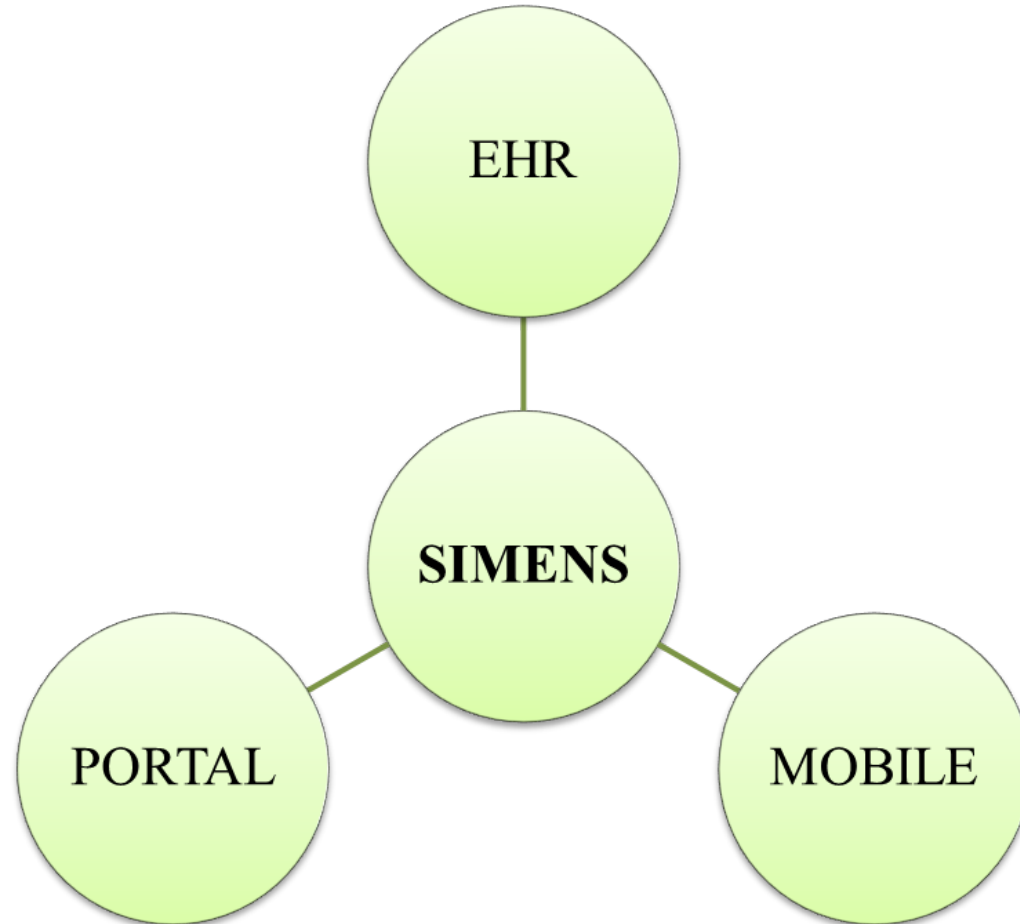
Quick access to health data

SIMENS+

From data collection to decision making



SIMENS core components



Designed from scratch and with AGILE method



Use case 1

Diallo, A.H., Camara, G., Lamy, J.B., Lo, M., Diagne, I., Makalou, D., Diop, M., Doupa, D., 2019a. Towards an Information System for Sickle Cell Neonatal Screening in Senegal. Stud Health Technol Inform 258, 95–99.

The Sickle Cell Disease (SCD)

- Also known as Sickle-cell anemia or Drepanocytosis is an inherited form of anemia
- Characterized by an insufficient number of healthy red blood cells to carry enough oxygen in the body
- Sickle cell anemia can lead to many complications, including:
 - Acute chest syndrome , Vaso-occlusive crisis , Stroke , Pulmonary hypertension , Organ damage , Blindness , Priapism , Leg ulcers , Gallstones ...
- SCD is an inherited disease that affects about 300,000 births worldwide
- There are 70 million people affected worldwide, 80% of whom live in sub-Saharan Africa
- Both the highest prevalence and highest mortality of sickle cell is in Africa
- In Senegal, there are no published studies on sickle cell prevalence
- There is a need:
 - for national comprehensive screening to identify patients
 - for developing a holistic care programs to provide therapeutics and education for families and children with the disease

Health Information System for Sickle Cell

CERPAD

- The Center for Research and Ambulatory Care of the Sickle Cell Disease (CERPAD) is created at Saint-Louis' region in Senegal
 - Funded by the Pierre FABRE Foundation, inaugurated in 2015
- Objective: contribute to the fight against sickle cell disease in Senegal
 - Systematically screen newborns in the maternity wards in the city of Saint-Louis
 - Ensure the follow-up and healthcare of the diseased patient
 - Propose a model for neonatal screening and early care adapted to Senegal's public health system

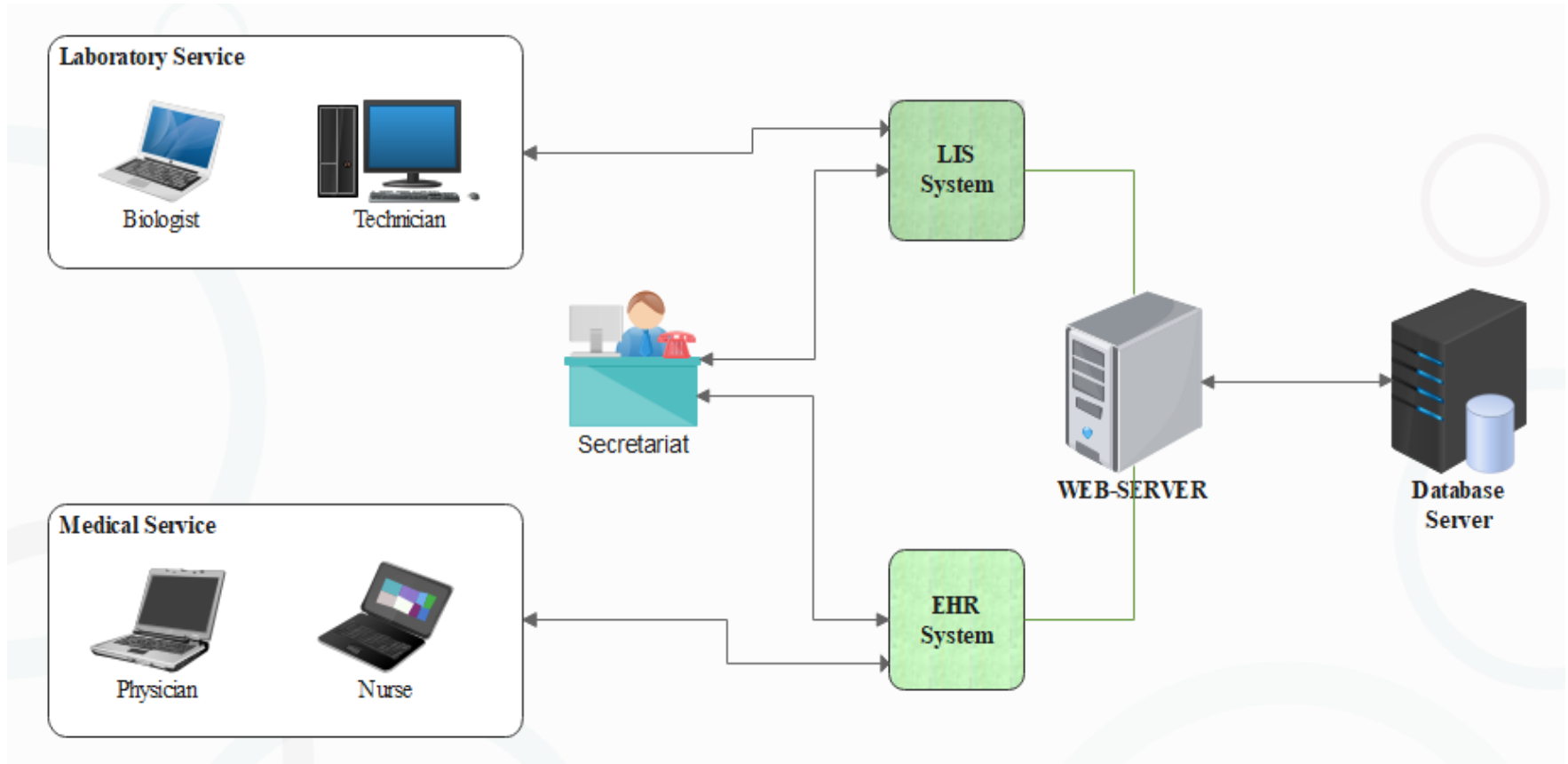
Health Information System for Sickle Cell

CERPAD



Health Information System for Sickle Cell

Architecture



Health Information System for Sickle Cell

Electronic Patient Record

The screenshot shows the SIMENS+ Electronic Patient Record interface. The top navigation bar includes the SIMENS+ logo, the service 'Consultation', the user 'M. Ibrahima DIAGNE', a notification for '5 analyses obligatoires à faire', and a 'Déconnexion' button. The left sidebar contains navigation options: 'Consultations', 'En cours', 'Historique', and 'Statistiques'. The main content area is titled 'Etat Civil' and displays patient information in a grid format. A profile picture placeholder is shown on the left with the age '1an 8m 6j'. The information is organized into columns: 'Prénom' (Hidden Name), 'Nom' (SOW), 'Sexe' (Masculin), 'Date de naissance' (Hidden Date of Birth), 'Lieu de naissance' (CHRSL), 'Nationalité origine' (Sénégal), 'Nationalité actuelle' (Sénégal), 'Adresse' (Hidden Address), 'Téléphone', 'Email', 'GSRh' (O+), 'Type' (Interne (SS)), and 'Hidden Patient ID'. Below the main information, there are sections for 'Consultation' (Hidden consultation id) and 'Date & Heure' (Hidden Date). A list of medical history items is shown at the bottom, including 'Motifs d'admission et Constantes', 'Antécédents et Historiques', 'Consultation du jour', 'Examens complémentaires', 'Conclusion', 'Traitements médicamenteux', 'Transfert | Hospitalisation | Transfusion', and 'Rendez-Vous'. At the bottom right, there are 'Annuler' and 'Terminer' buttons.

SIMENS+ Service: Consultation Bienvenue: M. Ibrahima DIAGNE 5 analyses obligatoires à faire Déconnexion

Etat Civil

Age: 1an 8m 6j

Prénom	Hidden Name	Lieu de naissance	CHRSL	Téléphone	
Nom	SOW	Nationalité origine	Sénégal	Email	
Sexe	Masculin	Nationalité actuelle	Sénégal	GSRh	O+
Date de naissance	Hidden Date of Birth	Adresse	Hidden Address	Type	Interne (SS)

Consultation: Hidden consultation id | Date & Heure: Hidden Date

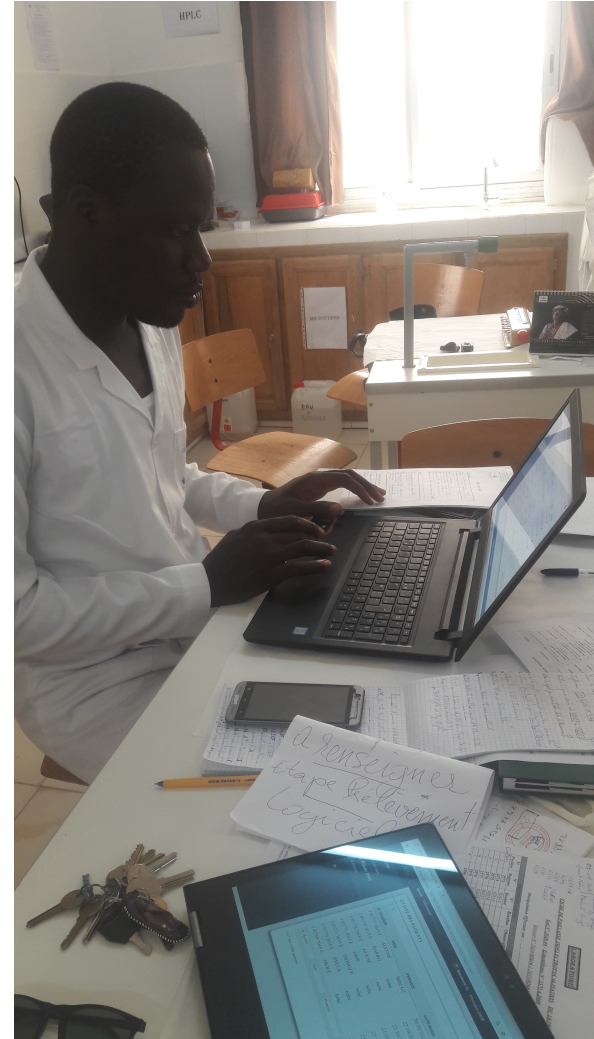
Hidden Patient ID

- › Motifs d'admission et Constantes
- › Antécédents et Historiques
- › Consultation du jour
- › Examens complémentaires
- › Conclusion
- › Traitements médicamenteux
- › Transfert | Hospitalisation | Transfusion
- › Rendez-Vous

Annuler Terminer

Health Information System for Sickle Cell

Realtime data collection



Health Information System for Sickle Cell

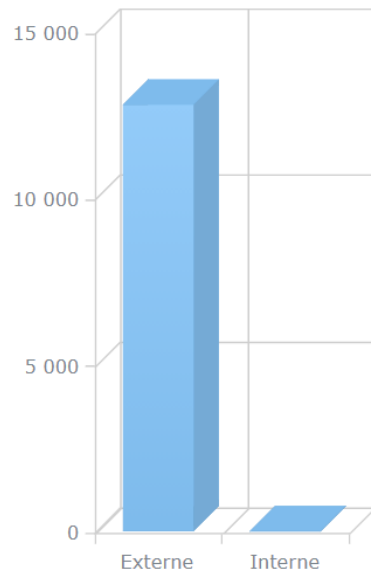
Quick and easy access to statistical data

INFOS STATISTIQUES



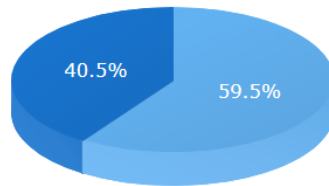
12904 patients dépistés

Externe	12867	99,71 %
Interne	37	0,29 %



37 patients internes

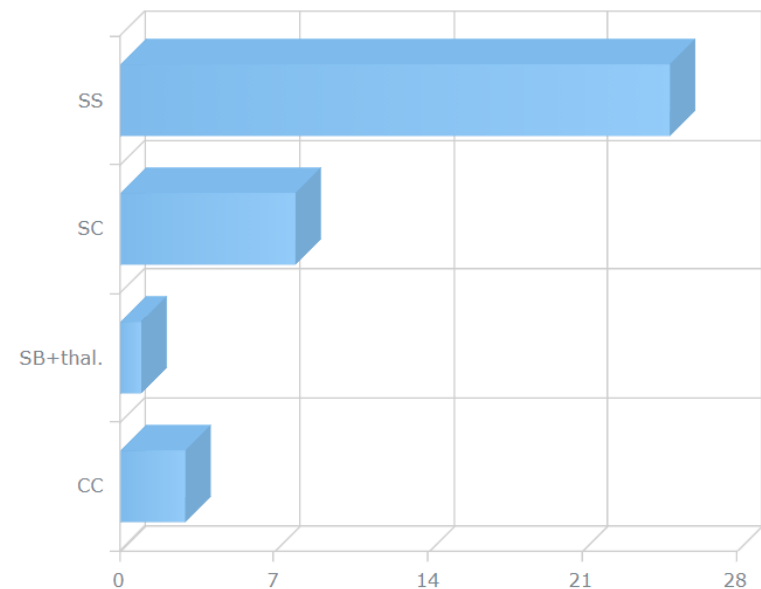
Masculin	15	40,54 %
Féminin	22	59,46 %



Feminin Masculin

3 profils de symptôme drépanocitaire majeur & un statut CC

SS	SC	SB+thal.	CC
25 - {67,57%}	8 - {21,62%}	1 - {2,70%}	3 - {8,11%}



1 2

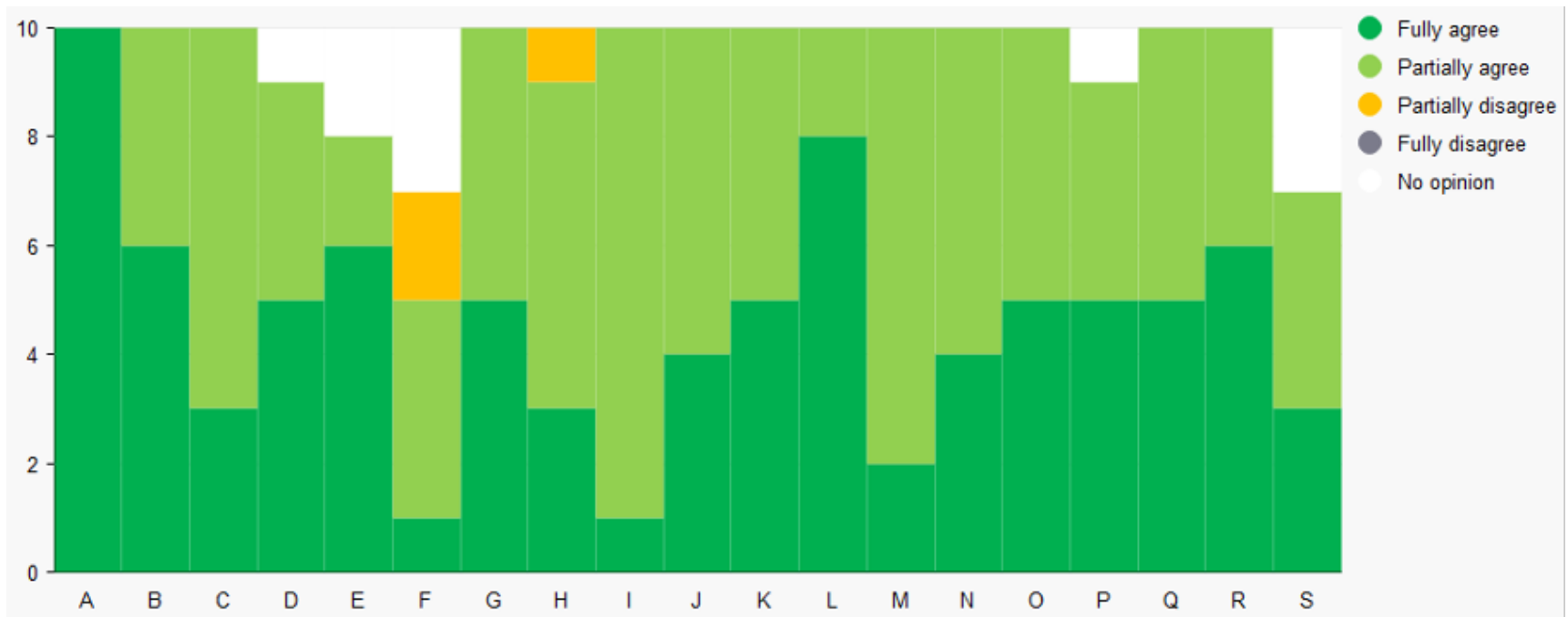
Health Information System for Sickle Cell

Lessons learned

Key		Fully agree	Partially agree	Partially disagree	Fully disagree	No opinion
A	The system improves the management of patient records	10	0	0	0	0
B	The system facilitates my work	6	4	0	0	0
C	The system improves the quality of my care	3	7	0	0	0
D	The system improves our ability to coordinate continuity of care	5	4	0	0	1
E	The system improves medical information sharing	6	2	0	0	2
F	The system improves decision-making	1	4	2	0	3
G	The system is easy to use	5	5	0	0	0
H	When using the system, the number of clicks is acceptable	3	6	1	0	0
I	System's response time is acceptable	1	9	0	0	0
J	System's session opening is acceptable	4	6	0	0	0
K	The system preserves patient's security and confidentiality	5	5	0	0	0
L	The system is reliable	8	2	0	0	0
M	The global quality of the system is excellent	2	8	0	0	0
N	The information in the system is exhaustive	4	6	0	0	0
O	The information in the system is quickly available	5	5	0	0	0
P	The information in the system is relevant	5	4	0	0	1
Q	The information in the system is quickly available when needed	5	5	0	0	0
R	The form and layout of the information in the system is acceptable	6	4	0	0	0
S	The information in the system allows me to make decisions	3	4	0	0	3

Health Information System for Sickle Cell

Lessons learned



Use case 2

Diallo, A.H., Camara, G., Lo, M., Diagne, I., Lamy, J.-B., 2019c. Proportional Visualization of Genotypes and Phenotypes with Rainbow Boxes: Methods and Application to Sickle Cell Disease, in: 2019 23rd International Conference Information Visualisation (IV). IEEE, Paris, France, pp. 1–6.

Problem statement

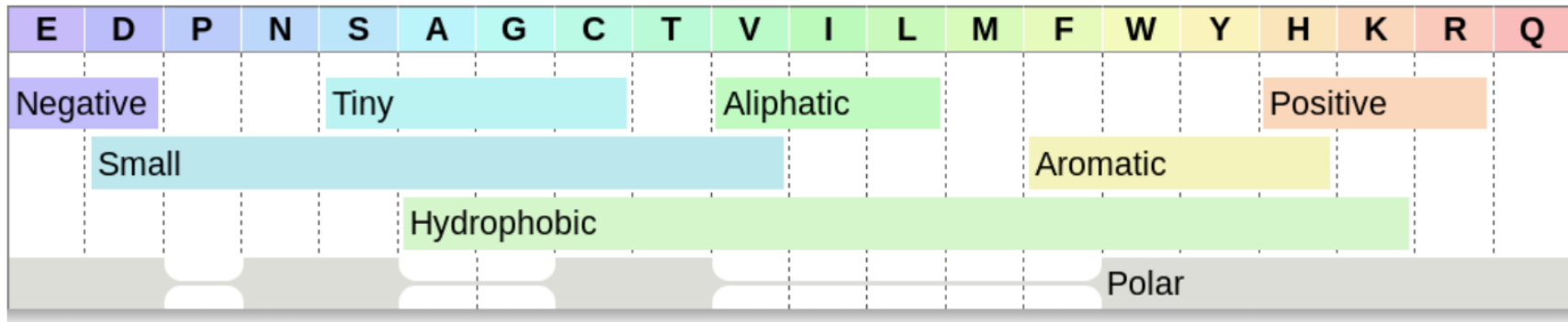
- Monitoring of genetic disorders
 - Complex because both phenotype and genotype must be considered
- How to visualize the observed proportion of each phenotype and genotype ?

Genotype and phenotype

- Genotype : information present in the genome
 - Each patient has two exemplars of each gene (except for chromosome Y)
- Phenotype : observed character (e.g. diseased or healthy)
 - Usually resulting from the genotype
- Translation as a set visualization problem:
 - $A = \{ a_1, a_2, \dots \}$ the set of alleles
 - A genotype is a triple: $G = (\text{alleles}, \text{proportion}, \text{phenotype})$
 - G has either 1 allele (both exemplar of the gene are identical)
 - or 2 alleles (two different exemplars)
 - \Rightarrow a set visualization problem in which sets have at most 2 elements

Proportional Visualization of Sickle Cell patient profiles

Rainbow boxes visualization approach



- Rainbow boxes : a recent technique for set visualization
 - elements => columns
 - sets => rectangular boxes
 - color => one color per element
 - box color is the mean of its elements color
 - non contiguous element in a set => box hole
 - elements are ordered so as to minimize the number of holes
 - box are stacked vertically by size

[Lamy JB et al. Rainbow boxes: a new technique for overlapping set visualization and two applications in the biomedical domain. *Journal of Visual Language and Computing* 2017]

Proportional Visualization of Sickle Cell patient profiles

Traduction comme un problème de visualisation d'ensemble

- $A = \{a_1, \dots, a_n\}$ un ensemble d'allèles
- Un génotype G
 - 1 allèle (deux exemplaires du gène sont identiques)
 - 2 allèles (deux exemplaires différents)
- G appartient à certains patients et détermine le phénotype
- Un génotype est un triplet :
 - $G = (a, n, p)$
 - $a \subseteq A$ avec $1 \leq |a| \leq 2$; $n \in \mathbb{R}$; p est le phénotype
- 3 classes peuvent être considérées :
 - malade (noté Di) => rouge
 - porteur sain (Ca) => orange
 - non porteur sain (He) => vert
- Ainsi $p \in \{Di, Ca, He\}$

$$\mathcal{A} = \{A, C, S\}$$

$$G_1 = (\{A\}, 30\%, He)$$

$$G_2 = (\{C\}, 12\%, He)$$

$$G_3 = (\{S\}, 11\%, Di)$$

$$G_4 = (\{A, C\}, 7\%, He)$$

$$G_5 = (\{A, S\}, 30\%, Ca)$$

$$G_6 = (\{C, S\}, 10\%, Di)$$

Proportional Visualization of Sickle Cell patient profiles

Encodage visuel

- 1 allèle => 1 élément => 1 colonne
- 1 génotype => 1 ensemble => 1 boîte
- Proportion du génotype => hauteur de la boîte
- Phénotype associé au génotype => couleur
 - malade => rouge, porteur => orange, sain non porteur => vert

$$\mathcal{A} = \{A, C, S\}$$

$$G_1 = (\{A\}, 30\%, He)$$

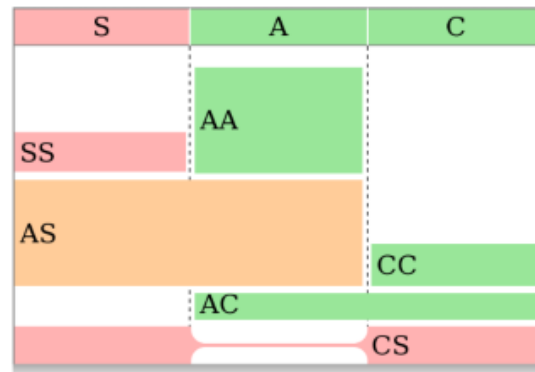
$$G_2 = (\{C\}, 12\%, He)$$

$$G_3 = (\{S\}, 11\%, Di)$$

$$G_4 = (\{A, C\}, 7\%, He)$$

$$G_5 = (\{A, S\}, 30\%, Ca)$$

$$G_6 = (\{C, S\}, 10\%, Di)$$



Proportional Visualization of Sickle Cell patient profiles

Encodage visuel

- Résolution d'un problème d'optimisation des boîtes arc-en-ciel
 - Trouver l'ordre optimal des colonnes
 - Minimise le nombre de boîtes à trous
- Utilisation d'un algorithme force brute
 - Générer toutes les configurations possibles
 - Tester les configurations une à une jusqu'à trouver l'ordre optimal

$$\mathcal{A} = \{A, C, S\}$$

$$G_1 = (\{A\}, 30\%, He)$$

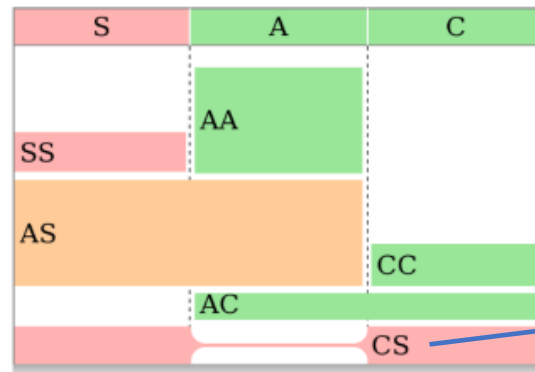
$$G_2 = (\{C\}, 12\%, He)$$

$$G_3 = (\{S\}, 11\%, Di)$$

$$G_4 = (\{A, C\}, 7\%, He)$$

$$G_5 = (\{A, S\}, 30\%, Ca)$$

$$G_6 = (\{C, S\}, 10\%, Di)$$



SC est une boîte à trou

Proportional Visualization of Sickle Cell patient profiles

Encodage visuel

- Résolution d'un problème d'optimisation des boîtes arc-en-ciel
 - Trouver l'ordre optimal des colonnes
 - Minimise le nombre de boîtes à trous
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$$\mathcal{A} = \{A, C, S\}$$

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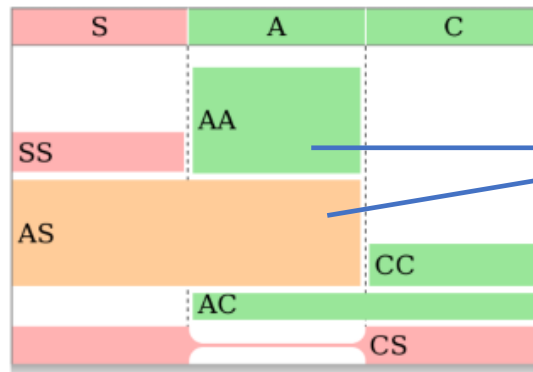
$$G_2 = (\{C\}, 12\%, He)$$

$$G_3 = (\{S\}, 11\%, Di)$$

$$G_4 = (\{A, C\}, 7\%, He)$$

$$G_5 = (\{A, S\}, 30\%, Ca)$$

$$G_6 = (\{C, S\}, 10\%, Di)$$



Are there twice as many AS patients as AA patients?

Proportional Visualization of Sickle Cell patient profiles

Encodage visuel

- Amélioration des boîtes arc-en-ciel pour l'ensemble de données avec des ensembles d'au plus 2 éléments
 - Toutes les boîtes ont la même largeur
 - Les boîtes correspondantes aux ensembles à 2 éléments sont au milieu des 2 colonnes

$$\mathcal{A} = \{A, C, S\}$$

$$G_1 = (\{A\}, 30\%, He)$$

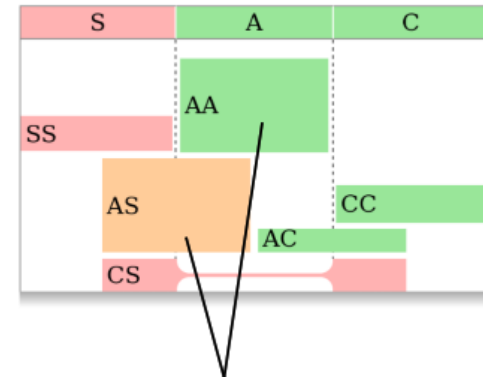
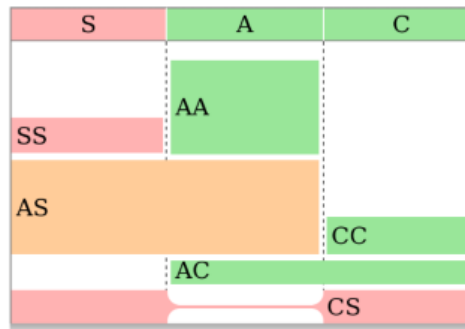
$$G_2 = (\{C\}, 12\%, He)$$

$$G_3 = (\{S\}, 11\%, Di)$$

$$G_4 = (\{A, C\}, 7\%, He)$$

$$G_5 = (\{A, S\}, 30\%, Ca)$$

$$G_6 = (\{C, S\}, 10\%, Di)$$

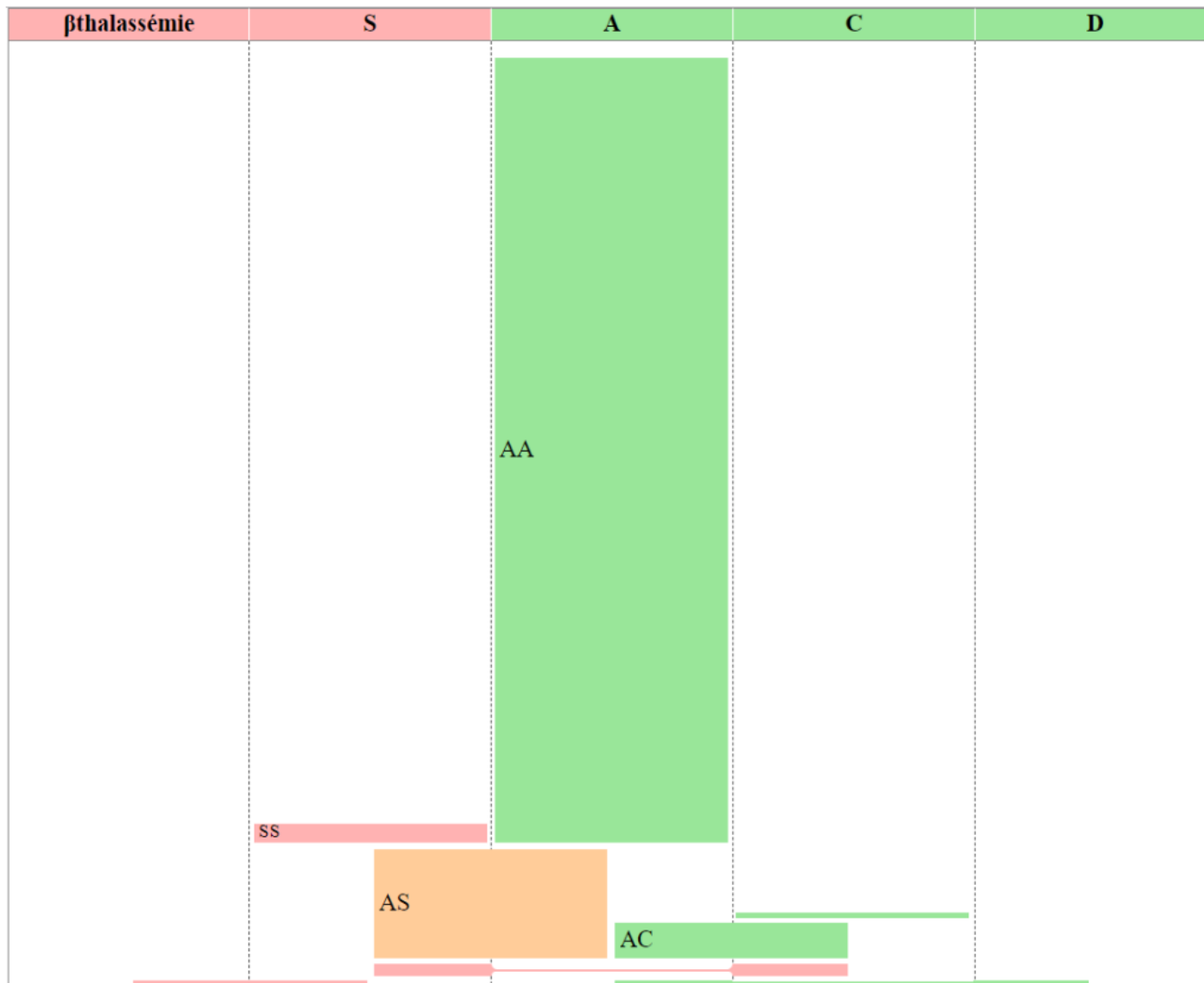


“Same proportion of AS and AA patients”

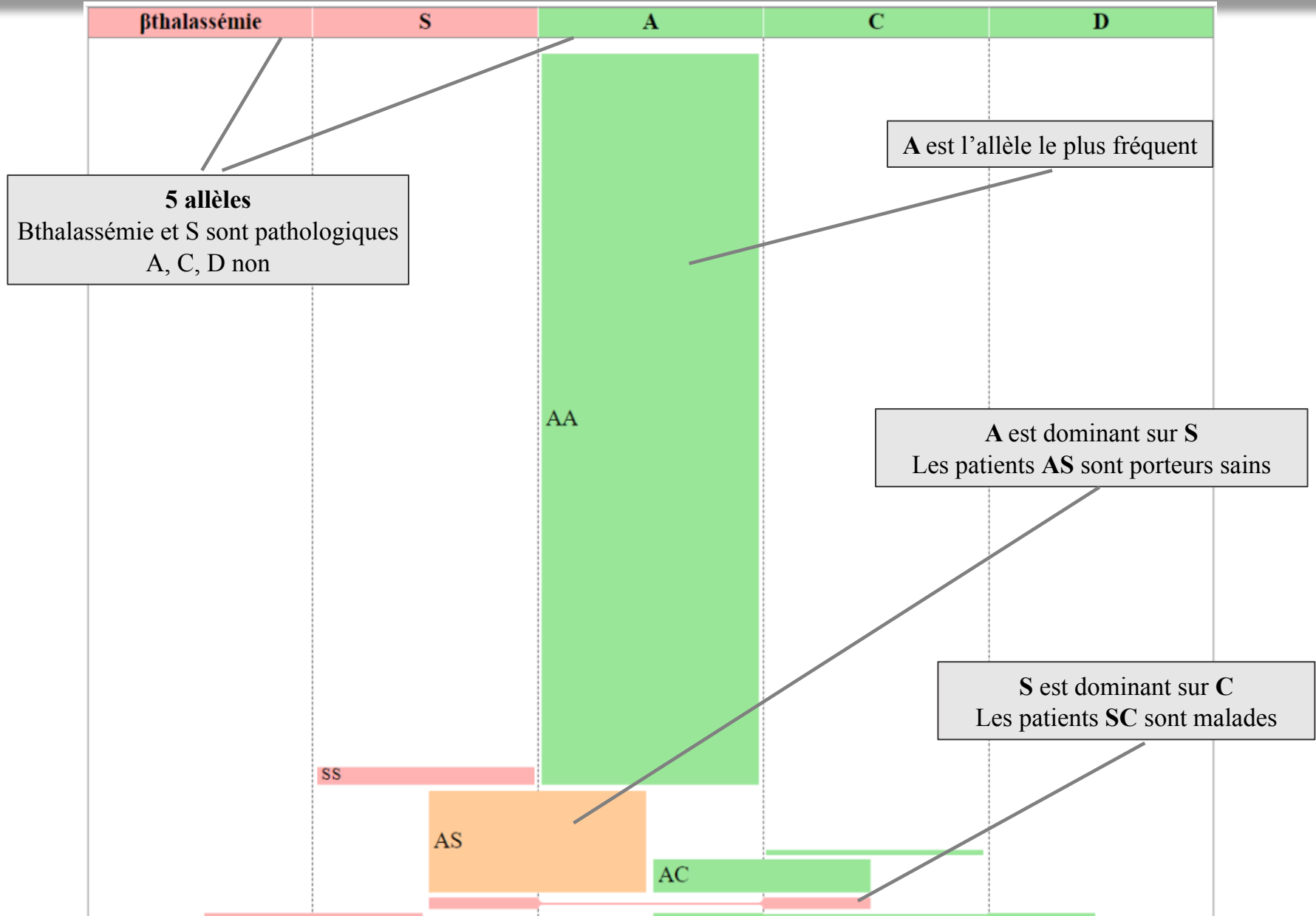
Expérimentation

- Application aux données du dépistage néonatal au CERPAD
 - Données collectées sur une période de 41 mois (du 25/04/2017 au 31/08/2020)
 - Maternité du Centre Hospitalier Régional de Saint-Louis (CHRSL)
 - Maternité du Centre de Santé Ousmane Ngom (CSON)
 - 11 189 nouveaux nés dépistés
- Comparaison la répartition des génotypes et des phénotypes entre plusieurs sous-groupes de la population
 - 3 groupes ethniques : Ethnie-1, Ethnie-2 et Ethnie-3

Proportional Visualization of Sickle Cell patient profiles



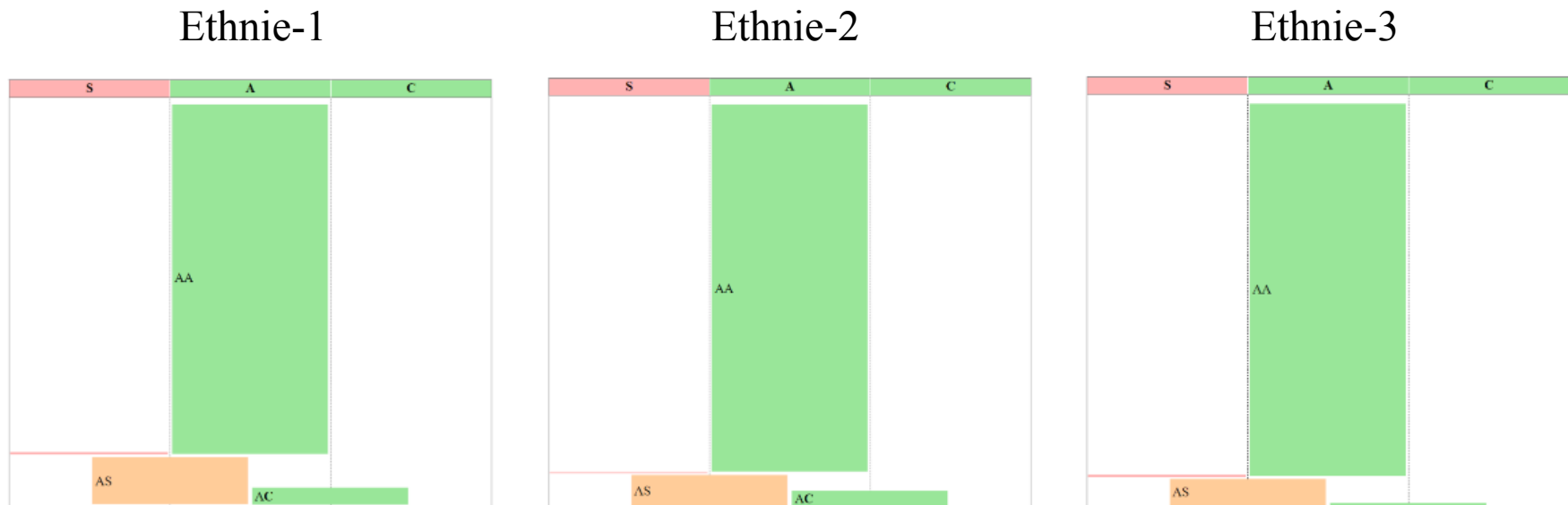
Proportional Visualization of Sickle Cell patient profiles



Proportional Visualization of Sickle Cell patient profiles

Comparison of 3 ethnic groups

- Similar overall “big picture”, but:
 - Healthy carriers are more common in Ethnie-1
 - Allele C is less common in Ethnie-3



Evaluation method

- Recueil de l'avis des 6 utilisateurs sur les boites arc-en-ciel
 - Facilite l'interprétation des données
 - Réduit le temps nécessaire à l'analyse et la compréhension
 - Sont performant, le temps de réponse est très satisfaisant
 - Fournissent des informations fiables et sûres
 - Affichent des images de bonne qualité
 - Sont facile à utiliser

Lessons learned

- 2 specialists of sickle cell disease screening at the CERPAD
 - They found the approach interesting
 - They liked the visualization of alleles, genotypes and phenotypes in a single image
- Other disorders are related to the same alleles as those found in sickle cell disease
- => experts suggested the visualization of additional phenotypes

Use case 3

*A. H. Diallo, G. Camara, M. Lo, I. Diagne, et J. B. Lamy, « **Iconic Visualization of Sickle Cell Patients Current and Past Health Status** », Stud Health Technol Inform, vol. 272, p. 71–74, juin 2020.*

Problem statement

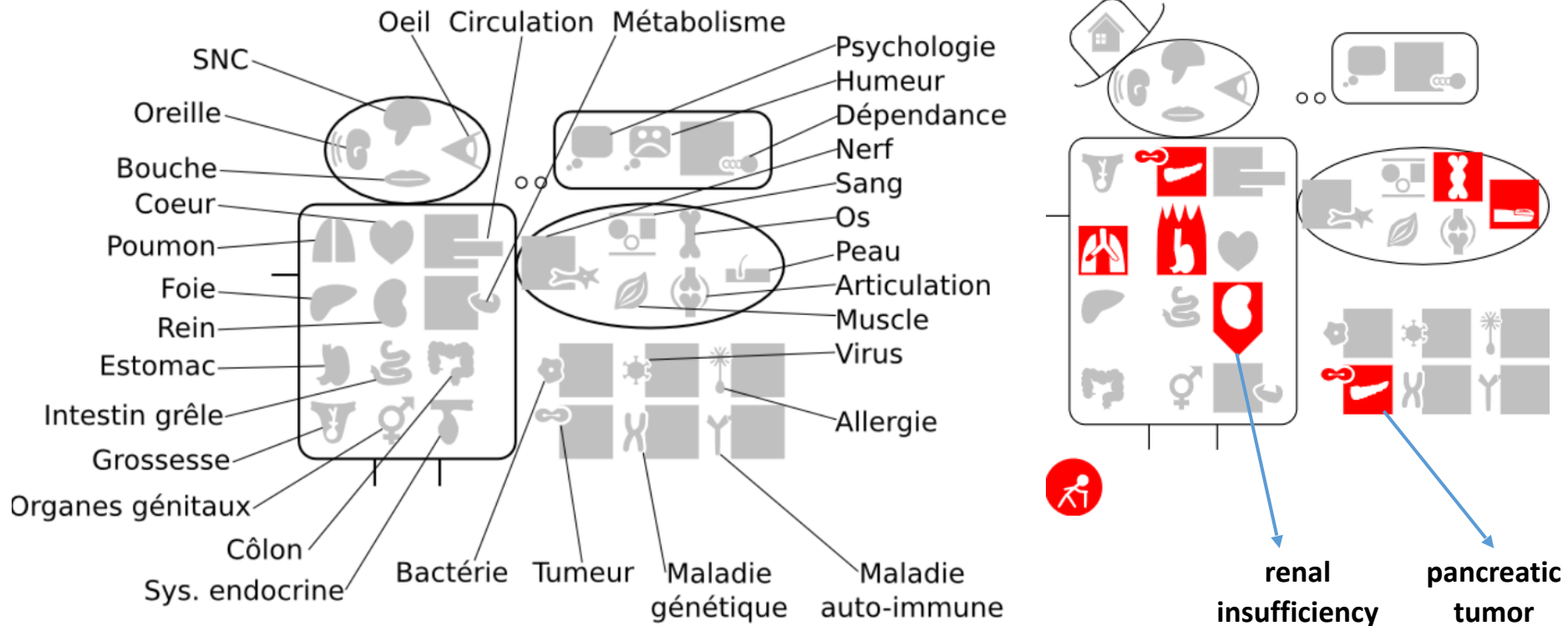
- Faced with a deluge of data on screening for Sickle Cell, doctors and biologists are distraught
 - The complexity of data related to the patient's medical history
 - Difficulties in making diagnostic and therapeutic decisions
 - Difficulties in understanding biological processes and interpreting a biological examination
- Data visualization tools are a solution to this problem
 - Iconic Language for Visualization of Medical Concepts (VCM)

Visualization of Medical Concepts (VCM)

- VCM tool is chosen for visualization of medical knowledge using an iconic language because:
- It is specific to the analysis and exploration of medical data
- It offers a visual interface presenting a Mr. VCM that is an anatomical diagram of man that presents the organs in the form of VCM icons
- The icons are in the form of attractive and good quality images
- It represents with icons the main concepts (clinical conditions, pathologies, treatments, monitoring,...) found in medical records or documents
- These icons can be used to identify the excerpts of interest in a medical document
- VCM consists of five basic concepts, each being associated with a color
- (1) The patient's current condition is represented in red, (2) the patient's risk in orange, (3) the patient's history in brown, (4) the treatments in green and (5) the monitoring in blue.

Iconic Visualization of Sickle Cell Patients data



Overview of the VCM language



The set of VCM icons according to anatomy and etiology.

Iconic Visualization of Sickle Cell Patients data

Method

- At CERPAD, we used VCM icons to visualize the medical terms related to:
 - The results of biological analyses carried out in the laboratory
 - The data of consultations carried out in the medical service
- In the CERPAD database, we identified the terms that were useful to visualize
- We manually made a correspondence between these terms and VCM icons
- The similar terms were mapped to the same icons
- We identified 76 terms in the CERPAD database for iconization, and we mapped them to 20 different VCM icons
 - Example: The term “Blood count” corresponds to icon  and “Creatinine” corresponds to  etc.
- We combined two icon based visual approaches :
 - An instantaneous anatomical approach with Mr. VCM
 - Temporal approach with a timeline

Iconic Visualization of Sickle Cell Patients data

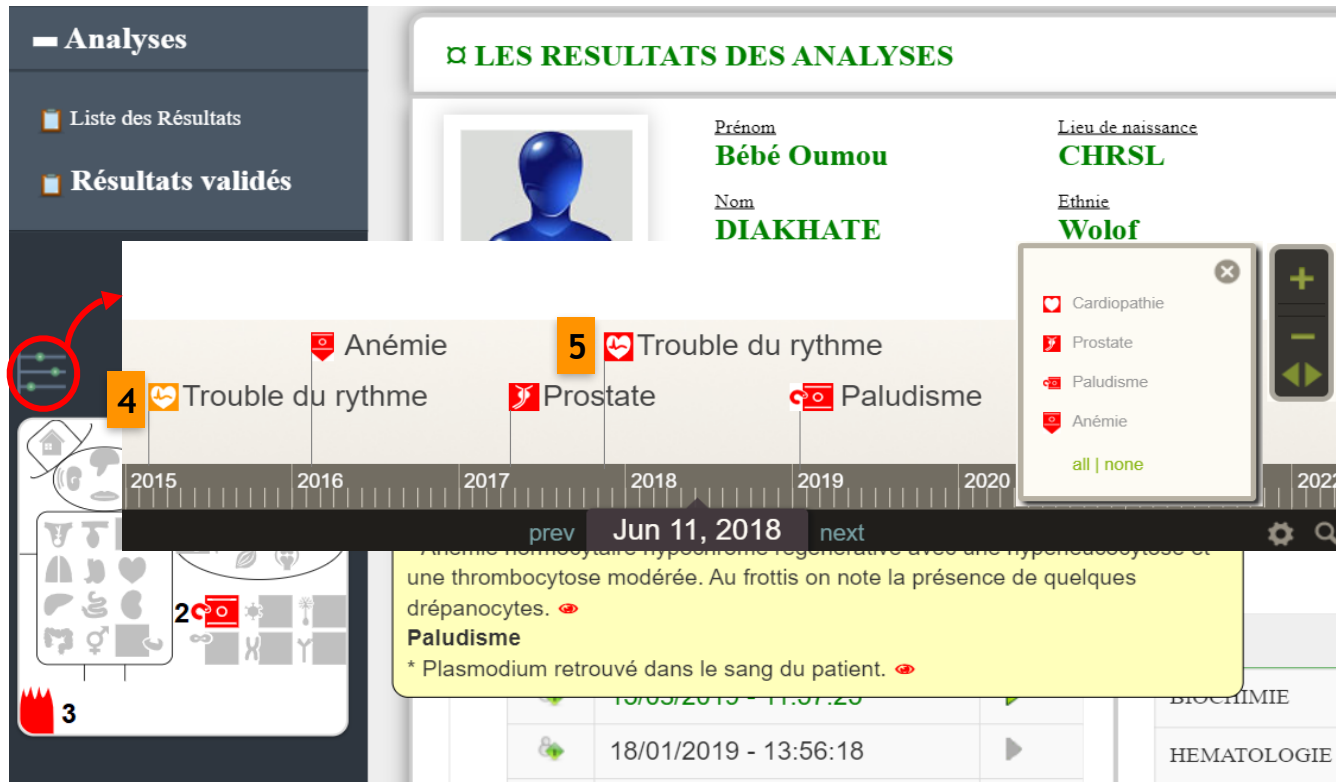
Mr. VCM shows the current status of the patient

The screenshot displays a medical application interface. On the left, a sidebar menu under 'Analyses' includes 'Liste des Résultats' and 'Résultats validés'. Below the menu is a grid of icons representing various medical conditions, with three icons highlighted: a red blood cell (labeled '1'), a parasite (labeled '2'), and a flame (labeled '3'). The main area, titled 'LES RESULTATS DES ANALYSES', shows patient information: Prénom **Bébé Oumou**, Nom **DIAKHATE**, Sexe **Féminin**, Date de naissance **18/04/2018**, Age: **1an 4m 30j**, Lieu de naissance **CHRSL**, Ethnie **Wolof**, Nationalité actuelle **Sénégal**, and Adresse **Pikine Bas Sénégal**. A yellow tooltip box is overlaid on the grid, providing details for 'Anémie' and 'Paludisme'. The tooltip text reads: 'Anémie * Anémie normocytaire hypochrome régénérative avec une hyperleucocytose et une thrombocytose modérée. Au frottis on note la présence de quelques drépanocytes. 🚩' and 'Paludisme * Plasmodium retrouvé dans le sang du patient. 🚩'. Below the tooltip, a table shows a date '18/01/2019 - 13:56:18' and a play button icon, with 'BIOCHIMIE' and 'HEMATOLOGIE' listed in the background.

- Icon #1 represents red blood cells
- Icon #2 represents parasitic infections
- Icon #3 shows that the patient suffers from an inflammation

Iconic Visualization of Sickle Cell Patients data

The timeline featuring VCM icons and textual labels



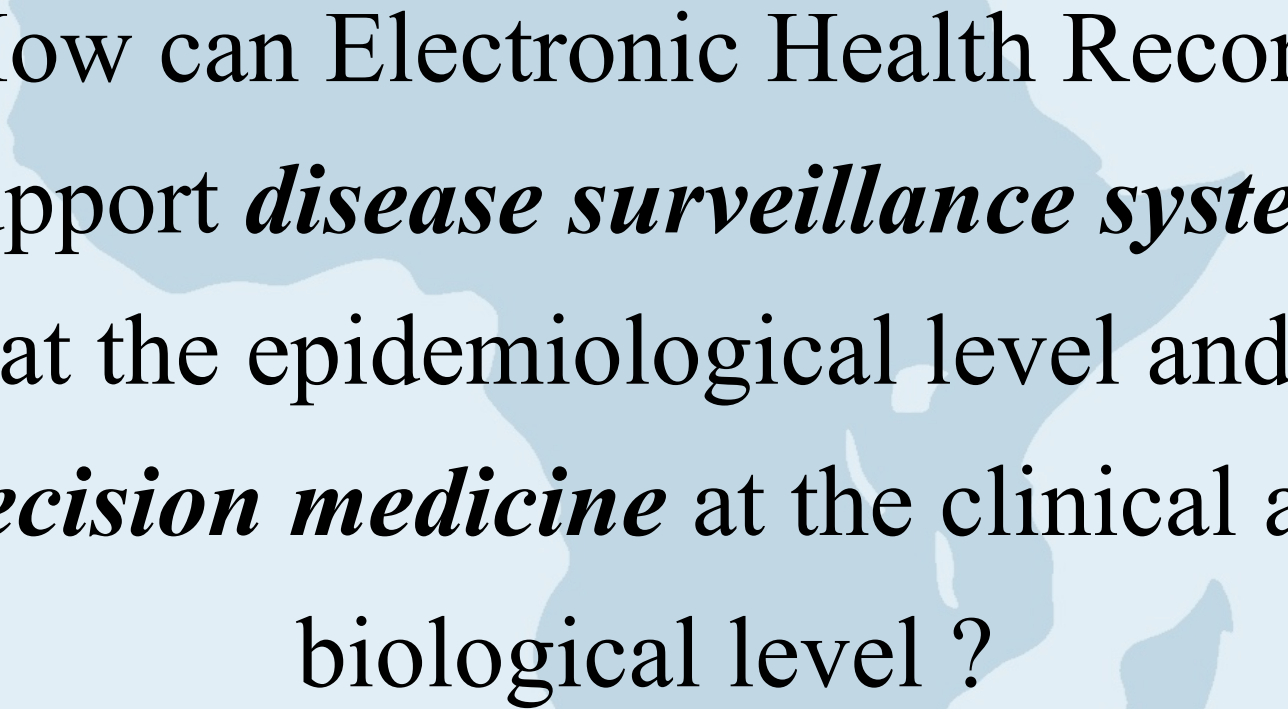
- Icon #4 shows a risk of rhythm disorder in February 2015
- Icon #5 shows that Cardiac pathology finally set in in the patient in November 2017

Iconic Visualization of Sickle Cell Patients data

Lessons learned

- Particularity of the use of VCM icons
 - Innovative, especially for the monitoring of sickle cell disease
 - VCM icons brings out information that might otherwise go unnoticed in the text data
- Importance of VCM icons for users (physicians and biologists)
 - For the biologist, it allows the identification of relevant information for facilitating the task of interpreting and concluding the results of laboratory tests
 - The physicians can visualize Mr. VCM and immediately get an idea of the patient's health state and his main disorders
 - The timeline provides them a very intuitive representation that gives a quick and general overview of the patient's state of health
 - The timeline presents the data from medical records in an iconic and chronological format that meets the expectations of biologists and physicians
 - the proposed visual approaches allow biologists and physicians obtaining quick information on the history, pathologies, symptoms, treatments, monitoring... for a given patient

Outcomes



How can Electronic Health Record
support *disease surveillance system*
at the epidemiological level and
precision medicine at the clinical and
biological level ?

Expected outcomes in using EHR in Senegal

- Improving the quality of the patients healthcare
- Reducing the cost and time all along the healthcare process
- Improving medical data archiving
- Ensuring in care continuity throughout the health pyramid
- Building realtime health surveillance system
 - Alert, prevention and control
- Designing clinical decision support system
 - Diagnosis aid, therapeutic suggestion, medical image interpretation
- Drawing reliable statistics
- Setting up dynamic dashboards
- Driving clinical research on real world data

Ongoing PhD topics within the SIMENS project

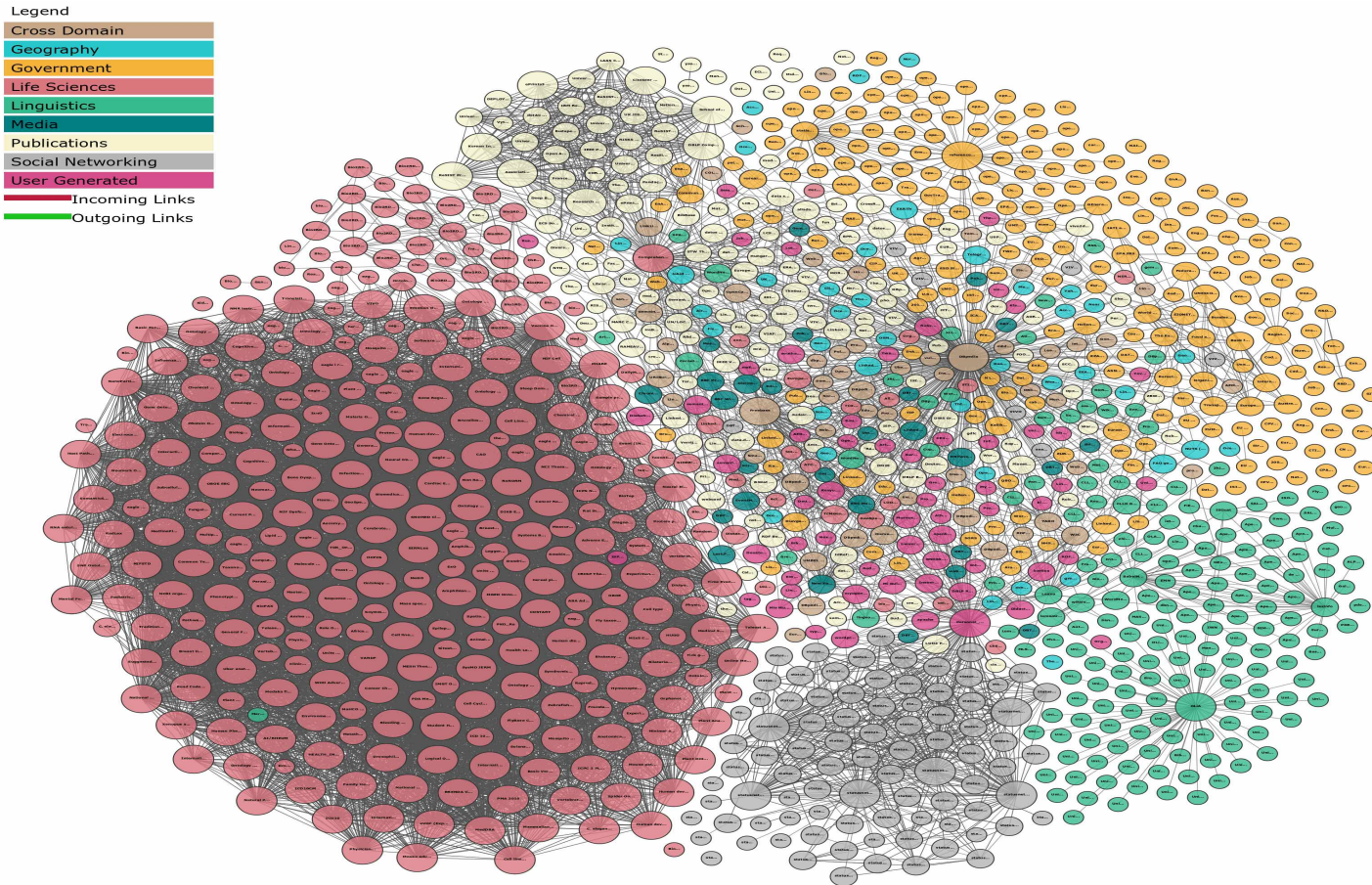
- Targeted neonatal screening of sickle cell disease
 - Detect potential cases of sickle cell diseased newborns within the HIS of Maternity wards
 - Avoid systematic screening of all newborns
- Predicting complications related to pathological pregnancies
- Prediction of cardiovascular event
- Prediction of diabetes complications
- Prediction of malaria diagnosis
 - Towards an Efficient Prediction Model of Malaria Cases in Senegal

Challenges

- Strengthen the technical platform of hospitals
 - Local and national networks (Intranet)
 - Fixed and mobile workstations (computer and mobile)
- Upgrade the medical staff
 - Training in the use of the computer tool
 - Awareness of coding and standardization of medical information
- Evaluate the contribution of hospital information systems
 - Improvement of the health care of the patients
 - Reduced cost and time of health care
- Ensure interoperability between EHR and with decision making tools
- Guarantee the security and confidentiality of data
- Integrate external / related data
 - Demographic, geographical, climatic, social, etc. => One Health ?
- Capitalize the data and knowledge of traditional medicine

Underlying problem raising new challenges

Towards massive medical data ...



... that needs to be linked, semantic-based and [open]

Core team



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Mr. Al Hassim DIALLO, PhD Student



Ms. Sophie SYLLA, PhD Student



Dr. Jacques Noël TENDENG, Physician



Prof. Jean-Baptiste LAMY



Ms. Fatou Lo NIANG, PhD Student



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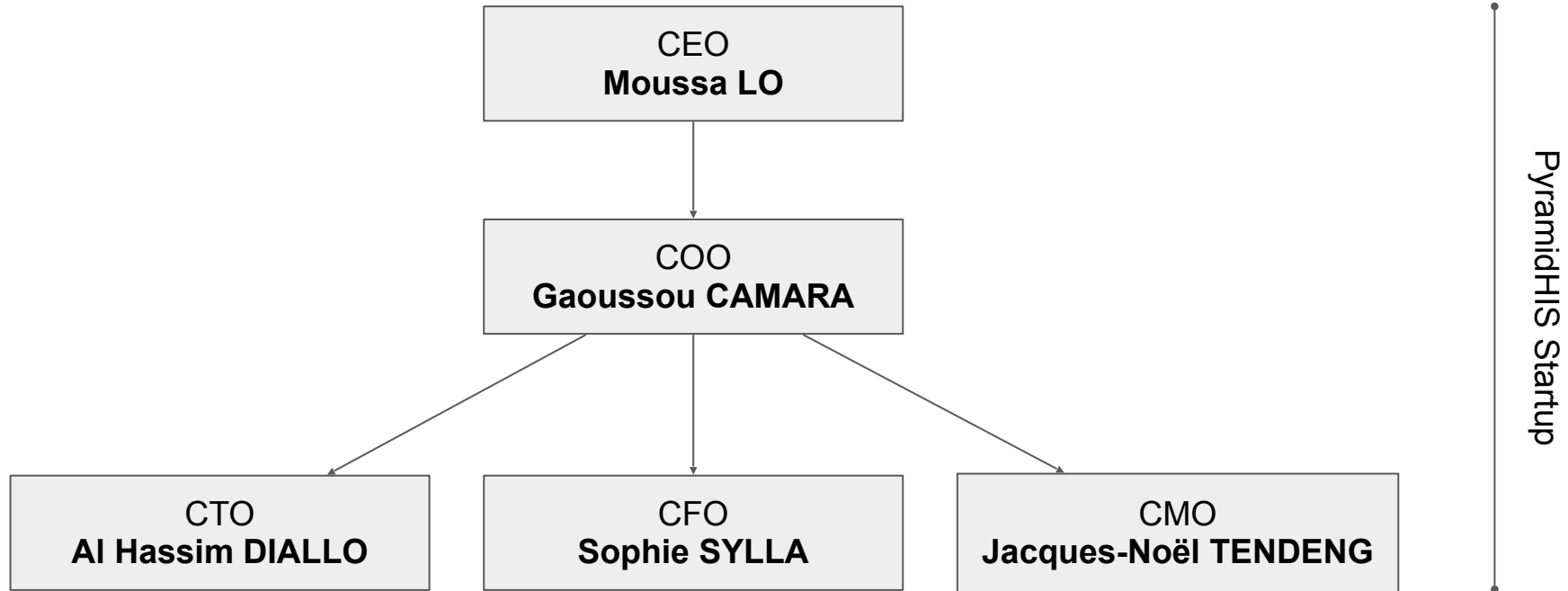
Prof. Ibrahima DIAGNE



Prof. Gaoussou Camara

SIMENS project becomes PyramidHIS startup

Pyramidal Health Information Systems



CEO: Chief Executive Officer
COO: Chief Operating Officer
CTO: Chief Technical Officer
CFO: Chief Financial Officer
CMO: Chief Marketing Officer

PyramidHIS+



References

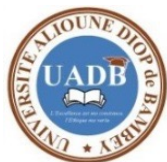
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