Sexual health determinants during the life course and migration of people originated from Haiti and living in French Guiana: a biographical and transdisciplinary study protocol of the Parcours D’Haïti study.

Leslie Alcouffe, Marc Alexandre Tareau, Gabriel Brun Rambaud, Aude Lucarelli, Mathilde Boutrou, Camille Thorey, Greta Cantalupi, Karl Kpossou, Florence Huber, Sébastien Rabier, Dévi Rita Rochemont, Théo Blaise, Estelle Thomas, Guerline Jean, Ruth Pierre Louis, Annette Zephirin, Félix Djossou, Hawa Cissé, William Faurous, Quentin Drouaud, Mayka Mergeay-Fabre, Antoine Adenis, Mathieu Nacher, Nicolas Vignier

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Abstract

French Guiana is a French overseas territory located in the Guiana Shield in South America, exposed to specific social and demographic challenges, notably in terms of migration. Haitians are one of the three main foreign communities in French Guiana, and face specific barriers in accessing healthcare and prevention. They are also one of the key populations for HIV infection. We describe here the protocol of the PARCOURS D’HAÏTIstudy, designed to update knowledge on the health of the Haitian population living in French Guiana, using a transdisciplinary approach to gain a detailed understanding of the determinants of health and the processes underlying HIV contamination. This mixed-methods study was based primarily on a quantitative epidemiological and biographical study of people originated from Haiti aged between 18 and 60 who had been living in French Guiana for more than 3 months. The biographical component was based on the use of a biographical grid providing information on variables year by year since birth. Secondly, a qualitative component included three sub-studies based on semi-directive interviews and focus groups with field professionals and people from Haiti, aimed at gaining a better understanding of the use of traditional and biomedical care, access to care and the mental health of people from Haiti. The study material was co-constructed with local stakeholders and community health workers. Recruitment of this discreet population was based on an original method involving all players in the field and mobilizing a wide range of places frequented by the Haitian community. Recruitment and data collection were then carried out by Haitian Creole-speaking peer investigators (community health mediators).

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French Guiana is a French overseas territory located in the Guiana Shield in South America, exposed to specific social and demographic challenges, notably in terms of migration. Haitians are one of the three main foreign communities in French Guiana, and face specific barriers in accessing healthcare and prevention. They are also one of the key populations for HIV infection. We describe here the protocol of the PARCOURS D'HAÏTIstudy, designed to update knowledge on the health of the Haitian population living in French Guiana, using a transdisciplinary approach to gain a detailed understanding of the determinants of health and the processes underlying HIV contamination. This mixed-methods study was based primarily on a quantitative epidemiological and biographical study of people originated from Haiti aged between 18 and 60 who had been living in French Guiana for more than 3 months. The biographical component was based on the use of a biographical grid providing information on variables year by year since birth. Secondly, a qualitative component included three sub-studies based on semi-directive interviews and focus groups with field professionals and people from Haiti, aimed at gaining a better understanding of the use of traditional and biomedical care, access to care and the mental health of people from Haiti. The study material was co-constructed with local stakeholders and community health workers. Recruitment of this discreet population was based on an original method involving all players in the field and mobilizing a wide range of places frequented by the Haitian community. Recruitment and data collection were then carried out by Haitian Creole-speaking peer investigators (community health mediators).

Keywords :
HIV, HBV, Sexual and Reproductive Health and Rights, Transient and Migrants, Migrants' Health, Socioeconomic factors, Sexual Behavior, Violence, Gender-Based Violence, Health Care Quality, Access and Evaluation, Health Services Accessibility, Cultural Representations, French Guiana, Haiti.

7446 / 10 000 words maximum

Introduction :

French Guiana is a French South American overseas territory in the Guiana shield close to the Amazon with a population of 286,618 inhabitants in 2021 (1). Because of its location and history, this territory is inhabited by people of diverse origins and nationalities (2). As a result, more than 60 languages are spoken in French Guiana, and around 1/3 of today's population was born abroad (1–3). Migration from Haiti represents a major social and demographic challenge in French Guiana (2). According to 2017 census data, 9.3% of the population in French Guiana is originated from Haiti, one of the three main foreign communities along with Brazil and Surinam. It is estimated that one in 10 inhabitants speaks Haitian Creole in daily life (3). Population movements from Haiti, have existed since the country's political turbulence in the 80s, and were reinforced by the earthquake in 2010, the closure of the Dominican border in 2015, the 2018 social crisis in Haiti, and the murder of the Haitian president in 2021. Studies conducted on the sexual health of migrant women in French Guiana in 2021 showed that Haitian women make up the vast majority of the cohorts in health centres set up to welcome migrants, suggesting that migration flows from Haiti continue to be very dynamic (4).

French Guiana is a territory where precariousness is common, with more than half of Guianese inhabitants having a low standard of living, and more than 20% a very low standard of living (5). This reality particularly affects households where the reference person was born abroad: in that case more than three quarters live below the poverty line (5). After arriving in French Guiana, people's living conditions deteriorate, not only in terms of housing, but also socially and administratively: many people arriving and living in French Guiana do not have a residence permit (4).

French Guiana also faces major health challenges. In 2020, life expectancy at birth was still lower than in continental France in a context of dynamic birth rates (6,7). Seven major health determinants have been identified by the Haut conseil de la Santé Publique, including sexual and reproductive health, gender equality, infectious risks, food, nutrition and mental health (8).

French Guiana is the French territory most affected by HIV, with a prevalence >1% in the general population (9). The majority of people living with HIV in French Guiana are of foreign origin (10). Recent studies in French Guiana (one based on the slope of CD4 decline and the other on virus phylogeny) showed that, among the foreign population living with HIV, more than half had been infected in French Guiana (10,11). The link between migration and living conditions in the country of arrival has already been established. The ANRS Parcours 2012-2013 study highlighted the issue of HIV acquisition in the Ile-de-France region and late detection of chronic hepatitis B virus infections among immigrants from sub-Saharan Africa, in relation to their poor living conditions after arriving in France (12,13).

In terms of health and history, Haiti is a country that has been particularly affected by HIV, since the 1970s and throughout the epidemic (14). In 2021, according to the World Bank, 1.8% of the Haitian population was living with HIV (15). The Haitian population in French Guiana is disproportionately affected by HIV infection: according to surveillance data, 46% of the HIV cohort participants under follow-up in the Cayenne hospital out patient department originated from Haiti. Between 2013 and 2018, Haitians represented 36.4% of new HIV infections in French Guiana (16). Diagnoses are often made later than for native-born people: for Haitian people living with HIV (PLHIV), the time between seroconversion and diagnosis was 4.5 years on average (compared with 3.1 years for PLHIV born in France) and was 5 years greater among men than among women (17). The magico-religious importance and impact of stigma has already been explored among the Haitian population in French Guiana (18). Some diseases, notably HIV, have a high level of social stigma, which can have an impact on people's use of prevention and care. A similar observation can be made for hepatitis B. In French Guiana, the prevalence of chronic hepatitis B virus (HBV) infection is estimated at nearly 1.5%, compared with 0.3% in continental France. Once again, Haitians are particularly affected: the presence of HBs antigen concerns 2.5% of Haitian women registered in the French Guiana pregnancy registry (19).

Another study on knowledge, attitudes and practices showed the frequency of risky sexual behaviour that can expose people to HIV among migrants, without however specifying them by country of origin (20). A phylogenetic study conducted in French Guiana showed that people originated from Haiti were less likely to have viruses from large transmission clusters than other immigrants and were more likely to have viruses from small transmission clusters or dyads (11). We thus hypothesize that there are singular conditions leading to a singular epidemiology in this community.

In addition to this local data focusing on sexual health and infectious diseases, international literature highlights several health issues among Haitian migrants worldwide that should be investigated in French Guiana (21,22). Research suggests that their access to cervical cancer prevention and screening may be inadequate. The mental health of those who have experienced adversity may be impaired and specificities of care would exist (23,24). In addition, common health issues could have consequences linked to poorer access to care (25). The interrelationships between traditional medicine, vodou, herbal medicine and modern medicine need to be explored (26).

All these factors therefore seem to point to the particular health, sexual reproductive health and rights needs of the Haitian population, a large and growing part of French Guiana's population. The Haitian population in French Guiana is a key population for public health, not only in terms of improving their health, but also the health of the entire Guianese population.

We hereby describe the Parcours d’Haïti study protocol, conceived to update knowledge on the Haitian population living in French Guiana, using a transdisciplinary approach, in order to gain a detailed understanding of health determinants and underlying processes of HIV or HBV contaminations.

Methods:

Study objectives

From a quantitative perspective, using notably a biographic approach, the main objective of the present study was to evaluate the frequency of sexual behaviour exposing people from Haiti to the risk of HIV contamination after their arrival in French Guiana, and its association with their living conditions. Secondary objectives consisted in describing migration routes, living conditions, access to health insurance coverage and healthcare, contacts with medico-social structures, social support, general state of health, mental health and levels of food insecurity after arrival in French Guiana. With regard to sexual and reproductive health and rights, the objectives were to study the delay in first screening for sexually transmitted infections (STIs), as well as the factors associated with earlier screening; to study the delay in entry into care and retention in care for people living with HIV or HBV, and their determinants; to investigate the use of birth control methods, the frequency of wanted and unwanted pregnancies, as well as the use of abortion. With regard to emotional life, the objectives were to describe the relational and sexual life.

From an exploratory perspective, the objectives were to investigate and describe the social representations of HIV and HBV infections and their impact on the use of prevention and biomedical and traditional care. In addition, representations of the Guyanese healthcare system and its prevention services were explored, as well as an anthropological understanding of representations of the body and illness in relation to the ethnomedicinal conceptions of people of Haitian origin living in French Guiana. Finally, another objective was to explore the obstacles and facilitators to accessing mental health care, to understand the mental health problems encountered and the responses provided to migrants in French Guiana, from the point of view of health professionals, social workers and local non-governmental organizations (NGOs). From a phylogenetic perspective, we aimed at describing the distribution of clades of the Pol gene in the viruses of PLHIV from Haiti.

Hence, the Parcours d'Haïti study is a mixed-methodology study. Firstly, a "quantitative" component, based on an observational, cross-sectional, biographical and epidemiological study, descriptive and analytical by questionnaire and hetero-administered biographical framework. The questionnaires were administered by Haitian Creole-speaking mediators, for the most part from the local community. Secondly a "qualitative" component, based on a socio-anthropological ancillary study using participant observation and semi-structured interviews (itself developed along several dimensions). And thirdly, a phylogenetic analysis of HIV Pol gene sequences based on sequences collected as part of routine care (a resistance genotype analysis is systematically performed before antiretroviral therapy initiation).

Ethics :

The study involved the human person and is covered by the Jardé Law as a category 3 research involving the human person, which provides for the analysis of anonymised personal medical data previously collected during routine care. The sponsor and the person directing and supervising the research undertaken ensured that this research is carried out in accordance with the French Law no. 2012-300 of 5 March 2012 on research involving the human person and the Declaration of Helsinki in its latest version.

The study protocol and related participants documents were reviewed and approved by the Comité de protection des personnes Sud-Est I (October 11th, 2021), together with three substantial modifications along the course of the study carried out between 01/11/2021 and 31/07/2023. Also, an ancillary qualitative study (number 2022-A00927-36) has been reviewed and approved by the Comité de protection des personnes Sud-Est I (May 09th, 2022).

The controller and processor of data recorded during this research was the Centre Hospitalier de Cayenne, in accordance with the French Data Protection Act no. 78-17 of 6 January 1978, amended by Act no. 2004-801 of 6 August 2004, and the European Union Regulation (EU 2016/679) entitled General Data Protection Regulation.

This research falls within the scope of the "Reference Methodology" (MR-003). The Centre Hospitalier de Cayenne has signed an undertaking to comply with this "Reference Methodology" and has a certificate of compliance N°2215826 v 0 from 20/11/2019; certificate renewed on 21/12/2021 under the N°2224668 v 0. A privacy impact assessment was carried out in accordance with MR-003.

This research was registered on the http://clinicaltrials.gov/ website, under the NCT N°: NCT05174234 and has a ID-RCB number 2021-A02185-36.

Before the start of inclusion, agreements were signed with all participating centers, as well as with relay points to facilitate inclusion by general practitioners, associations and NGO.

All those involved in the research have been trained on good clinical practice and the rules of confidentiality and medical secrecy. Prior to data collection, for all quantitative and qualitative aspects of the study, participants were provided with full information on the research and a declaration of consent was completed. Finally, each participant was given an anonymized number and all information was pseudonymized. Similarly, semi-structured interviews could only be recorded after the participants had given their consent. Concerning viral sequences, after participant‘s consent, the Pol gene sequence will be extracted from existing sequences, anonymized and transferred securely to the partner laboratory of the Oswaldo Cruz Institute of Fiocruz Rio De Janeiro for analysis. No personal or identifying data will be transmitted to Fiocruz.

Study populations and inclusion criteria :

For the quantitative epidemiological and biographical component, participants were included in 3 groups : a "general population" group, a group of people living with HIV, and a group of people living with HBV.

The inclusion criteria for all groups were as follows: being born in Haiti (regardless of current nationality), having been in French Guiana for more than 3 months, being between 18 and 60 years of age and having no objection to participate in the study. For the group of people living with HIV, the inclusion criteria were as follows: living with HIV and with a diagnosis dating back more than 3 months (whatever their status with regard to hepatitis B and C), being followed up by one of the study's partner doctors at the hospitals in Cayenne, Kourou or Saint Laurent du Maroni, or in outpatient care, or by a partner association. For the group of people living with chronic hepatitis B, the inclusion criteria were: living with a chronic HBV infection and diagnosed for more than 3 months (not co-infected with HIV), and being followed-up by one of the study's partner doctors in the hospitals of Cayenne, Kourou or Saint Laurent du Maroni, or in outpatient care, or by a partner NGOs.

For the general Haitian population group (not known to live with HIV or HBV), the inclusion criteria were: to declare that they were not infected with either HIV or HBV, to be under the care of one of the study's partner doctors, or to be recruited in the public space of one of the cities targeted by the study (Cayenne, Matoury, Rémire-Montjoly, Macouria, Kourou, Montsinery-Tonnegrande, Sinnamary, Maripasoula, Saint-Laurent-du-Maroni or Mana). Non-inclusion criteria were: being unable to answer the interviewer in French or Haitian Creole, being under guardianship or tutelage or under legal protection, having already answered the study questionnaire.

For the exploratory qualitative sections on health anthropology, mental health and access to care substudies, the inclusion criteria depended on each sub-study and included :

- Professionals: health professionals, social workers or local NGOs, experienced in working with migrants living in French Guiana between 2021 and 2023, and agreeing to participate to the study.
- Community: representative of the Haitian community, whether or not living with HIV and agreeing to be interviewed.

Sample size :

The number of subjects required was calculated so as to have sufficient power (80%) to estimate the frequency of the main indicators (sexual behaviour that exposes you to the risk of acquiring HIV), based on an expected percentage of 50% with a precision of 5%, using the following formula:

$$N=\frac{U_{\alpha}^{2} x\,\pi(1-\pi)}{\Delta}$$

$U_{\alpha}^{2}=1{,}96\ \textit{for an agreed risk of}\ 0.05$
$\pi=\textit{frequency of the factor studied , here}\ 50\%(0.5)$
$\Delta=\textit{accuracy required , here}\ 5\%(0.05)$

From estimates of a total of 384 participants per group, and in order to take into account incompleteness of data collection, the target was set at 400 PLHIV and 400 PLHBV. Considering a 1:2 ratio, one thousand six hundred inclusions was planned in the general population group, in order to have sufficient power to carry out multivariate analyses on all study indicators, and to perform analyses on sub-populations of interest such as women, men, young, people who arrived after 2015, people living in extreme poverty and people who have already used transactional sex.

Concerning the feasibility of including PLHIV from Haiti, the number of patients actively followed-up in Guiana's hospitals was estimated at 889 in 2021. For the group of PLHBV from Haiti, the cohort in 2021 is 250 people actively followed-up in hospital departments. These data are largely underestimated, as they do not take into account those who have been lost to follow-up. In terms of the general population, nearly 10% of the Guianese population is of Haitian origin. Thus, the inclusion objectives seem achievable in view of the study's target population.

Participants enrollment, sampling approaches and monitoring :

For the quantitative aspects of the study, sampling of the Haitian population in French Guiana – little explored, partially hidden (living in informal settlements and without papers) and rapidly evolving –was carried out by combining several methods. Inclusion sites were chosen on a non-probabilistic and reasoned basis. Locations were selected based on literature analysis, census data, knowledge of the peer community workers, knowledge of partner non-governmental organizations, and accessibility and safety. These elements are listed in figure 1. Finally, partner hospital departments, outpatients centers (health care access offices, French Red Cross prevention and health centers, and primary care centers) and general practitioners were identified. The hospital services selected were those that limited bias on morbidity (particularly chronic diseases). The medical departments selected for participants screening and enrollment were maternity, pediatrics, dermatology and the emergency room. In view of the enrollment sites mentioned, an over-sampling of women was expected and judged acceptable.

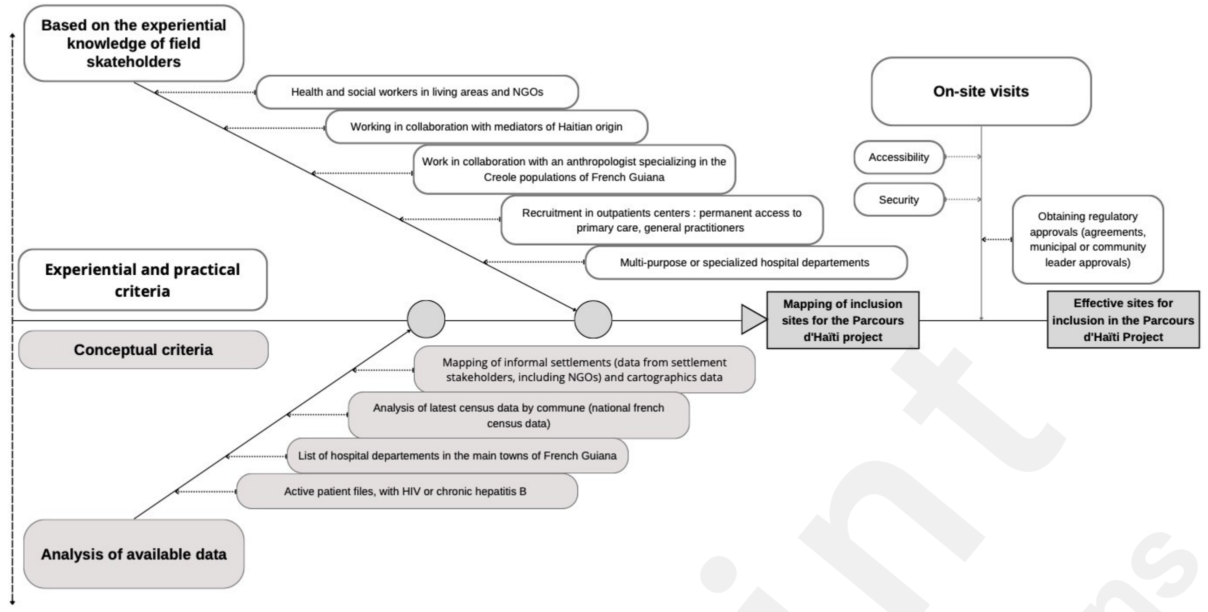

Figure 1: Selection criteria for mapping and choosing locations for inclusion in the Parcours d'Haïti study between 2021 and 2023.

At the inclusion sites, random recruitment was carried out: all people meeting the inclusion criteria were invited to take part into the study. Inclusion was halted once we reached a reasonable number of participants from a statistical power perspective and representativity of the study populations.

In order to improve representativeness of the sample, additional recruitment using the snowball method was planned among eligible health and social care professionals and resource persons. Each volunteer participant received 8 cards with an alphanumeric code, to be distributed to eligible people within their circle. Those who received a card and wished to participate were able to contact the peer investigators to schedule an interview according to their availability. The entire protocol was explained to them, and they were able to ask any questions they wished before agreeing to take part. This method was scheduled in order to improve the quality of the sample, minimize selection bias in terms of care and social support, as well as insecurity.

A hygiene kit (mask, toothpaste, hydro-alcoholic gel, condoms, guidance and prevention leaflet) were given to each person included to thank them for the time they spent answering questions, in accordance with the Comité de Protection des Personnes Sud-Est I.

For the qualitative components, the samples were chosen on the basis of predefined criteria to represent the different profiles of stakeholders and individuals. Sampling was stopped for each component when data saturation in answers was reached.

Study monitoring:

According to the monitoring plan, all participants’ non-opposition form were monitored by a clinical research assistant, together with identity, inclusion criteria and inclusion group. If reported by the monitoring, participants duplicates or unmatched inclusion criteria led to participants exclusion. Also, where possible, non-objection forms were completed by the study investigators in conjunction with the clinical research associate. Before data entry, all information collected on the participants' biographical grid was daily proofread by a peer-investigator. In the event of incomplete or inconsistent data, a review was carried out with the investigator who completed the questionnaire. Finally, the data entered were analyzed and checked for logical correctness.

Data collection tools:

All of the study's collection tools were co-constructed with health mediators (community health workers) of Haitian origin, the partner structures, the study's partner physicians (HBV and HIV specialists), the team from the COREVIH Guyane, researchers from the Clinical Investigation Center Inserm CIC1424 and the study's scientific partners. The terms of acceptability, confidentiality and quality were at the center of all discussions. The data collected from Haitian-born people aged 18 to 60 years, included in the quantitative epidemiological section, were collected using two tools: a cross-sectional epidemiological questionnaire on a tablet, and a paper biographical grid where information was collected year after year (attached document). These tools have been pre-tested and adjustments made. These questionnaires were both hetero-administered, with interviews being conducted in either French or Haitian Creole, and generally took around 60 minutes to complete per participant. The interview took place at the time it was proposed, or during an appointment scheduled at the participant’s convenience.

The cross-sectional epidemiological questionnaire collected data related to arrival and stay in France, history of administrative procedures to stay for medical reasons, sexual and reproductive health, coerced or transactional relationships over the lifetime, use of birth control methods before and after arrival in French Guiana, use of HIV screening tests, general health status, mental health status (PHQ-4 scale and psycho-trauma PTSD-8 scale), substance use (AUDIT-C scale), health insurance coverage, refusal of care experience, food insecurity and hunger, and use of non-allopathic medicine (27–29). For the groups of participants living with HIV or HBV, two short complementary modules were completed in the cross-sectional questionnaire, and follow-up and treatment histories were also collected biographically, and medical questionnaires containing routine biological and medical information were completed. Cross-sectional questionnaire data were collected using ODKCollect® software on tablets. Data entry was performed offline, then data was extracted manually using an R script to transform instances into a csv database (30). Biographical data were collected on paper biographical grids, then coded using a dictionary of variables and corresponding labels.

The second main tool used was a biographical grid, with the following information collected retrospectively year after year over the lifetime: residential history, administrative history, health coverage, history of professional activities, sources of income, history of relationships, pregnancies and children, history of screening tests for HIV, HBV and cervical cancer screening, history of illnesses and hospitalizations, health or social support structures encountered since arrival in French Guiana, perceived annual well-being, hunger and significant events. For the groups of participants living with HIV or HBV, follow-up and treatment histories were also collected biographically. The biographical grid data were then entered into EnnovClinical by a clinical study technician. The decision to freeze the quantitative databases was taken on March 13, 2024, once the data entry and control processes had been completed. The controls continued until June 07, 2024.

Migration routes were also collected on a map, then entered manually into a csv database.

For the groups of participants living with HIV or HBV, two short medical questionnaires containing routine biological and medical characteristics were completed by the physicians in charge of the patient, based on the patient's medical history and the results of biological tests.

Finally, a satisfaction questionnaire was administered by telephone at the end of the study participants who agreed to leave their contact details with the investigators, focusing on the experience and potential benefits derived from taking part to the study and the in-depth personal interview with a mediator. This section was collected by an investigating mediator by telephone using ODKCollect ® software.

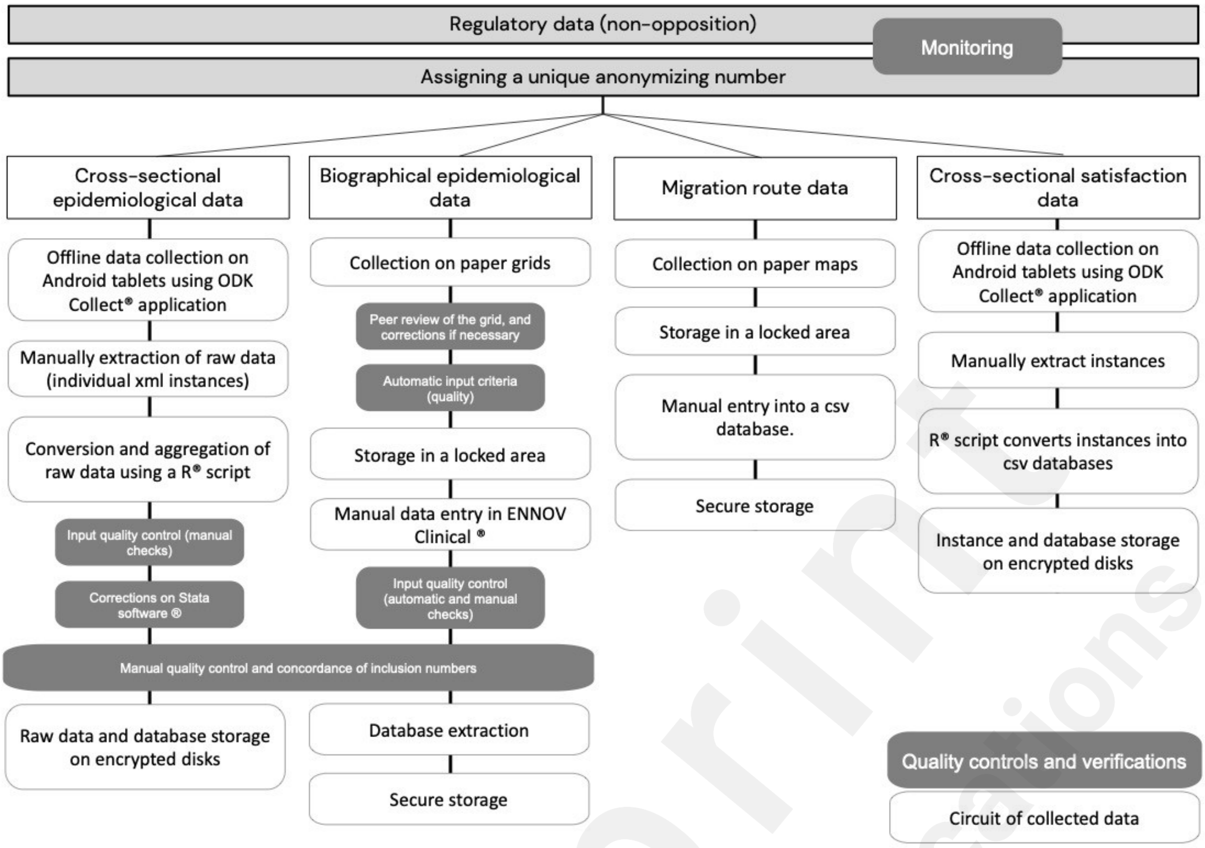

Figure 2 - Flow of quantitative, epidemiological and biographical data collected during the Parcours d'Haïti study, and quality control and checks on data.

Qualitative data were collected via semi-directive face-to-face interviews, each lasting around 45 minutes. With regard to access to healthcare, the themes addressed were health determinants, and access to and use of medical care by migrants in French Guiana. In the case of mental health, we explored the mental health problems of migrants in French Guiana, existing healthcare services, obstacles encountered, violence suffered and its link with sexual health. The interviews were in part recorded using a smartphone, anonymised and fully transcribed.

An ethnographic dimension was also added to the qualitative axis, with active observation in Haitian migrants' neighborhoods. Traditional practitioners were followed in their care, without the preparation of traditional remedies, as well as in the treatment of patients whenever possible.

<u>Analysis plan:</u>

As the analyses had not yet begun at the time of submission of this work, this paragraph is written in the future tense.

Statistical analysis of quantitative and biographical data :

With regard to the statistical analysis of quantitative information, the major indicators will be described using percentages, as well as a mean or median with their standard deviation or interquartile range, depending on their distribution. Analytical work will be carried out using a biographical and social epidemiology approach, using the tools of epidemiological analysis to study the associations of behaviors and health indicators with social determinants. Factors associated with biographical key indicators will be analyzed year after year, using discrete-time logistic regression models that take into account time and the values of indicators collected in the biographical grid year after year. Factors associated with indicators collected at the time of the study will be analyzed using Poisson regression with robust variance. Stata® software will be used to perform the analyses.

An analysis of the participants' support and care structures will be carried out on the basis of specific questions that will be analyzed by clustering and a bipartite network approach using methods derived from graph theory. These analyses will provide a better understanding of the levers and care itineraries that can be developed. R® software will be used for these analyses (packages tidyversetidygraph).

Qualitative analysis:

The qualitative study is of a hypothetical-deductive type, conducted in a discursive and recursive approach using semi-directive interview grids for individual interviews and in a freer manner for discussion groups. These interviews involve a conversational dynamic in which the interviewer and participants interact in a progressive, recursive and flexible manner in order to obtain a broad and comprehensive view of the subject. All interview observations will be triangulated with field observations. The collected data (recorded or handwritten) will be analyzed thematically, manually or using a specialized software (MAXQDA2022 ®).

Phylogenetic analysis:

For the analysis of Pol gene clades, the data (nucleotide sequences) will be extracted from the HIV resistance genotype by the Pasteur laboratory in French Guiana, an analysis conducted for all people living with HIV before antiretroviral therapy. A phylogenetic tree will be produced from these sequences, and the clades to which they belong will be analyzed. The results of the phylogenetic analyses (clades) will be described in the form of phylogenetic trees and cross-referenced with social and biographical determinants, and associations will be analyzed using Chi-square tests performed using Stata 15.1® software. These analyses will be carried out in part by Fiocruz.

Results (e.g. user statistics, evaluation outcomes). If your study consists of different stages/parts, subheadings in this section should mirror subheadings in the methods section to describe these parts.

For 20 months, the Parcours d'Haïti study was implemented and conducted in French Guiana. The initial study was enriched and developed, and 3 substantial modifications were made.

In November 2021, the first participant was included in the quantitative epidemiological component, which focused on PLHIV and the general Haitian population. In June 2022, a PLHBV group was added to thestudy. Several approaches were developed, using a mixed methodology: a quantitative cross-sectional approach, a quantitative biographical approach, a qualitative mental health approach, a qualitative approach to access and use of care, an anthropological and ethnobotanical component, and finally a "satisfaction" component. These elements are developed chronologically in figure 2.

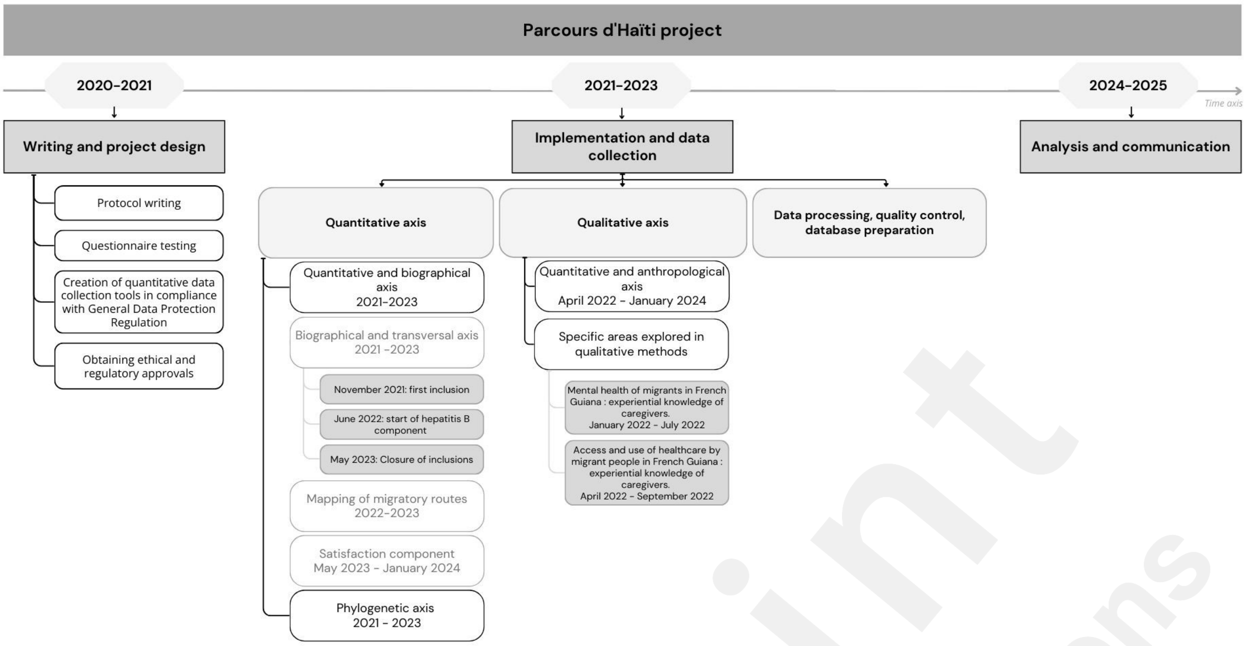

Figure 3 - Chronological timeline of the different axes of the Parcours d'Haïti research study, between 2020 and 2025.

Quantitative and biographical data:

For the quantitative component, inclusions were completed by May 31, 2023. Data quality control has been extended to June 2024. Analysis is scheduled to begin in July 2024. The collection of migratory routes was completed on May 31, 2023. The first results are expected at the end of 2024.

Qualitative and anthropological data:

Qualitative data were collected along the 3 axes mentioned above. The first section, on mental health, has been completed, and the first results on mental health are expected at the end of 2024. Concerning the section on access to and use of healthcare, this section has been completed, the interviews analyzed, and this work published in October 2023 (31). Data collection for the anthropological component ended in January 2024, with the first results expected in September 2024.

Phylogenetic analysis:

Phylogenetic data has been collected, with first results expected by the end of 2024.

Discussion (e.g. with the subheadings "Principal Results", "Limitations", "Comparison with Prior Work", "Conclusions")

For a long time it was difficult, particularly in France, to carry out surveys on people in relation to their native origin. In this work, after much reflection, the choice was made to work on people born in Haiti. Haiti's history and very specific geographical situation suggest that Haitians arrive in French Guiana with their own particular baggage (for example, the natural and health disasters of 2010 and 2012). It's always difficult to work on a specific population, according to its country of birth, without running the risk of adding stigma to the discrimination already experienced by people living with HIV. However, since 2001, several studies have led the scientific community to consider the link between HIV and immigration from the angle of inequalities (32,33). A number of indicators point to the even greater difficulties faced by Haitians in French Guiana. A number of other elements reinforce the idea that Haitian-born people living in French Guiana are subject to particularly precarious situations, inequalities and even discrimination, all of which are likely to have an impact on their health (34). Again keeping in mind the risk of essentialization, the literature reminds us that health is mediated by social and political processes.

Limitations

The study methodology has a number of limitations: firstly, the target population is hidden, most of them undocumented, and the situation (particularly in informal settlements) is rapidly changing. As information on their distribution was incomplete, it was difficult to assess the representativeness of this population on the territory, in the absence of up-to-date comparative data.

One of the limitations of this study is the strong stigma attached to the Haitian community, particularly the association of the terms Haiti and HIV, which has an historically negative connotation. This association could reinforce the stigma already attached to this population and limit acceptability.

The recruitment targets for the hepatitis B and HIV groups were ambitious, and the active referral files did not take into account patients lost to follow-up, nor the growing proportion of patients followed up in the city (which is difficult to reach).

As regards to the inclusion of participants living with hepatitis B, the follow-up departments for these patients were late in signing up since this study group was added at a later stage, limiting the time available for inclusion.

Strengths

The biographical approach is the first and principal strength of this work, as life courses are inscribed in time. This approach makes it possible to study the whole of a person's life, while placing events in the political and social context in which they took place. This approach also limits memory bias, by grounding events in key life dates (e.g. children's births). This biographical approach was supplemented by a cross-sectional, qualitative, anthropological approach, and for people living with a chronic virus (HIV or Hepatitis B), by a medical questionnaire. For people living specifically with HIV, a phylogenetic analysis was also proposed. All these sources make it possible to triangulate information and reinforce the internal validity of the results.

This is the first in-depth, mixed-methodology study on Haitians living in French Guiana, shedding light on a significant population that is key in terms of public health. Despite the fact that the population is hidden and rapidly evolving, French Guiana is a small territory. Collaboration with the main actors in the field, with mediators from the community, and with an anthropologist specialized in French Guiana's Creole communities increased the chances of obtaining a representative sample of the Haitian population living in French Guiana between 2021 and 2023.

Despite discussions on this point, targeting the Haitian population could be a source of discrimination, particularly when recruiting people living with HIV. In this study, the information and explanations provided by the mediator-interviewers helped maximize understanding by building a relationship of trust with the participants, providing them with intelligible information, making them understanding what was at stake and limiting stigmatization. The mediators played a major role in promoting understanding, compliance with ethics, confidentiality and respect for participants' rights. The approach taken by community mediators played a major role in the project's feasibility and the number of inclusions. The Parcours d'Haïti mediator-community network was undeniably a strength.

Comparison with Prior Work

The ANRS Parcours 2012-2013 survey, a biographical study carried out in the Paris region among migrants from Sub-Saharian Africa, was divided into 3 groups equivalent to those presented in this protocol (general population, PLHB, and PLHIV). This study almost achieved its objectives with regard to the group of people living with HIV, but fell short with regard to the group of PLWHB and the general population (35). This study revealed difficult living conditions on arrival and established the link between these living conditions and the acquisition of HIV in France (35). The MAKASI study, carried out in 2019 as a follow-up to ANRS Parcours 2012-2013 among migrants from Sub-Saharian Africa far from care, revealed low levels of health coverage and precarious administrative status, including among people who have been in the French territory for several years (36). Previous surveys carried out in French Guiana show a very high level of food insecurity (37,38). A number of studies have shown that the health of migrants in French Guiana and hexagonal France is deteriorating (4,39). In terms of sexual health, recent studies highlight the high level of exposure to sexual violence among migrant women, the high level of transactional relationships used as a survival strategy, and the cumulative violence experienced by this population (4).

In the ANRS Parcours 2012-2013 survey, up to 50% of people from sub-Saharian Africa surveyed contracted HIV after their arrival in France, and of these 58% acquired HIV during the settlement period (between 0 and 6 years after migration) and 42% after settling (more than 6 years after migration) (40). With regard to HIV, a number of studies have been carried out in French Guiana in recent years (including phylogenetic studies), enabling us to understand the factors driving the epidemic (9–11,14,16,17). Elements similar to those found in the ANRS Parcours 2012-2013 study were highlighted, with the majority of foreigners living with HIV having acquired the virus after migrating to French Guiana (10,11). The studies carried out showed that HIV was diagnosed later in Haitians than in native-born people, but was detected more quickly in Haitians than in Surinamese or Brazilians (17).

Assumptions and hypothetical study outcomes

Quantitative and biographical data :

In comparison with the results found in the literature, and particularly in the ANRS Parcours 2012-2013 study led in Paris area, we hypothesized that the study would reveal difficult living conditions after arrival in French Guiana, and that these conditions will last for a long time. We will try to confirm that the departures from Haiti were precipitated by historical events and that the routes are more or less complex depending on the path taken. We hypothesized that migratory routes vary according to migration periods. We hypothesized that access to a residence permit is burdensome, and that this is a factor negatively impacting the health of people arriving on the Guianese territory. We presume that access to non-formal housing is very limited and determined by the level of education and knowing someone in French Guiana previously. We hypothesized that relationships are determined by social conditions, but that motherhood in women is more determined by age and social representations, even when living conditions are precarious. We hypothesized that many people do not have the health coverage to which they are entitled, that health care services, although available, are not necessarily accessible (for reasons that include transport, health coverage, health literacy and possible discrimination). We will also try to confirm the hypothesis that having contacts with NGOs and social services improve access to care compared to those who have not benefited from this support. We also make the assumptions that people from Haiti experienced high levels of food insecurity after arriving in French Guiana, and that many people are isolated.

We also hypothesized that the mental health of Haitians living in French Guiana is impaired when living conditions are precarious, violence has occurred or when relatives are separated.

During these years, people may be exposed to situations of sexual vulnerability and to unwanted sexuality, transactional, paid or even forced sex, exposing them to a greater risk of contamination by HIV or sexually transmitted infections and psychological trauma. In terms of sexual health, we hypothesized that whatever the inclusion group, a large proportion of the population has been exposed to sexual violence and transactional relationships, and that these phenomena particularly concern women. Finally, we hypothesized that the use of contraception is low, and that recourse to abortion is very limited.

Concerning the follow-up of PLHIV and PLHBV, we hypothesized that Haitian populations in French Guiana used screening relatively early, and that those diagnosed with HIV infection enter care relatively early, in line with the screening and mediation services available in the region, notably through the French Red Cross. We also think that impaired social conditions, social isolation and low health literacy are associated with a delay in screening. A catch-up certainly exists for women during pregnancy. It is likely that periods of disruption of care are closely linked to the social situation of the people concerned, which changes from year to year. The biographical approach will enable us to confirm the hypothesis that in the years during which a break occurred, the person faced more often social or administrative difficulties. In addition, we assumed that periods of loss of follow-up are more frequent among PLHBV, linked to an incomplete understanding of the disease, the absence of therapeutic indications for a large proportion of PLHBV, prolonged follow-up intervals and a lesser civil society investment than with PLHIV. With regard to people living with HIV, we hypothesized that they will report unprotected sex in the years following their infection.

Finally, we hypothesized that conducting a long interview focusing on health issues is likely to contribute to respondents' access to and use of healthcare.

Qualitative and anthropological data :

One of the aims of the qualitative study was to gain a better understanding of the cultural representations associated with health within the Haitian community. The relationship between care and life course, especially migration, will also be studied. We hypothesized that this anthropological approach will reveal a number of internal logics specific to Haitian ethnomedicine. It should also lead to a better understanding of the cultural motivations underlying the different ways in which patients seek care, and ultimately help to improve the conditions of prevention and care for Haitian patients.

Phylogenetic analysis:

The phylogenetic approach assumes that it will be possible to determine the origin of viruses from published viral sequences (Genbank®), and that from the molecular timeline it will be possible to reconstruct the history of transmission, and the time lag between acquisition and transmission of the virus, important information for a better understanding of the particularities of the epidemic in this population. We hypothesized that infections occur most often with sequences compatible with intra-community transmission before and after arrival and therefore that prevention should be carried out at community level.

Expected fallout

The results of this study are likely to improve our understanding of the sexual vulnerability of people from Haiti, with a view to setting up a sexual health pathway incorporating a diversified range of appropriate screening and prevention services. This pathway will help to reduce the risk of infection by HIV, HBV and STIs, as well as unwanted sex and unwanted pregnancies. It will help improve the pathway for entering and remaining in care in general, and following the discovery of HIV or chronic HBV infection. It will tie in with work already underway to develop prevention and care services directly in the informal settlements where a large population of Haitians live. The results of this study are likely to help medical, psychological and social support in conjunction with all the institutional and voluntary players.

It will also provide a better understanding of the path taken by people living with HIV or HBV once they have been diagnosed, and produce information that can be used to implement measures to prevent them from loss of follow-up.

The results and resulting proposals will be communicated as a high priority to actors in social support, prevention and care, grouped around the COREVIH Guyane. One action is already underway as part of roadmap 2 of the French sexual health strategy, involving the deployment in French Guiana of nurse/mediator pairs equipped to carry out STI and HPV point of care screening, in order to reach the populations furthest from health structures. The results of the Parcours d'Haïti study will help to meet the data needs of this priority population and provide a framework for action.

Conclusion:

The Parcours d’Haïti study is original regarding its methodology (a mixed study using biographical methods with community co-construction), its territory (a French territory in South America) and its study population (a large but vulnerable population). Analyses will test the various hypotheses, notably the potential and significant impact of poor reception conditions on the health of individuals and the persistence of HIV transmission in the region. These expected and original results may lead to an adjustment of the reception policy for Haitian people in French Guiana, and to the implementation of efficient sexual health programs. The joint development of these programs with community representatives will be a prerequisite. Ideally, this study could be duplicated in other settings where people from Haiti migrate (e.g. Canada and the USA), and extended to other people on the move facing difficult living conditions on arrival. Finally, the use of peer investigators (health mediators) for this study improved respect for participants' rights and data quality. This work is likely to contribute to the development of the profession of health research mediators in the future.

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Conflicts of Interest

No conflict of interest to declare.

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Abbreviations :

ANRS : Agence Nationale de Recherche contre le Sida et les hépatites (French national AIDS and hepatitis research agency)
HBV : Hepatitis B Virus
HIV : Human Immunodeficiency Virus
PLHBV : People living with hepatitis B virus
PLHIV : People living with HIV.
STI : Sexually-transmitted infections
CNIL : Commission Nationale de l'Informatique et des Libertés (French Data Protection Authority)
RNIPH : Recherche N'Impliquant Pas la personne Humaine (Research Not Involving Humans)
NGO : Non-Governmental Organizations

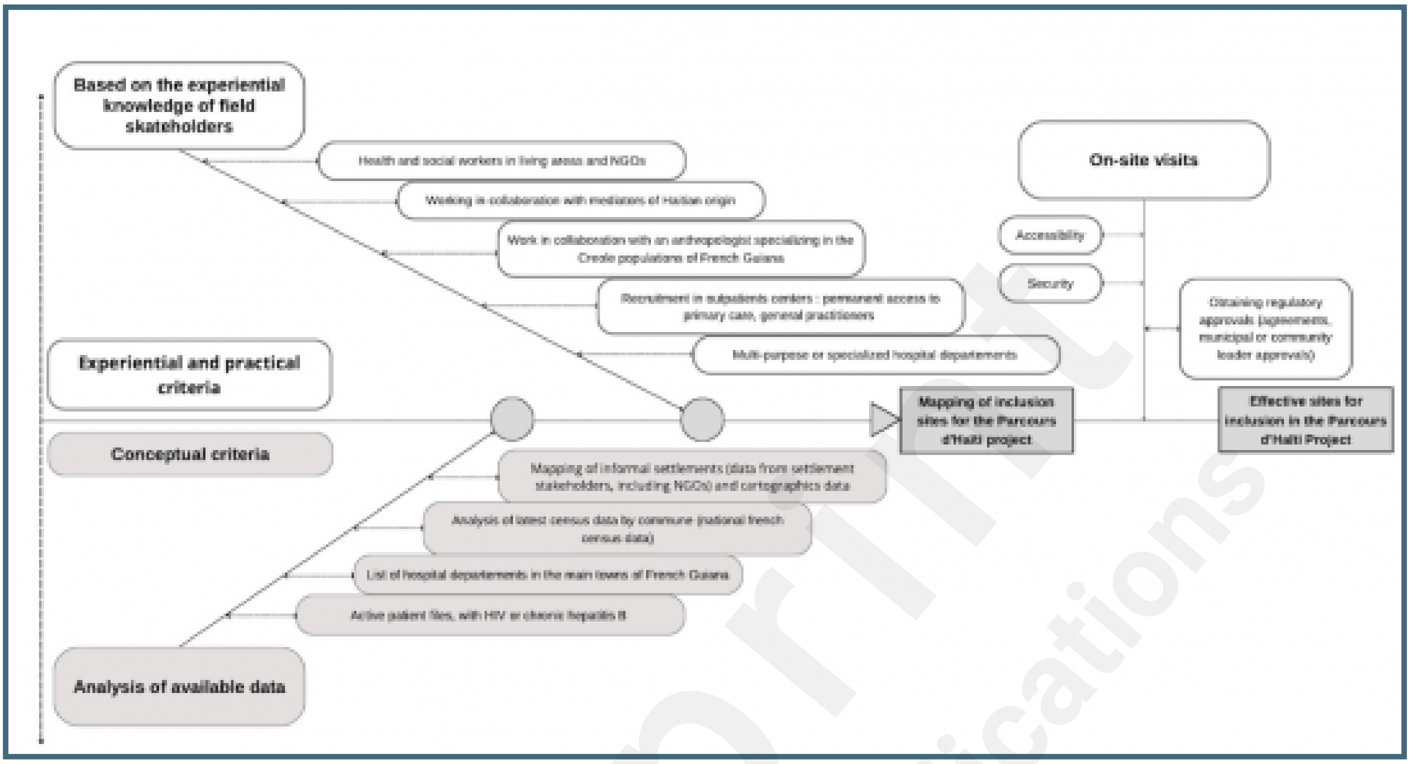
Supplementary file:

- CRF_Map_Parcoursdhaiti
- CRF_ODK_Parcoursdhaiti
- CRF_Parcoursdhaiti_Biographicalgrid
- CRF_Qualitativeaxis_Parcoursd'haiti
- CRF_Satisfaction_Parcoursdhaiti

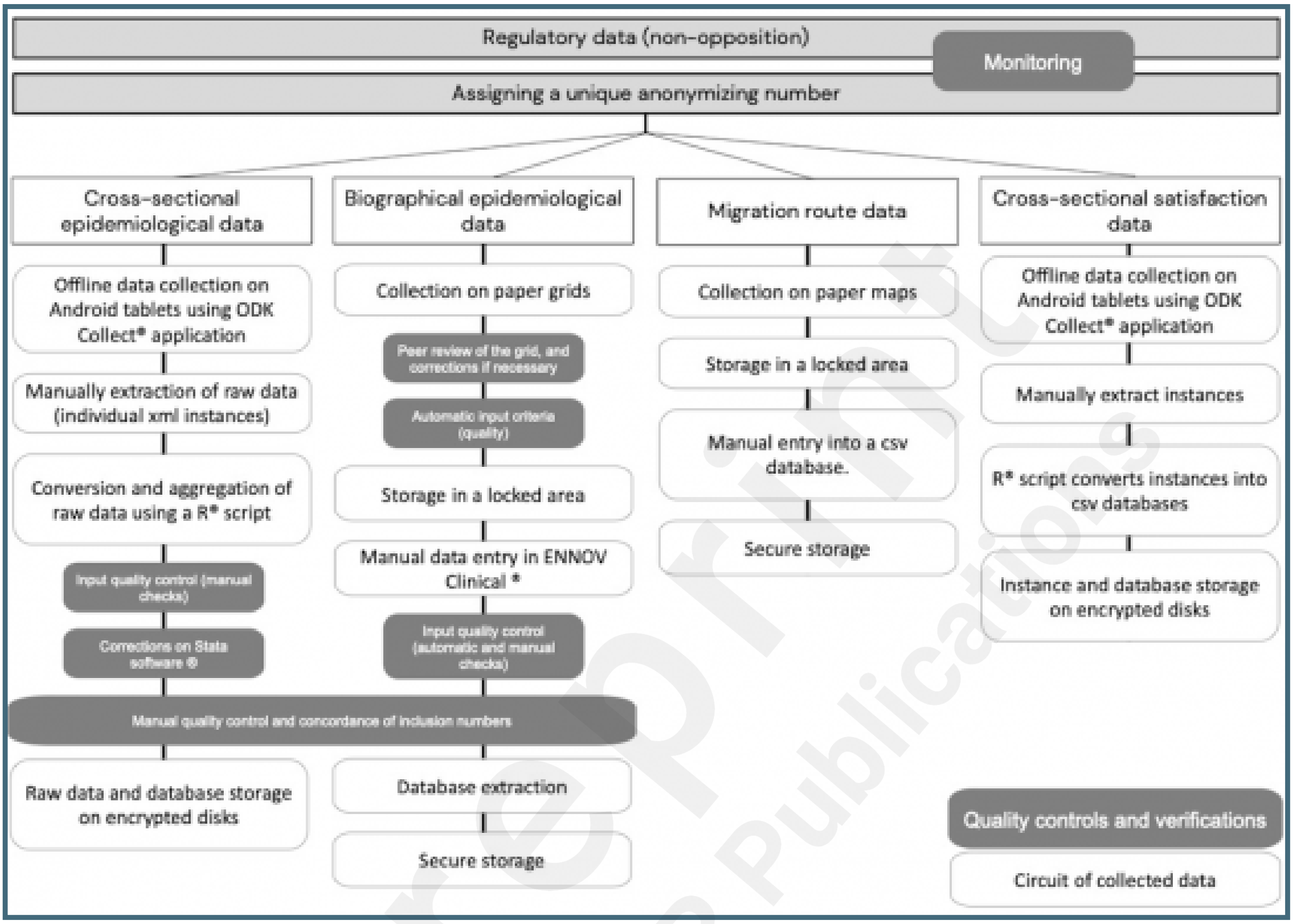
Supplementary Files

Figures

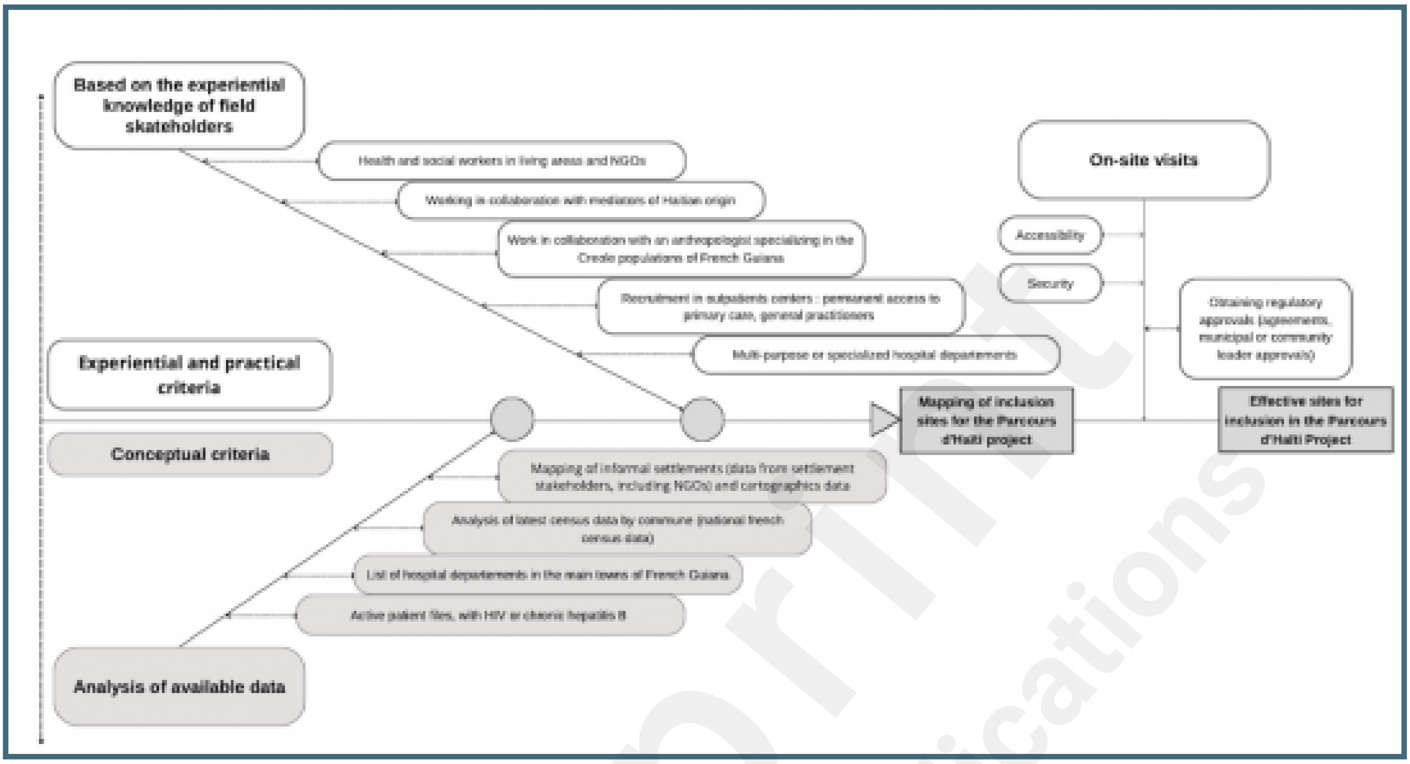
Selection criteria for mapping and choosing locations for inclusion in the Parcours d'Haïti study between 2021 and 2023.



Flow of quantitative, epidemiological and biographical data collected during the Parcours d'Haïti study, and quality control and checks on data.



Chronological timeline of the different axes of the Parcours d'Haïti research study, between 2020 and 2025.



CONSORT (or other) checklists

Questionnaire used.
URL: http://asset.jmir.pub/assets/7084f85d95764385325f64ce877be6b0.pdf

Questionnaire used.
URL: http://asset.jmir.pub/assets/e3b5128b9fbbfb02ca89fb09315aba24.pdf

Questionnaire used.
URL: http://asset.jmir.pub/assets/13275b7b3f8c5eae7315c4238f128e51.pdf

Questionnaire used.
URL: http://asset.jmir.pub/assets/deeaca643fdbe009363f856c5a5cab1b.pdf

Questionnaire used.
URL: http://asset.jmir.pub/assets/b15b2555893bfd3b9a3825c5eece1662.pdf