

Field survey report Drepacare Project

Global South eHealth Observatory
Fondation Pierre Fabre

A free personalised mobile app for information, prevention and follow-up, for sickle cell anaemia sufferers, their relatives, and health professionals in Africa and France



Mr Amaury Bertaud, Pierre Fabre Foundation

April 2019, Mali

Contents

- I. FOREWORD..... 1
- II. CONTEXT..... 2
 - A. Sickle cell anaemia 2
 - B. Mali..... 2
- III. ORIGINS OF THE PROJECT 3
 - A. Origins of the project..... 3
 - B. The team..... 3
 - C. Aims 3
- IV. HOW IS A MULTI-NATIONAL APP ORGANISED? 4
 - A. Teams of ambassadors for each country 4
 - B. Partners throughout the world..... 4
 - C. Tools for evaluating a tool 5
 - D. A scientific committee composed of volunteer nurses, doctors and researchers 5
- V. NEW, INNOVATIVE FUNCTIONS 6
 - A. Introduction to the functions..... 6
 - B. The most popular functions..... 7
- VII. WHAT IS THE ECONOMIC MODEL OF A FREE APP? 8
 - A. Remarks 8
 - B. Drepa Home Care: Telemedicine and home hospital treatment 8
- VIII. WHAT IMPACT DOES THIS HAVE ON PATIENTS? 9
 - A. Impact on patients..... 9
 - B. Discussions with DrepaCare ambassadors in Mali 9
 - C. Survey amongst users in Mali 10
- IX. AMBITIOUS PERSPECTIVES..... 13
 - A. Having a fully functional app..... 13
 - B. Add new functions 13
 - C. Developing partnerships..... 13
 - D. Creating a user database 13
 - E. Implementation of telemedicine 13
- X. CONCLUSION: A PROMISING NEW PROJECT..... 14
- XI. BIBLIOGRAPHY 15

I. FOREWORD

This survey was carried out in Bamako through:

- Meetings with users: patients, doctors and technicians using the app in the Centre for Sickle Cell Disease Research and Control [Centre de Recherche et de Lutte contre la Drépanocytose].
- Meetings and discussions with ambassadors of DrepaCare in Mali.
- An interview with the DrepaCare team, based in France.

Thanks to everyone for sharing their experience of DrepaCare and for their honesty.

II. CONTEXT

A. Sickle cell anaemia

Sickle cell anaemia is the commonest genetic disease in the world. A disease that affects levels of haemoglobin (used to transport oxygen around the body), its symptoms include anaemia, sensitivity to infection, episodes of extreme pain caused by poor blood circulation and lack of oxygenation of tissue (especially bones), and vaso-occlusive crises which cause major complications such as cerebrovascular accidents, acute thoracic syndrome and osteonecrosis.

It is believed that about 300,000 children are born with the condition every year, 2/3 of them in Sub-Saharan Africa [1]. Without treatment, the mortality rate in children with sickle cell anaemia is over 50% [2]. The number of sickle cell anaemia patients is increasing in both low-income and high-income countries [3]. Nigeria, the Democratic Republic of Congo (DRC) and India account for 57% of births of children with sickle cell anaemia [4].

The episodes of pain, and complications of the disease, require frequent admission to hospital and suitable treatment. However, the treatment is not always possible because of absence of medical structures, trained health personnel and innovative patient-monitoring tools. In addition, there are few specialists and millions of patients. This situation is made worse by the heavy workload of doctors specialising in sickle cell anaemia, remote locations and availability of health professionals. In addition, the health professionals, between two consultations, often do not have access to histories of attacks or admissions to other hospitals and health centres, details of complications and other information useful for monitoring sickle cell anaemia patients.

B. Mali

In Mali, sickle cell anaemia affects 5,000 - 6,000 newborn babies every year, that is, almost 12% of the population. The disease is treated at the Bamako Centre for Sickle Cell Disease Research and Control (CRLD). Almost 10,000 patients are treated in this specialist centre.

However, despite the progress of digital devices and the arrival of e-health, there are no e-health tools to support sickle cell anaemia patients in dealing with their disease on a daily basis.

III. ORIGINS OF THE PROJECT

A. Origins of the project

The DrepaCare project came about following a friendship struck up between three Public Health Master's Degree students Laetitia, Maryem and Anouchka, at the University of Paris 13. Awarded a "Master 2" because of their student-entrepreneur status, they substituted their six months of training with a project on sickle cell anaemia.

Their wish was to innovate to help sickle cell anaemia patients. It was their personal stories that led them to enter the campaign. Laetitia suffers from sickle cell anaemia and Anouchka lost two family members to the same disease. The mission was officially launched in January 2017.

In April 2019, over 2,700 people were using DrepaCare.

B. The team



- Anouchka Kponou, prevention manager and overseer of the African teams, is a biotechnology engineer specialising in nutrition, and holds a Public Health Master's Degree specialising in human nutrition.
- Laetitia Defoi has been a State Registered Nurse since 2014, and holds a Master 2 in Public Health specialising in human nutrition. She is a sickle cell anaemia sufferer. The difficulties she has lived through, and her personal experience as an expert patient, are a great asset. She is the manager of the communications and public relations centre.
- Meryem Ait Zerbane holds a degree in pharmacy and also has a "Master" in public health specialising in human nutrition. She is responsible for the finance centre.

C. Aims

DrepaCare is an association that fights for an improvement in the life quality of sickle cell anaemia sufferers. Its aim is to provide information, work towards prevention, support and help sickle cell anaemia sufferers through the creation of e-health tools, support groups, information videos and testimonies.

The first mobile app for providing free personalised prevention, information and monitoring, aimed at sickle cell anaemia sufferers, relatives and health professionals, appeared in France and Africa in 2018.

IV. HOW IS A MULTI-NATIONAL APP ORGANISED?

A. Teams of ambassadors for each country

The African DrepaCare teams work in the same way in each country. Teams of volunteers are coordinated by the Africa teams manager, Anouchka Kponou.

The team in Mali consists of a male and female ambassador and a member of the scientific committee. The ambassadors represent the DrepaCare project at every event in the country.

The teams' manager supervises and coordinates all the activities. Every year, she compiles a specific timetable for each country, working together with the representatives. In Mali, it is centred mostly on the following axes:

- Searching for partnerships with associations and public and private organisations.
- Familiarising people with the DrepaCare project and the mobile app.
- Presenting and explaining the tool to future users.
- Organising prevention and information sessions as well as support groups.
- Getting comments from users, including difficulties encountered, technical problems, expectations.
- Working together to improve the DrepaCare project solutions with sickle cell anaemia sufferers, their relatives, and health professionals.
- Sharing all the DrepaCare publications and questionnaires.

Representatives are supported in their activities by volunteers recruited as and when required. A daily, weekly or monthly report is submitted to the team manager so that the efficiency of the actions and the timetable can be assessed.

Communication between teams is via collaborative working tools, including WhatsApp and G-Drive. There is a WhatsApp working group for all ambassadors, and one dedicated to each country.

B. Partners throughout the world

The DrepaCare project's international partners are public organisations, foundations and associations.

Public organisations:

- Ile de France Regional Authority [La région Ile de France]
- Rare red-cell diseases group [La Filière des maladies rares du globule rouge]
- Seine Saint Denis Departmental Authority [Le département de la Seine Saint Denis]
- Aids Information and Prevention Regional Centre [Le CRIPS]
- French Blood Society of Île de France [EFSEtablissement Français du Sang Île de France]

Foundations:

- The SAP Foundation

France Associations:

- Senegalese Association for Combating Sickle Cell Anaemia (Senegal)
- [Association Sénégalaise de lutte contre la drépanocytose - ASD]
- All for Life Congo (RDC)
- DREPAZEROCYTOSE (Gabon)
- NGO The Future of Africa (Benin) [ONG avenir d'Afrique]
- Association Dorys (France)

- ASAD (Martinique)
- The Research Team for Action for Sustainable Development [Equipe de recherche-Actions pour le Développement Durable - ERADD] (Mali)

C. Tools for evaluating a tool

To assess the efficiency of the tool amongst the community of DrepaCare users:

- Satisfaction surveys are circulated by e-mail and social networks in every country.
- User comment videos are produced.
- Support groups designed to find out about users' needs and expectations have been organised online or in actual sessions.

D. A scientific committee composed of volunteer nurses, doctors and researchers

The role of the scientific committee is as follows:

- To evaluate the tool.
- To prescribe the tool.
- To send details of users' needs.
- To provide scientific information and take part in videos that provide information and cultivate awareness.
- To help spread the tool amongst their colleagues.

V. NEW, INNOVATIVE FUNCTIONS



A. Introduction to the functions

The DrepaCare app brings together daily functions that are useful to sickle cell anaemia sufferers wherever they may be. They are organised into three groups:

- Personalised monitoring:

"*Pain*": the sickle cell anaemia sufferer selects the location and threshold of his/her pain. The data recorded will generate histograms which can then be downloaded and shown to the specialist doctor either by e-mail or at an appointment.

"*Hospital History*": This is the history of all visits to or stays in hospital as recorded personally by the patient. It also generates a downloadable histogram, which can be e-mailed to the doctor.

"*Alarm*": In the event of an attack, the user can automatically send alert messages to previously input numbers and can thus be helped in good time.

- Prevention:

"*Hydration*": This function helps the patient to reach his or her daily targets. To do this, the patient chooses the amount of water to be drunk and the reminder times. He/she will then be notified according to the choices. Good hydration levels make the blood more fluid and limit vaso-occlusive crises in sickle cell anaemia sufferers.



"*Medication*": This allows the patient to note down all treatments and associated dosages. The patient will then receive adequate notification in order to increase treatment observations levels in patients.

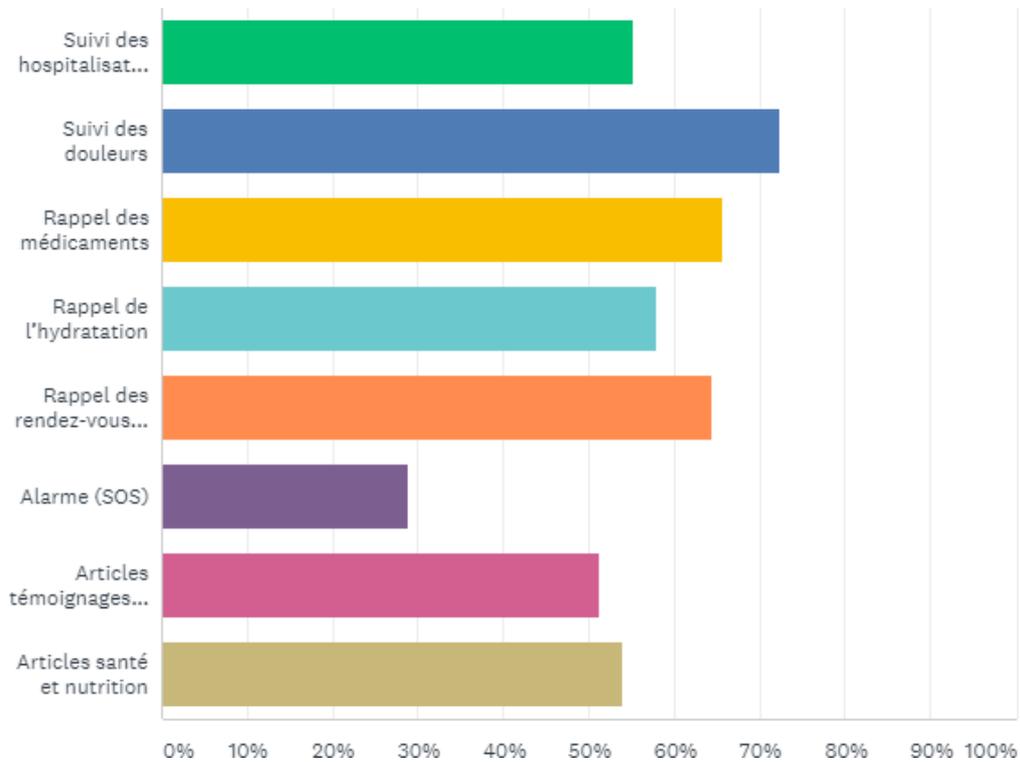
"*Genotype*": This function allows partners, couples and parents to determine the risk of passing the disease on to their children.

- Information:

"*Health and Nutrition*": This is a collection of informative and preventive articles which touch on specific themes relating to nutrition and sickle cell anaemia.

B. The most popular functions

According to a survey conducted in March 2019 and covering 76 DrepaCare users across the world, the most commonly used functions are:



From top to bottom: "hospital history", "pain", "medication", medical appointment alarm", "alarm (SOS)", "testimonies", "health and nutrition publications"

VII. WHAT IS THE ECONOMIC MODEL OF A FREE APP?

A. Remarks

In France, home care for sickle cell anaemia patients is paid for completely by social security.

According to a market study, the DrepaCare teams have arrived at a turnover of €434,261 per year for the treatment of 100 sickle cell anaemia patients.

B. Drepa Home Care: Telemedicine and home hospital treatment

The economic model of DrepaCare is based on home hospital treatment and telemedicine. The aim is to introduce these systems in France during 2020 and in Africa during 2021.

DrepaCare would like to introduce its clients to the care agency and receive a percentage. DrepaCare is in touch with a home hospital treatment agency, Sky Medical, for a home care partnership. The agency provides patient care while DrepaCare maintains the link between them and patients and prescribers. They thus ensure that a treatment protocol is created.

DrepaCare hopes that the profits from these operations will produce sufficient resources to duplicate it in the seven other African countries in which DrepaCare is currently deployed.

VIII. WHAT IMPACT DOES THIS HAVE ON PATIENTS?

A. Impact on patients

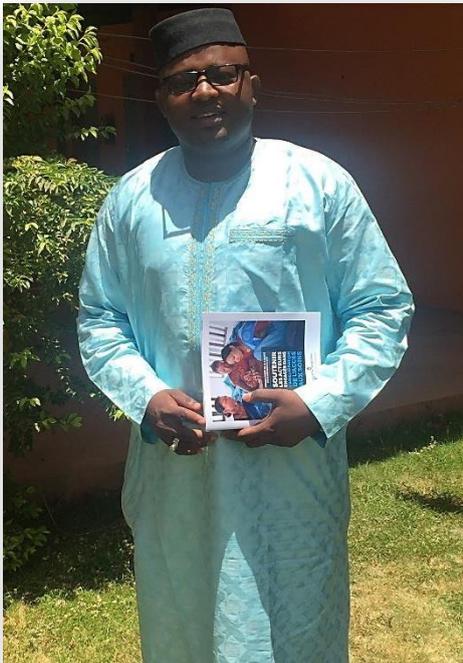
According to a survey conducted in April 2018, with a sample of user patients in France and Africa:

"50% no longer forget their treatment"

"71% have access to better information"

"82% have good or better levels of hydration".

B. Discussions with DrepaCare ambassadors in Mali



Dr Abdoul Kadri Issoufi is a pharmacist and head of the stock management division of Pharmacie Populaire in Mali. A former health worker for the Centre for Sickle Cell Disease Research and Control in Bamako, he has recently been appointed as a DrepaCare ambassador in Mali.

"This is a chance for us to get this app, which will facilitate communication and information. With this app, patients going through an attack will easily be able to contact their doctor.

They will be more familiar with the factors that lead to attacks. For example, stay-at-home mums have to do a lot of hard physical work. The app will help them learn their limits and control their condition better.

The app will also provide for information on genetic risks and help in the choice of marriage partner.

The key to knowing DrepaCare will be first and foremost through the social and video networks. We also wish to introduce methods of communication in Mali, such as sickle cell anaemia awareness days."

C. Survey amongst users in Mali



Ibrahima Camara is Malian, and a teacher of mathematics in Ségou. In December 2010, he discovered that he has SC sickle cell anaemia. He found out about the DrepaCare app in 2018 following advice from a colleague who saw a health programme on Canal+.

"The app is very useful, especially with its timetable function which helps with planning meetings"



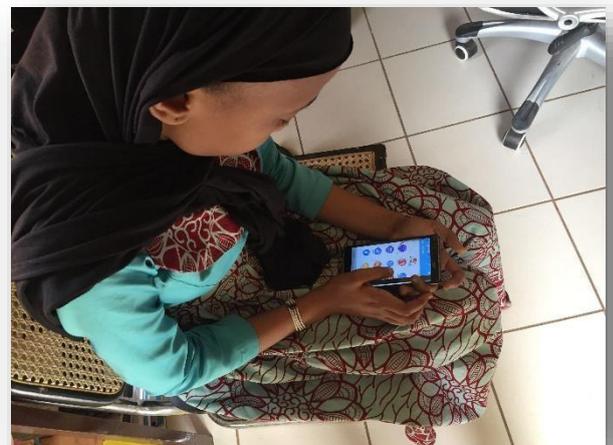
He regrets that there is no user's guide to help him with using the device and better understanding the other functions. Ségou is about 3 hours by road from Bamako, and he would therefore particularly welcome a function that provides him with a direct link to the treating doctor in order to talk with him directly via the DrepaCare platform or via Visio.



Aissata Hamadou Dicko is a 19-year-old Malian girl. She was diagnosed with SS sickle cell anaemia at the age of 6 months. She has regularly visited the Centre for Sickle Cell Disease Research and Control since 2010. She discovered DrepaCare in 2018 on Facebook, thanks to the "all-inclusive sickle cell anaemia" group.

"Mostly I use the hydration functions, which remind me to drink plenty. I also use the pain function whenever I have an attack."

She also read all the testimonies of the sickle cell anaemia patients. She would like to contact the doctor directly via the app but has no idea how to do that.





Tidiane Sow is Malian and lives in Sikasso, about 6 hours by road from Bamako. He discovered that he had SS sickle cell anaemia at the age of 6, after a long-drawn-out investigation by his parents. It was in 2018, while browsing through Google Play Store, that he discovered the DrepaCare app.

"What I find really useful in this app is the pain monitoring function and the testimonies."

He has not yet used the app as an interface for communicating with doctors.



Mamadou Diallo is Guinean, 25 years old, and a nurse. He was diagnosed with SS sickle cell anaemia at the age of 3 years. Mamadou lives in Guinea but has to travel to Bamako for his treatment. He found out about DrepaCare when watching "Bonjour Santé" on Canal+ in 2018.

"The possibility of remote monitoring is the function that I appreciate the most. I also use the appointment reminder function and now record my pain levels regularly."

However, he has had problems with registering and accessing his account. He has had to recreate his profile several times.



Above: Dr Kene, of the Centre for Sickle Cell Disease Research and Control, and Mamadou Diallo adjusting the settings for the "alarm" function in the DrepaCare app.



Alassane Dembélé is a Clinical Research Assistant at the Centre for Sickle Cell Disease Research and Control. He is responsible for the centre's sickle cell anaemia patient database. He discovered the DrepaCare app in 2019.

"The hospital history function shows how many times each patient has visited the hospital. Patients need to be made aware of the importance of using this app."

He also appreciates the pain function, which can be used by doctors during appointments.

"The hydration function is an excellent initiative, and would be even better if the quantity of water to be drunk, according to the patient's characteristics, was shown"

He initially had a few difficulties with connecting. He would welcome more information on how to use the alarm function.

IX. AMBITIOUS PERSPECTIVES

A. Having a fully functional app

The principal areas for improvement identified are:

- Problems during installation
- Bugs
- Use of an app not suited for people with reading difficulties

B. Add new functions

The following functions will soon be developed:

- On-line consultation with a doctor.
- Geolocation of alarm messages and option of choosing a voice message or a text message.
- Availability of prescriptions on the app.
- Summary and history of vaccinations.
- History of treatments, stays in hospital, consultations, pain episodes and examination results.
- Home hospital treatment for minor attacks.
- Adaptation of the "pain threshold" function for people with reading difficulties.

C. Developing partnerships

This aspect is of first importance for:

- Accessing more reference points for combating sickle cell anaemia in each country, in order to benefit from more prescribers.
- Obtaining new financial support for developing a new version of the app.
- Having the health ministries validate the tool as a scientific device.

Partnership currently being developed:

- Association for Combating Sickle Cell Anaemia in progress (Benin).
- National Sickle Cell Anaemia Sufferers' Association of Cameroon (in progress).
- DrepaStop Niger (being developed).
- Malian Association for Combating Sickle Cell Anaemia (a recent development in Mali).

D. Creating a user database

This database will consist of all users of the app. The "contact my carers" function will link carers and patients.

E. Implementation of telemedicine

On the basis of information registered by their patients, doctors can prescribe home hospital treatment for minor attacks. Patients can also arrange appointments with their doctors, and request home hospital treatment which will be given and monitored by freelance health workers.

To achieve that, a real field study has been launched in Africa. The aim is to reduce hospital treatment costs, reduce the number of "medical deserts", and offer patients home hospital treatment in Africa.

X. CONCLUSION: A PROMISING NEW PROJECT

DrepaCare is an innovative initiative which has responded to a real need in patients suffering from a serious genetic diseases; however, there is room for improvement.

It offers very new and very real ideas such as the hydration, pain and hospital treatment function. It counters the very real problem of information and awareness about sickle cell anaemia. It reaches a section of the public that really needs support and accompaniment. The app is hugely appreciated by users, patients, doctors and health workers alike. DrepaCare is not just an app; it is a network of sickle cell anaemia patients centred on support groups, communication platforms and testimonies. The real strong point of DrepaCare is the awareness aspect.

However, the app still needs to develop technically and in terms of guidance. Some functions are still not working fully, such as the alarm. The app is not available on all supports. It only works on Android and does not work properly on tablets.

DrepaCare is used in France but is not yet fully incorporated into the African network. A number of teams of ambassadors have been identified in seven countries, to accompany the extension process. In addition, some users are disappointed that there is no user's guide to accompany the use of the various functions.

DrepaCare is an ambitious project with great potential, such as the inclusion of new functions and extension of its use into new countries. These areas of potential rely on a worldwide network of partners that is increasing in size.

XI. BIBLIOGRAPHY

- [1] Modell B, Darlison M, M Global epidemiology of haemoglobin disorder and derived service indicators. Bull WHO, 2008; 86(6):480.
- [2] Grosse SD, Am J Prev Med, 2014.
- [3] Piel et al, Plos Med, 2013; Weatherall DJ, Blood, 2010.
- [4] Piel at al, Plos Med, 2013.