

Tackling disease education gaps of People with Haemophilia in Sub-Saharan Africa through the design and implementation of an original Artificial Intelligence (AI) conversational agent.

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Digital Innovators
14.02.24













# How to improve disease knowledge of People with haemophilia in Sub-Saharan Africa and improve their QoL?

**Artificial Inteligence** 



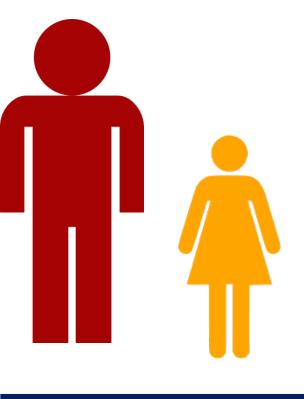


Challenges & Stakes Sub-Saharan Africa

Conception, Design et development and implementation of an Al chatbot

**Outcomes** 

**Lessons learnt** 



## Haemophilia: A Rare Congenital Blood Disease

Deficiencies in FVII and FIX
Coagulation cascade
Haemorrhages- Pain

1 in 10,000

818,928

256,840

Estimated number of People with Haemophilia

Haemophilia A & B and unknow

## Challenges and Opportunities of Haemophilia care in SSA





## Education is the cornerstone of haemophilia"

The importance of early diagnosis and care cannot be overstated with haemophilia, and access to information is the first step towards this goal

### Shift in paradigm and new area of opportunities to support population's health



- Advent of Generative Al
- Large language model (LLM): a deep learning algorithm performing a variety of natural language processing
- •Applications: patient disease education, symptoms management, healthcare delivery, health behaviours

Al Chatbot: 'Exploit natural language technologies to engage users in information-seeking and task-oriented dialogue with the ability to mimic human behaviours"



Methodological approach



## First case study Senegal



**CLINICAL/EPIDEMIO** 

304 PAH (258 HA,46 HB)

Prev: 1/10 000

**Estimated Population 1800** 

**PWH/ Carriers** 



**Challenges** 

Lack of knowledge



DIGITAL ACCESS AND

**LITERACY** 

80% of adult population has a smartphone

Daily use but rarely for education





## Gaps in knowledge

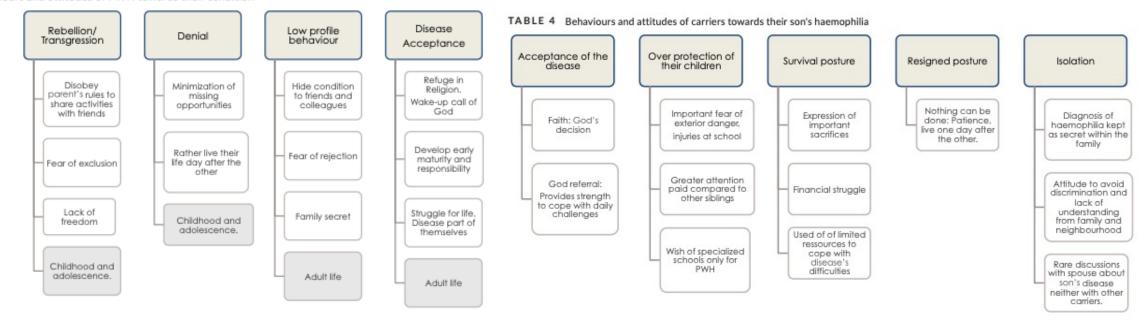
- 23% only could name the severity of disease
- Only 32% could explain with accuracy the Detailed Inheritance pattern of the disease for both populations
- Gaps in disease prevention/ Risks numbers

## Coping Strategies rooted in the cultural and social context

**PWH** 

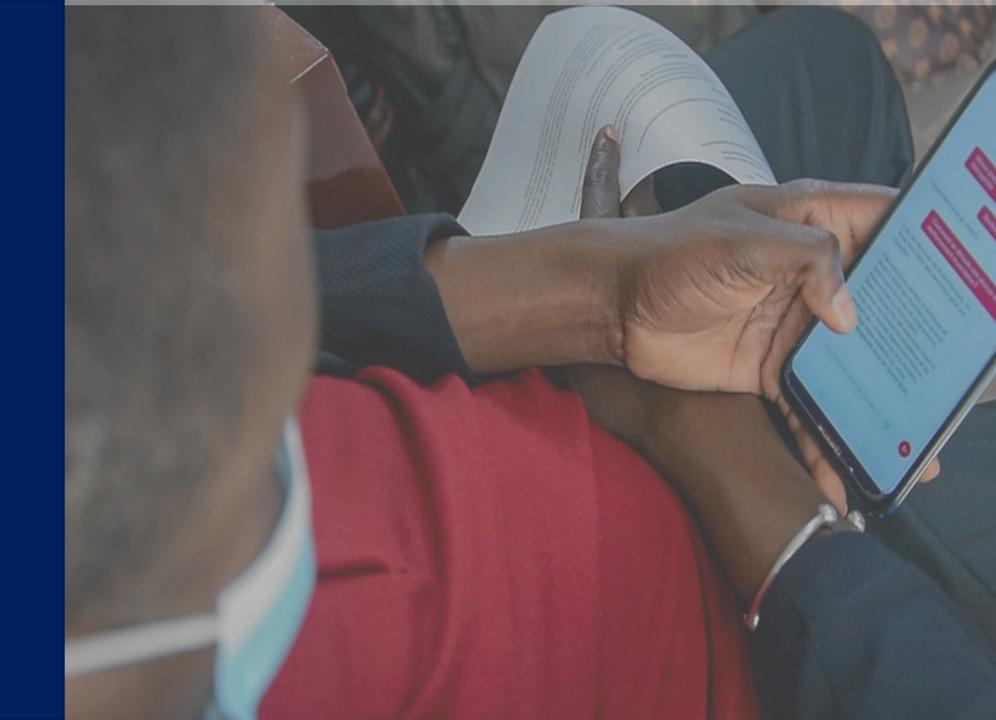
Carriers

TABLE 3 Behaviours and attitudes of PWH towards their condition



Saytù Hemophilie:

Original AI chatbot



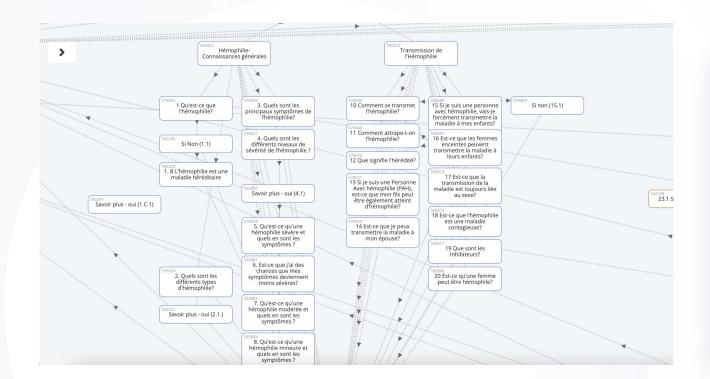
## **Key milestones**

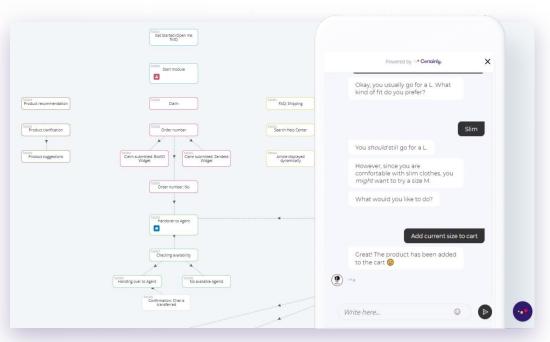


Baamtu, Certainly, Task Force, Equipe multidisciplinaire



#### -CERTAINLY BUILDER





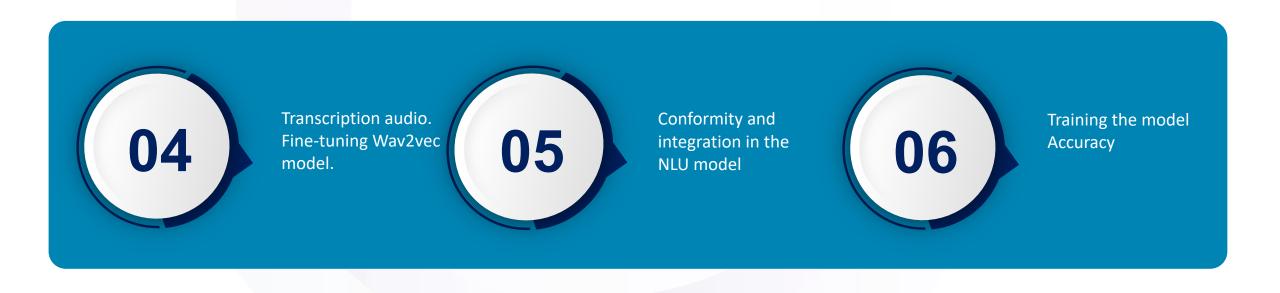


INCLUSIVE, MULTI-DISCIPLINARY AND INTERNATIONAL APPROACH

## Unique Framework to develop a Wolof Chatbot

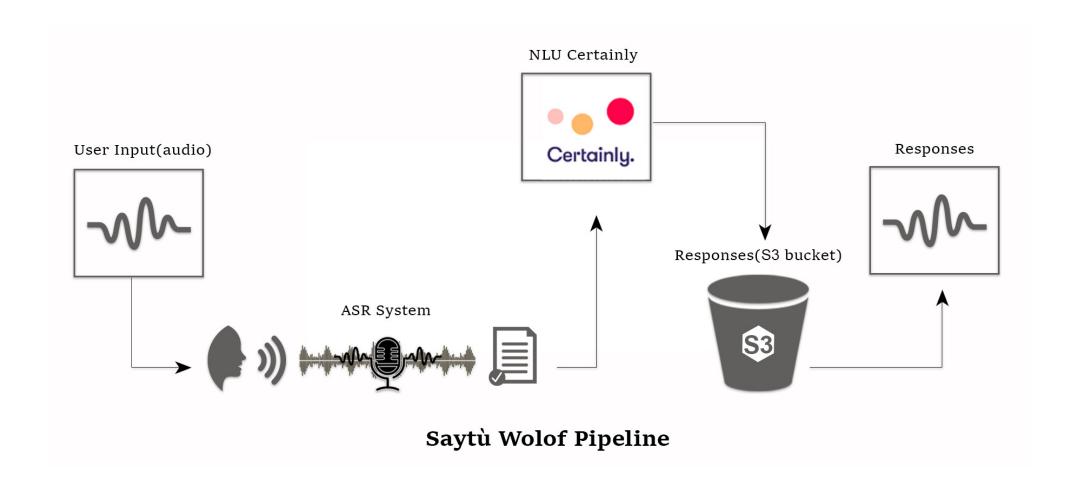


## Unique Framework to develop a Wolof Chatbot









"Saytù Hémophilie": Taking care ...



#### Al educational chatbot

## To support symptoms management and risks prevention of haemophilia











Data protection

Interface user-friendly based on local needs : Wolof, French

Access to care

Disease management

Education accessible at any time.









Ask all your questions about Haemophilia!















Terms of Service and data safety

Choose your country



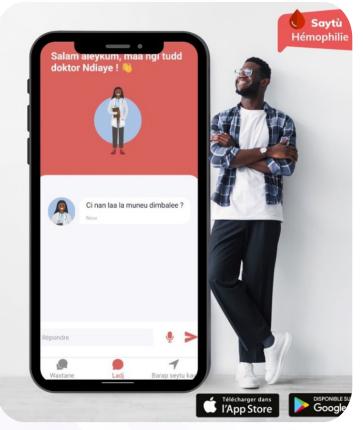


## Collaborative approach focused on PWH, carriers and family members' needs







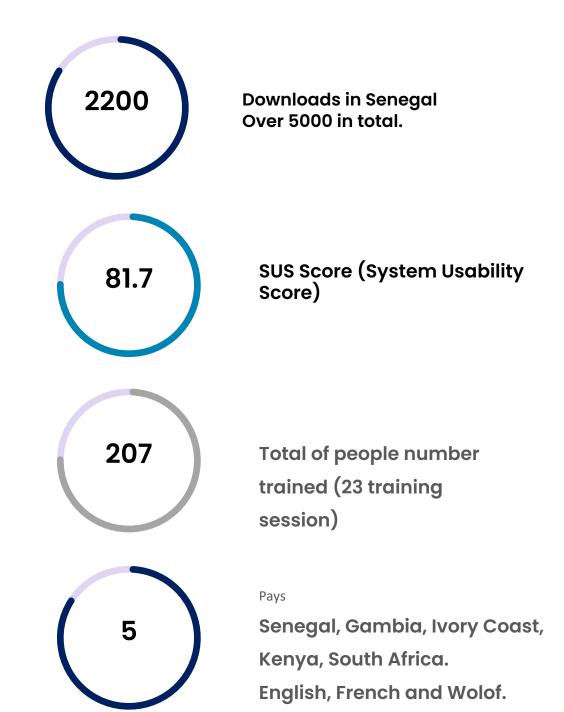








## **Key numbers**



## Results: SUS

#### The System Usability Scale (SUS) questionnaire

- Usability with 10 items questionnaire
- Total Population. N=57
- PWH. N=32
- Obligate carriers. N=17
- Other relatives. N=8
- Data collected with online form via focus groups



- Average SUS score: 81.7
  indicating a very usable
  system.
- Average SUS score for women carriers lower (82.3) vs men (85.6)
- No significant difference between regions.
- Mean scores over average (4)

## **SUS Score**

**TABLE 3** Results of the SUS questionnaire per question.

Questions	Mean scores <sup>a</sup>	Std. deviation (SD)
1. I think that I will use this system frequently	3.2	1.2
2. I found the system unnecessarily complex	3.2	1.2
3. I thought the system was easy to use	3.3	1.3
4. I think that I would need the support of a technical person to be able to use this system	3.1	1.4
5. I found the various functions in this system were well integrated	3.0	1.3
6. I thought there was too much inconsistency	3.5	.9
7. I would imagine that most people would learn to use this system very quickly	3.2	1.0
8. I found the system very cumbersome to use	3.5	1.0
9. I felt very confident using this system	3.3	1.3
10. I needed to learn a lot of things before I could get going with this system	3.4	1.2

<sup>&</sup>lt;sup>a</sup>Converted scores as described in 2.3 Measures (Material & Methods).



## **Publications**

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ORIGINAL ARTICLE



#### Unravelling the knowledge, beliefs, behaviours and concerns of Persons with Haemophilia and their carriers in Senegal

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#### Abstract

Introduction: In many sub-Saharan countries, haemophilia exists in an environment of poor knowledge and poor access to treatment. To improve the quality of life of Persons with Haemophilia (PWH), understanding their unmet needs and the sociocultural realities is essential

Aim: This study aims to explore disease knowledge, beliefs, behaviours and concerns of PWH and carriers as a way to find adapted solutions to address the unmet needs. Methods: Based on an interview guide, we performed a qualitative study with indepth interviews of 26 PWH and 14 carriers.

Results: Eighty per cent of adult PWH were able to name the severity of haemophilia, but only 32% could describe with accuracy the mode of transmission of haemophilia. Only 23% of carriers were able to inform the severity of the disease. All carriers and adult PWH acknowledged at least one visit to a traditional healer. Acceptance of the disease through religion is the dominant coping strategy observed. High costs of treatment, fear of social rejection, difficulty of management of pain and bleeding at home were the main concerns.

Conclusions: Results demonstrate important gaps in knowledge, especially within the carrier population, mothers in Africa playing particularly an important role in the survival and empowerment of PWH. Findings also indicate the important weight of cultural determinants in disease management and behaviours of PWH and thus their important role in the development of educational materials taking into account these determinants.

#### KEYWORDS

carriers, developing countries, haemophilia, qualitative study, Senegal

#### 1 | INTRODUCTION

Haemophilia is a genetic condition affecting 1 out of 10 000 people around the world. The lack of diagnosis is one of the main health challenges for PWH, as only 25% of the global haemophilia patient population have been identified. In Senegal, for example, a study

reports a prevalence of 2.3/100 000 male births, accounting for only 11.6% of the expected figure in the country.2 Very few studies have focused on haemophilia in sub-Saharan Africa, the epidemiological data being mainly obtained from Senegal,2 South Africa,3 Zimbabwe, 4 Nigeria, 5 Cameroon 6 and Ivory Coast. 7.8 These studies highlight worrying trends as reported by Diop et al<sup>2</sup> who emphasize

Haemophilia. 2020;00:1-7. wileyonlinelibrary.com/journal/hae © 2020 John Wiley & Sons Ltd 1 Received: 28 March 2023 Revised: 31 May 2023 Accepted: 1 June 2023

DOI: 10.1111/hae.14815

#### ORIGINAL ARTICLE



Check for updates

#### Design, development and usability of an educational AI chatbot for People with Haemophilia in Senegal

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#### **Funding information**

Novo Nordisk Haemophilia Foundation (NNHF)

#### Abstract

Introduction: Gaps in the disease knowledge of People with Haemophilia (PWH) in Senegal are important barriers to the effective management of haemophilia. Digital health systems for chronic diseases in low- and middle-income countries are suggested to improve education and self-management. Artificial Intelligence (AI) chatbots could improve knowledge and support symptom monitoring.

Aim: Development process and usability testing of an AI chatbot to assess its future

Methods: An AI chatbot prototype was designed based on a multilingual conversational engine using Natural Language Processing. A sequential mixed method was used including a co-creative design process with a task force made up of PWH and medical doctors. Usability was assessed through the System Usability Scale (SUS) questionnaire.

Results: An AI chatbot in French and Wolof, named Saytù Hemophilie, was developed for Android and Apple iOS devices. It was assessed as a very usable system with a SUS score of 81.7, above average. 42% would prefer to use the Wolof version even if they were very satisfied with the French version. The level of Wolof in the app did not always correspond to users' levels. Participants praised its accessibility and reliability, and its ability to enhance self-learning.

Conclusions: Findings suggest that a culturally adapted digital conversational agent is likely to be used by PWH in Senegal and their families to improve education and self-management of haemophilia. Relevance and impact are foreseen for other communities in Africa and beyond.

artificial intelligence, chatbot, digital health, education, haemophilia, Senegal, usability

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#### **WOLOF SAYTÚ HEMOPHILIE**

Intentions des questions	Réponses
lan mooy feebaru wayum deret ?	4
Ndax dinaa mun a dawal welo ?	1
yan xeetu jafe-jafe wayum deret ñoo am ?	1
Naka laay waññee metit gi ci cër yi ?	
lan mooy feebaru wayum deret gu tar ak lan moo	
Ban barabu fajukaay moo ma gën a jege ?	

#### Temps de réponse en secondes min, moyen et max par question

Questions ▼	Temps de réponse min	Temps de réponse moy	Temps de réponse max
ñaata xeetu wayum deret ñoo am	6,64	6,64	6,64
ñaata keetu ema fili moo am	2,57	2,57	2,57
ñaata feetu wayum deret ñoo am	5,75	5,75	5,75
ñaa taxyëtu témakiñ	4,22	4,22	4,22
ñaa tax xeetu wayum deret ñoo am	6,04	6,04	6,04
ñaa ta xeetuhémo fi ni ñoo am	3,69	3,69	3,69
yaram bic yaram di cëram	6,66	6,66	6,66

igo(ullet)-

WOLOF





	Citations
Accessibilité	18
Stimule l'apprentissage des connaissances	15
Facilité d'utilisation	3
Fiable	7
Rassurant	6
Fluide	3

'Simple'

'C'est très fiable'

'Facile à utiliser'

'Le wolof correspond tellement à nos besoins'

'C'est comme avoir un docteur en poche!"

'C'est le bonneur des hémophiles car cela vient à temps nommé!

'C'est comme si c'était mon meilleur ami à qui je peux parler tout le temps"

"Le wolof est trop sophistiqué, trop pur"

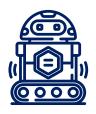
"On dirait qu'il ne comprend pas mon wolof"

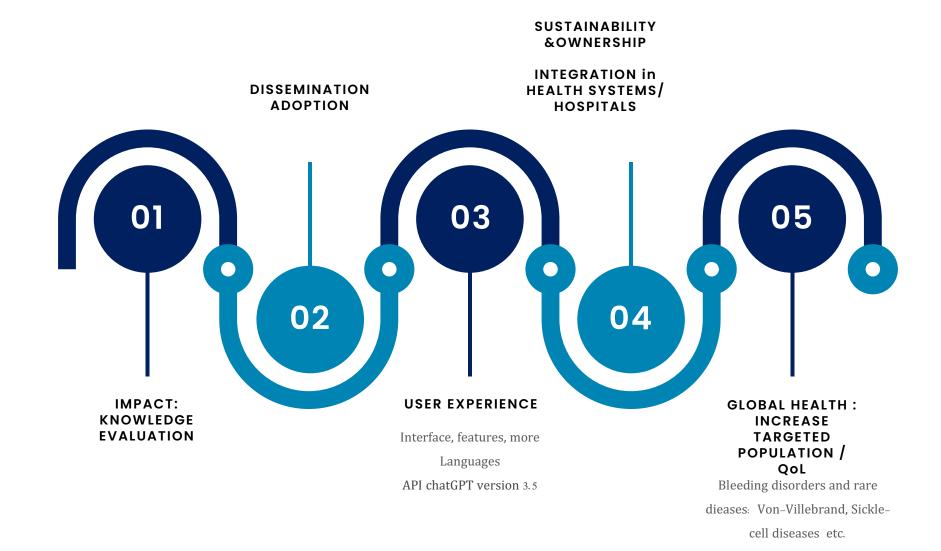
'Saimerais bien être connecté même quand je n'ai pas accès à internet

•









### Certainly x ChatGPT:

Powered by ... Certainly.



Welcome lam Dr Njie and I am available to answer all your questions about haemophilia

What can I help you with?

I need information on the treatment?

Treatment for hemophilia includes replacement therapy with clotting factors and non-replacement therapy. Replacement therapy involves injecting the missing clotting factor into the blood. Non-replacement therapy uses a drug called Emicizumab (HEMLIBRA) to increase blood clotting potential. Prompt treatment of bleeding is important to reduce pain and complications. It is recommended to consult a doctor for more information on treatment options.

Thank you!

You're welcome! If you have any more questions, feel free to ask.

How can I find treatment centers in Nairobi?

There are several treatment centers in Nairobi, including Kenyatta National Hospital (Haemophilia Comprehensive Care Clinic) and Moi Teaching and

Powered by ... Certainly.



How can I find treatment centers in Nairobi?

There are several treatment centers in Nairobi, including Kenyatta National Hospital (Haemophilia Comprehensive Care Clinic) and Moi Teaching and Referral Hospital.

Thank you!

You're welcome! If you need any more information or assistance, feel free to ask.

I need a medical doctor

Certainly, in case of emergency, please call the KNH CLINIC LINE at +254 734 022 663. They will guide you and recommend the nearest health center. You can also contact Dr. Kithinji Victoria at +254716609643 for further assistance.

Amazing!

Certainly, I'm glad you think so! If you have any more questions or need further assistance, feel free to ask.



Write here...

Do carriers can bleed?

Certainly, carriers of hemophilia can experience abnormal bleeding. Some common manifestations among symptomatic carriers include heavy menstrual bleeding, pain during menstrual bleeding, postpartum hemorrhage, abnormal bleeding following trauma or medical interventions, and abnormal bleeding during the pre-menopause transition.

Thank you so much!

Certainly, you're welcome! If you have any more questions or need further assistance, feel free to ask.

This is helpful

Certainly, I'm glad I could help! If you have any more questions or need further assistance, feel free to ask.

Can my son be circumsized?

Certainly, the decision to circumcise your son should be made in consultation with a hematology team at a resourced hematology treatment center. Factors such as individual patient factors, venous access, wound care, and expertise and resources at the hospital Certainly, in case of emergency, please call the KNH CLINIC LINE at +254 734 022 663. They will guide you and recommend the nearest health center. You can also contact Dr. Kithinji Victoria at +254716609643 for further assistance.

Amazing!

Certainly, I'm glad you think so! If you have any more questions or need further assistance, feel free to ask.

What are the guidelines on education?

I am only a demo of the LLM feature, and so far have only been trained in a few specific topics regarding haemophilia and its treatment. I apologize, but I don't have information on the guidelines for education.

Lunderstand

Certainly, I apologize for not being able to provide information on the guidelines for education. Is there anything else I can assist you with?

## Conclusions

Lessons learnt



#### Time is of essence:



Collaboration
Patient-led approach
Ethics



Field approach: Socio-cultural determinants Local ownership & Adoption

## Get in touch



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