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Bottom-Up methods for low resource HMIS

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Abstract This proposal defines project for a research into data processing and analysis methods adapted to health information systems in most developing countries. I argue that HIS in developing countries have been historically marked by top-down approaches in which methods aimed at administrative monitoring have been defined by remote actors, and implemented without much local adaptation. This way of creating health information is at odds with the progressive emergence and adaptation of norms and methods in most developed countries HIS.

My research aims at defining data centered methods for local adaptation of common health information methods. I will concentrate on three important dimensions of a bottom-up approach to HIS. First, I will define an approach to local indicator definition. Using EMR data from HIV care in Kenya, I will show how a generic definition of retention in HIV care is impacted by data quality and local characteristics, and I will explore robust alternatives to this definition. Second, I will use routine data from a Results Based Funding program in Bénin to define an algorithm for data quality screening and facility performance monitoring adapted to local conditions of exercise. Finally, using widely available data from Niger, I will implement a data-hybridization strategy to produce an actionable high resolution map of Niger population.

This project will contribute to research in the Global Health Metrics field in different ways. It will contribute to the research, mainly from the ICTD community, on flexible standards for data collection. It will offer a framework for the analysis and use of real-world low quality data. Finally, it will contribute to statistical methods for health system data surveillance and monitoring. As a whole, it will provide important contributions to the definition of localized approach to generate information for decision makers in health systems.

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1 Introduction

1.1 General Overview

Evidence based decision making is increasingly presented as the best way to design public health policies at national and local levels [1, 2, 3, 4, 5]. The ability of statistics to offer rational basis to make decisions [6, 7], allied with progress in data collection and analysis techniques engender enthusiasm and hope in the ability of governments and other actors to design and implement analytical tools to improve the political and administrative processes, some even calling for a *Data Revolution* in policy making [8, 9].

Meanwhile, if this principle seems to be set, what constitutes relevant evidence in an administrative context, and how it should be generated is less clear and depends on local contexts and traditions. Bergeron and Cassel note that knowledge and expertise of public health deciders are "a network involving many different actors, structures and tools, concepts and spatial and institutional arrangements" [10]. Producing knowledge for public health decision thus relies on localized and contextual approaches, that are not easily generalized to other situations. In the world of Global Health Metrics, the local and contextual dimension of statistical systems can sometimes be lost in an undue generalization. Meanwhile, the historical conditions of emergence of evidence generation systems for public health are very different in different parts of the world.

In most rich countries, a long history of public statistics development resulted in the emergence and stabilization of well defined data sources, of methods and of roles along which the generation of public statistics are produced. In these countries, there seems to be a convergence between the two values noted by Desrosières for statistics : statistics as a measure of reality, and statistics as a norm [11, 12]. Meanwhile, this should not hide the important historical debates and struggles that happened around simple objects such as averaging population statistics [7, 6], measuring hospital mortality or even collecting hospital data. As such, strong public health information systems really are the result of local equilibriums and of adaptations to local statistical cultures, but were started by individuals making ad-hoc use of different data sources and inventing and standardizing methods on the run[13].

In sub-Saharan Africa, evidence generation for public health policy makers is in a very different situation. The weakness of statistical systems in sub-Saharan Africa has been well described and documented [14]. Most sub-Saharan countries can't rely on a robust vital statistics system to plan population targeted intervention. National Health Information Systems are often considered weak [15, 16], and are affected by multiple uncoordinated demands for data collection and reporting. These demands may come from local authorities or from international donors and partners, which jeopardizes their accuracy [17] . Moreover, the development of statistical systems in former colonies has been fostered in a context that had more to see with the need of control of colonial powers than with the search for evidence and decisional guidance [18, 19, 20].

Colonial statisticians, often weakly skilled and trained [19, 21], nonetheless set the nomenclatures and conventions around which land and populations would be described and analyzed [22, 20]. In the meantime, whereas European statistical systems were developed and structured by social activists willing to tailor welfare systems [7, 12], colonial statistical systems were geared towards efficient land administration and exploitation [22, 23] with little interest on population. In Sénégal in 1926, the first population estimation was made thanks to the availability of taxation records, but with no vital statistics records[24].

After the decolonizations, the administrative mindset of evidence generation was completed by the expert mindset of the developmental state [25]. Developmentalist expertise transformed African societies into objects of external studies and knowledge more than self-administering political entities, thus prolonging the outwards orientation of colonial statistics. The development and the rollout of neoliberal statistical management in the 90's, and the generalization of Monitoring and Evaluation (M&E) for different projects [11] only strengthened and deepened this tendency. The low investment in data collection and excruciating exigency for unrealistic precision, the importation of external

methods and definitions, the overarching generalization of categories for administrative simplicity, all these features can be traced back to colonial statistics.

1.2 Work hypothesis

My main work hypothesis is that the underwhelming performance of health information systems in developing countries stems from the top-down nature of their design and implementation.

By top-down I mean systems in which the purported usage of information calls for specific data collection and analytical tools. Most HMIS design recommendations for an ex-ante design of both data analysis and measure framework, from which data collection should be inferred. [26, 27, 28, 29]. Also, M&E guidelines such as those of Global Health agencies like the Global Fund exercise important drives on HMIS organization in sub-Saharan African countries on which they are imposing definitions, classifications and reporting methods, to provide sufficient information for the evaluation of funded programs[30].

The mindset behind these approaches is influenced both by the colonial administrative tradition, for which standardized statistical tools should provide a normed information, and by the developmentalist expertise tradition, along which an hyper directed data collection system is aimed at providing a unique and narrowly defined piece of knowledge. National Health Information Systems are then organized around these multiple narrowly defined needs for information, and are directed towards answering questions asked by level national or international specialists.

The critic of this type of statistical work is often conducted from a postmodernist perspective, questioning the structures and processes that produce statistical knowledge in developing countries. This critic, if it is sometimes useful to the practicing statistician, often poses a radical critic of the quantitative approach to public affairs, offering little place for incremental improvements [31]. In this dissertation, I explore ways through which this top-down approach to evidence generation in health systems can be reversed, to promote data analysis approaches that start with the data collected in the health systems, from which relevant information is extracted in an ad hoc way.

This approach is justified by two elements. First, the observation that strong national statistical systems emerged from both norm and local improvisation and trial and error [13, 32]. Second, my approach is thought in the context of the development of the field of *Data Science* as a complement or an adaptation of traditional statistics to new analytical tools and improved computational capabilities. I understand data science literally, meaning a scientific approach taking data as an object of study *per se*, from which the analysis starts, and which conditions all subsequent reflection.

1.3 Aims

My principal aim will be to define, implement and test *bottom up* approaches to improve Health Information Systems data use in developing countries. This aim will be reached through three specific aims, which address different key processes in health information systems. The Health Metrics Network defined the three main processes of Health Information Systems as the indicators definition and standardization, data sources and data management (database hosting, data cleaning and data processing) [29].

I will address each of these processes with a specific aim, and will explore how methods based on available data and processes can improve the performance of Health Information Systems.

Indicators / Flexible Standards Defining categories and metrics based on which people are going to be counted is an essential piece of the statistical work [7]. It is an essential step in the simplification involved in the activity of measurement. The field of Global Heath relies on important taxonomies, like the International Classification of Diseases and metrics, like the Disability Adjusted Life Years, to unify description and measurement of health across the globe, and allow comparison and benchmarking

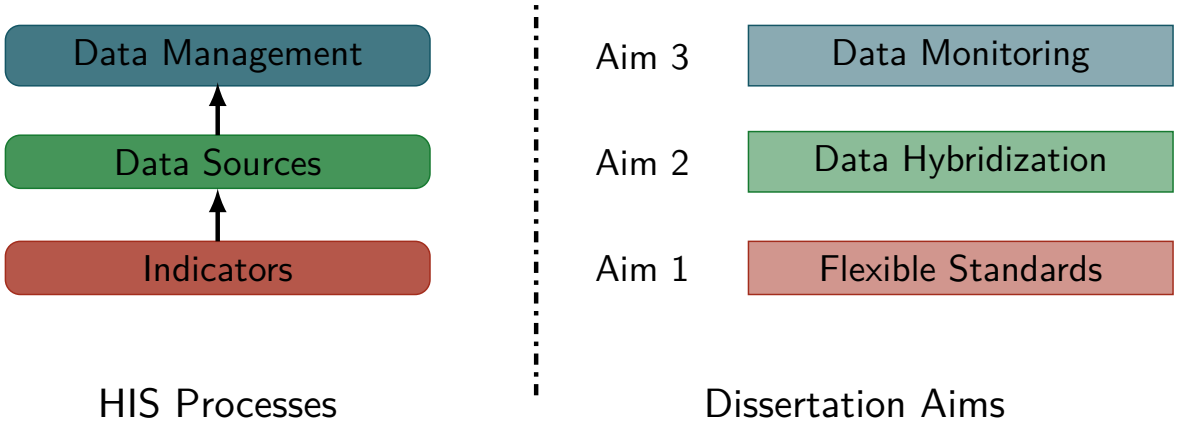

Figure 1: HIS Processes and corresponding dissertation aims

[33, 34]. Meanwhile, at local level, the use of globally defined metrics may have its limits, as it does not allow adaptation to local contexts and situations. The measure of retention of HIV patients in care is an example of this. Understanding the outcome of patients after they enter care is essential to evaluating HIV care systems performance [30]. Meanwhile, the high variation of results between programs and the low specificity of currently used indicators leads researcher to question the way Loss to Follow Up is defined and retention is measured globally [35, 36, 37, 38]. Using Electronic Medical Records, we will model how the measure of retention is affected by local contexts and data quality, and will explore better more robust ways to measure HIV care outcomes.

Data Sources / Data Hybridization Unavailability of population data in a large number of countries is a well known issue [39, 40]. As a result, spatial distribution of populations, an essential piece of evidence to develop public health policies, is often unavailable at a policy relevant scale. To palliate these shortcomings, approaches for mapping of populations have been developed, involving the use of macro-level rasters of covariates such as land coverage or night light [41, 42]. These approaches give interesting insights into how populations are distributed, and their output can easily be used for other public health work using the GPS coordinates system. Meanwhile, in situations with very low information on populations, the results of these top-down approaches is often little more than an overlay of covariates. Additionally, their results are hard to use for public health policy planning, as they do not link population to commonly used localization conventions such as places names. My third aim is to hybridize multiple data sources on population to produce a population map of Niger linked to the lowest level of population settlement possible.

Data management / Data Monitoring Data quality is an important concern of Health Information Systems professionals [43] who link it directly to the ability of Information systems to provide good information [44]. The definition of data quality is directly linked to an idea of trustworthiness, which may affect the use of certain data sources to generate evidence [45], and the quality of health data receives a large amount of attention even from high level actors in Global Health [15, 46]. The best way to ensure data quality is through routine audits of primary data [47]. Meanwhile, this approach is costly and may have some cost-efficiency issues. Additionally, it makes little use of historical data, which makes it vulnerable to issues in primary data. My second aim will be to develop a cost effective approach to data quality screening informed by historical data and including a notion of risk attached to data quality.

1.4 Novelty and scientific contribution

My dissertation is contributing to three main areas of research surrounding Health Information Systems. One is a research area mostly invested by the Information and Communication Technologies field (ICT) and interrogates the importance of local adaptation of information systems and its impact on the definition of standards. The second domain of relevance is more linked to the Global Health field, and on works that interrogate how data collected inside health systems can be used to best inform decision making. The last domain of contribution is mainly of interest for the statistical field, and explores the use of statistical methods in applied policy contexts.

1.4.1 Local Adaptation and flexible standards

In the ICT field, defining standards for data collection systems that can be implemented at local levels but respond to national or international norms. Jørn Braa, describing the approach that presides to the design and development of DHIS2 remarks that "the top-down and all-inclusive approach to standardization [is] common among ministries and central agencies" and pleads for a *flexible standards* following the idea that "the individual standards must be crafted in a manner which allows the whole complex system of standards to be adaptive to the local context" [48]. The need for local adaptability of Information Systems is seen as a key issue of ICT in developing countries [49, 50, 51, 52] and thus some ICT solutions have been designed and explored in the forms of tools like the District Health Information Systems (DHIS2) or standards like the Open Health Information Exchange initiative (OpenHIE)

My two first aims explore ways in which indicators definition or data quality evaluation can be adapted to local situations. In both situations, flexibility is introduced through objective rules : specificity and robustness of the measure of retention in the first aim, and cost-effectiveness in the second aim. The two rules are different in nature, as one is internal, and based on the characteristics of the data while the other is external, and based on operational characteristics such as the cost of supervision. This approach is innovative, and can be applied to a diversity of questions. An extension of this work could also be the definition of methods for aggregation and comparison of locally defined metrics.

1.4.2 Imperfect data Usage

Health Information Systems data is often underused, or not used at all by its intended users[29]. This underuse is often blamed on the perceived bad quality of primary data that would make it unfit for statistical analysis [47, 53, 54, 45, 55, 56, 57, 58]. Approaches to solve this issue have mainly focused on improving primary data quality to improve data use [59, 60, 61, 62], but some authors have also pointed to the possibility to use even imperfect routine data to answer specific public health questions[63, 64, 65]. These approaches rely on the nature of routine data, which is usually highly dimensional and structured times series. This type of data enables the use of robust modeling methods at an adequate level of aggregation, to control and correct for data errors.

My dissertation contributes to this line of research in two different ways.

Aim 1 and 2 also offer improved insights in routine data quality and its impact on health indicators. Aim 1 explores a micro level modeling of data quality and its impact on the measure of patient retention. It will also define retention indicators less sensitive to data quality. Aim 2 is concerned with expected value imputation and aberrant values detection, which is an essential aspect of understanding data quality. It will also implement solutions to analyze and display overdispersed data, often observed in health systems.

Aim 1 and aim 3 also examine methods to enrich the data used, using EMR metadata or hybridizing different data sources. Both approaches are an extension of usual approaches to health data, and make full use of the richness of modern data collection tools, and of the wide availability of public data sources.

1.4.3 Statistical methods for health data monitoring

For our aim 2, I am interested in two types of literature that address issues of health data monitoring : epidemiological surveillance and service quality monitoring. Epidemiological surveillance is interested in spotting changes of regime in reported counts of cases for different diseases, while quality control data, more inspired by an industrial approach to data monitoring, is interested in spotting outlying performances of specific units in a health system. In both literatures, a common algorithm for data inspection can be described in the three following steps :

1. Impute expected domain of a variable under a null hypothesis
2. Test the null hypothesis
3. Display result for human decision

How each of these steps is in effect implemented will be influenced by the specific approaches and expected information. The current reference approach to syndromic surveillance systems is the Farrington method [66], modified by Noufaily to improve handling of seasonality and power of detection tests [67, 68]. In this approach, a quasi-Poisson distribution of indicators is fit and the detection threshold is defined as a corrected Z-score for these expected distributions. In the quality monitoring literature, of Spiegelhalter [69] offers a good overview of methods in use, relying on Z-scores of observed distributions. The same approach is also described in a generic hierarchical modeling framework to identify outstanding facility level effects[70, 71].

I will explore a combination of both approaches to provide actionable information on available data in a health system. Indeed, we will handle data quality screening as a surveillance issue, aiming at spotting aberrant data in time series, and will then implement quality monitoring algorithms to identify outlying facilities. Describing the result of the combination of these two approaches to analyze data distribution in space and time will be an innovative application of existing methods.

In the meantime, my implementation of quality monitoring algorithms will differ from existing literature in an essential way. In most quality monitoring applications, the quantity of interest is the success of some type of procedure, measured by an outcome, of which death is usually the least desirable. In the context of Results Based Funding, on the other hand, the measure of success is much more a measure of access to a wide range of services. The denominator of such a measure is much less clear, as it is not defined at facility level, and there is often little information on target populations. I will thus need to define the null hypothesis in a multivariate or compositional way, stating that the relative importance of different indicators should be similar, modulo a stratification of health facilities. An approach to Z-Score combination is described by Spiegelhalter [69], on which we will build to define a facility level measure of performance.

1.5 Timeline

Aim specific timelines are explained in more detail in sections 2.3.1, 3.8 and 3.4.1. I will prioritize getting early results on Aim 2 to allow feedback and field testing from Bluesquare and have an opportunity to reorient my methods if needed. This will also leave time me to obtain potential additional data for Aims 1 and 3. All the aims should be finalized and papers written by the end of the first quarter of 2018, which would allow for a finalization of the dissertation by June 2018.

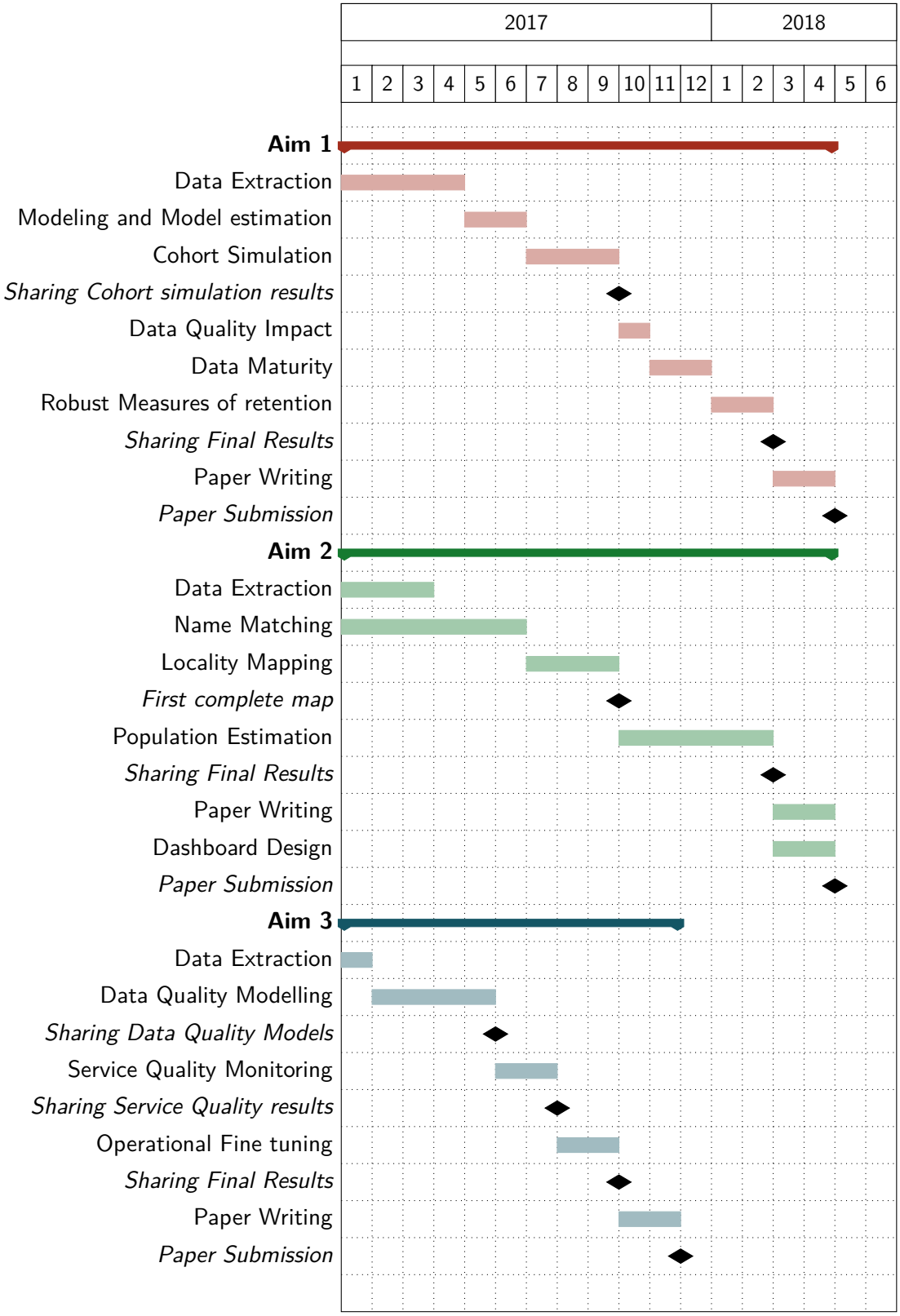

Figure 2: Dissertation Timeline

2 Aim 1 - Flexible Standards for categories definition

The measure of retention of ART patients in treatment is a key measure of HIV programs performance. HIV being a chronic disease, the measure of success of these treatments is indeed the survival of treated, patients, which is directly dependent to their adherence to ART treatment. As HIV programs have been rolled out in different countries, the importance of Lost to Follow Up patients (LTFU) in ART cohorts has been recognized, and since the early days of HIV care programs, efforts have been made to better measure and understand the phenomenon [72, 73, 74].

Initiating treatment programs, HIV practitioners used the categories that had been developed and used in clinical trials to categorize patients outcome. The definition of LTFU used in HIV programs thus comes from settings with highly controlled data collection and close patients follow-up. This definition is nonetheless problematic for public health treatment settings, as it is mainly a negative category, grouping patients who failed to attend their medical appointments and for which no definitive had been recorded. LTFU is thus defined by an absence of data about a patient more than by a positive element of information.

As HIV programs were rolled out, it soon became clear that the LTFU category, in many settings, is a mixed bag of patients with different status [75, 76, 77]. This poses problems for HIV programs evaluation, as the true outcome of HIV patient is often unknown, and different authors have proposed ways to correct retention measures by collecting additional data [78, 79, 80], or by fitting correcting models [81, 82, 83, 84, 85]. Finally, some authors started paying attention to how the very definition of patients retention could heavily impact the evaluation of HIV programs performance, [86, 35, 87, 88, 36, 37, 89].

An important underlying hypothesis of retention definition is that, if the patient had been coming to the facility for an appointment, this visit would have been recorded. This hypothesis makes sense considering the notion of LTFU comes from the clinical trial setting[73]. There is thus an equivalence established between patient's status and data quality in the facility. Meanwhile, assessing data quality of a database and its impact on the measure of retention is very difficult and seldom made. As a result, most reports on LTFU report high variations of results, and unsatisfactory sensitivity of LTFU rates on retention definition.

With the development and rollout of Electronic Medical Records (EMR) in facilities, there is an opportunity to improve on this situation. Most computerized data collection systems collect metadata on data entry, such as the date at which a form was entered, or the role of the person doing the data entry. This metadata could be mobilized to measure the quality of the data, and to understand the impact of data quality on the measure of retention.

This project main aim is to simulate and describe the impact of data quality on the measure of retention of patients in HIV cohorts. This will be achieved using three specific aims :

Impact of data quality on the measure of retention We will model the path through which data quality impacts the measure of retention, and will simulate the results of an HIV cohort with varying data quality.

Data Maturity As the time to data entry is an essential element of data quality and directly impacts the measure of retention, the ability to properly measure retention for a given periods improves in time. We will define a metric of data maturity to describe the ability of a database to properly measure retention for a cohort. This measure will be tested and validated on a simulated cohort.

Robust Retention Metrics Building on the insight gained in our previous aims, we will define, test and validate different robust retention metrics for HIV cohorts. These metrics will be evaluated on their ability to properly measure the retention of patients in a simulated cohort, and on their robustness to varying data quality.

2.1 Data Generation Process

2.1.1 HIV care process

HIV patients are visiting hospitals for regular appointments. At each visit, they are given an appointment for their next visit. The date for the v^{th} visit of patient i is noted V_v^i, and the appointment time for this visit is noted A_v^i. Thus, if $V_v^i > A_v^i$, the patient came late to his appointment, if $V_v^i < A_v^i$, the patient came early. We note $l_v^i = A_v^i - V_v^i$, the lag between scheduled appointment and actual visit. Figure 3 shows the distribution of l_v^i in our data. Unrecorded appointments are handled by divided the time between scheduled appointment and actual visit by 28, and consider the remainder. The spikes around 7, 14 and 21 days show either patients who were given an unrecorded appointment of less than a month, or is proof to the fact that patients have favorite days of visit.

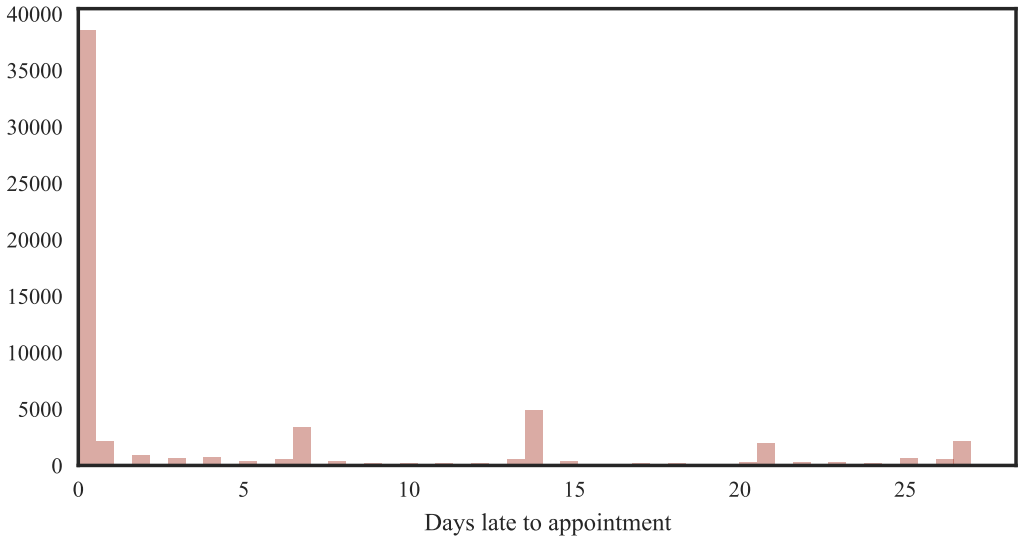

Figure 3: Distribution of l_v^i in our data.

The time between a visit and the next schedule appointment is set by the norms regarding the frequency at which patients should be evaluated, depending on their condition and medical history. Patients recently enrolled in care will be seen more frequently than patients with a longer history and no complications. We note ($\bar{f}_{vi}$) the visit frequency regimen of patient i at visit v. This unit is usually around a multiple of 28 days, as patients are likely to have a favorite week day for visit. Figure 4 shows the distribution of f_v^i in our data.

We can finally express the time between two visits as :

$$V_{v+1}^i - V_v^i = \bar{f}_{vt} + l_v^i$$

2.1.2 Data Entry

The date at which a visit is recorded in an EMR database is $R(V_v^i)$. By definition, $R(V_v^i) \geq V_v^i$, and the delay in data entry is noted :

$$R(V_v^i) - V_v^i = \delta_v^i \ geq 0$$

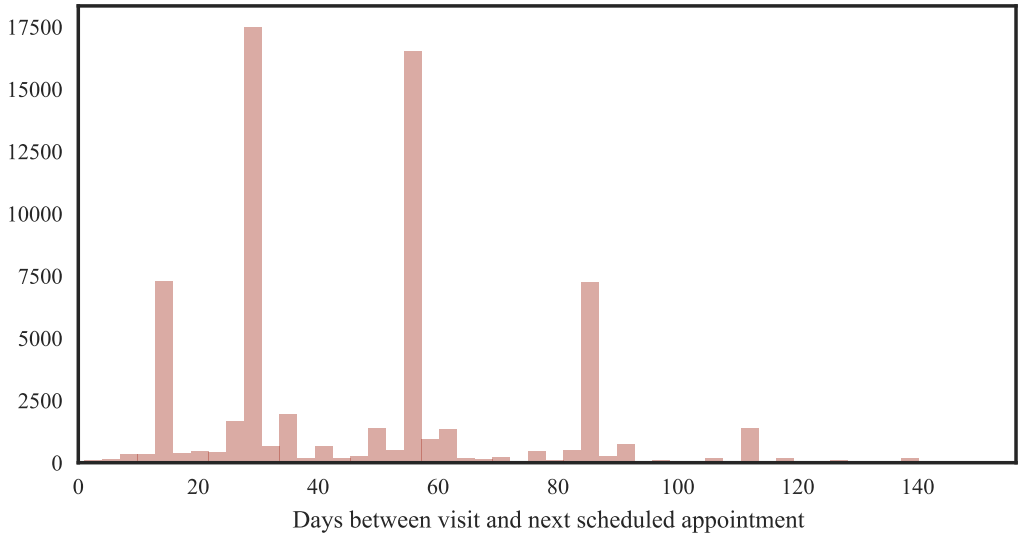

Figure 4: Distribution of f_v^i in our data. We see the visits are scheduled mainly 7, 28, 56 or 84 days after the previous visit

In some cases, the visit has not and will never be recorded, and we will note this situation as $\delta \to \infty$. δ may vary in a facility, depending on the workload, staffing or other factors. Figure 5 shows the distribution of δ in our data.

Finally, data entry is interrupted at the date T_{close} before the data is used for analysis. The time elapsed between patient i's last visit and the closing date is noted as $G_i = T_{close} - \max_v(A_v^i)$. For simplicity, we will equate the date of database closure with the date of analysis in a first step, and will relax this assumption when we will be measuring data maturity.

Figure 6 shows how these different parameters can play out for a given patient. This imaginary patient had a first visit on January 1st, and had an appointment scheduled on February 1st, to which he came 6 days late. After three months of being seen monthly, he switched to a quarterly follow up. He was early to his July appointment, but came to every appointment until the end of the year. The data was entered very quick at the beginning of the year, but v_2^i was never recorded. v_4^i was entered before v_3^i, and v_6^i could not be entered before the database was freezed for analysis on January 15 of the following year. This example gives a rough demonstration of the different situations and problems that can be encountered when analyzing the follow-up of the patient.

2.1.3 Loss to Follow Up definition

A central piece of the LTFU definition is the *grace period* during which a patient, even if he did not return to a facility, is considered actively followed. This *grace period* is denoted G_{o}.

A patient i is considered actively followed if he is not late to his latest appointment for more than G_{o} days.

$$l_{v^*i} \leq G_{\mathrm{o}}$$

Looking closer at this definition, we can see it regroups three different situations :

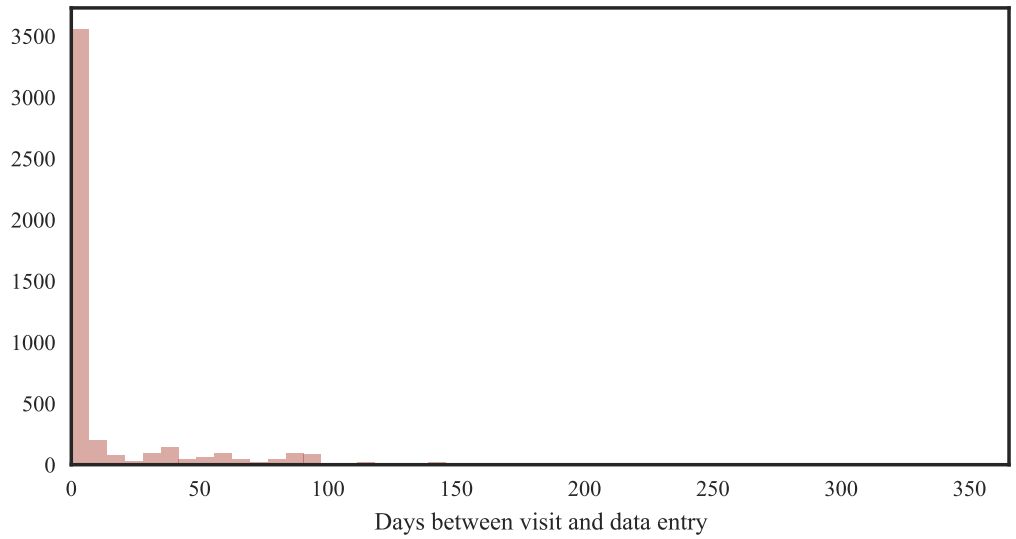

Figure 5: Distribution of δ_v^i in our data. Most of the data is entered in the first week following the visit, but we see some data can be entered much later

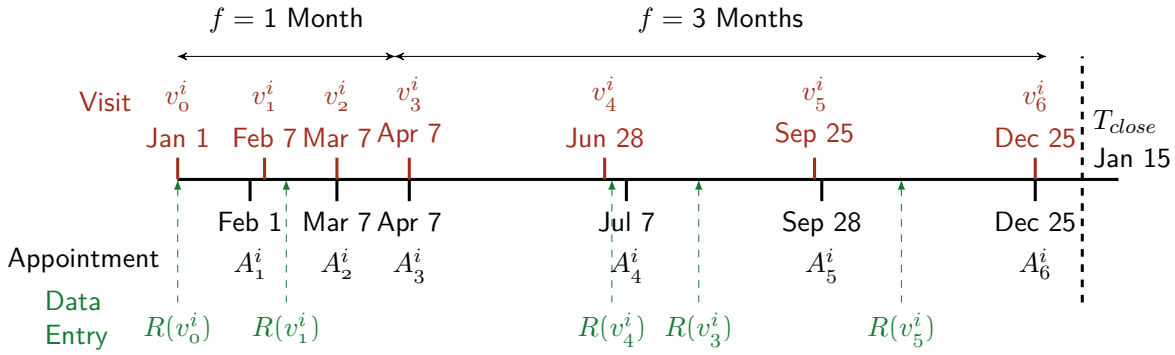

Figure 6: Individual follow-up and data entry process

1. The patient is LTFU and will never come back to the facility

2. The patient is late to his appointment but will come back, and $l_{v^*,i} > G_0$

3. The patient came for his visit $v^* + 1$ but $\delta_{v^*+1} > G_0$.

Using this definition, we can express the probability that patient is identified as LTFU based on the data at hand. Let's $X = 1$ be the event that a patient is actively in care, and $X = 0$ if the patient is LTFU. We can thus get $p(X = 0 | l_{v^*i} \leq G_0)$ as the combination of elements we can measure :

$$p(X = 0 | l_{v^*i} \leq G_0) = 1 - p(X = 1 \cap l_{v^*i} \leq G_0) - p(\delta_{v^*+1} > G_0)$$

We can understand $X = 1 \cap l_{v^*i} \leq G_0$ as the data quality term, and $\delta_{v^*+1} > G_0$ as an intrinsic myopia of the information system on the future. Meanwhile, differentiating between these two terms is important in order to understand uncertainty in the LTFU rate and better measure retention in the cohort.

2.2 Data

The data used for this paper is a Electronic Medical Records database obtained from the HIV program in Kenya during the ABCE study in IHME. In this facility, 4833 patients have been registered for HIV care, from 2005 to June 2012, totaling 69591 recorded visits. Data entry time is easily available for at least 4853 of these visits.

I hope to obtain additional EMR databases from different HIV program. This would allow me to better measure variability in appointments lags and data entry issues. All the data will be analyzed anonymously and in aggregate form. For each patient, I only use visit dates and scheduled appointment dates are used. If schedule appointment dates are missing, they will be imputed using observed visit patterns in the data. I will also use the metadata collected in the EMR, especially the dates of data saving will be used to estimate data quality.

We will not report precise data on HIV programs performance, and all the data used will used to inform our simulation model.

2.3 Methods

Our work will be done in three main steps. First, we will estimate the relevant quantities in our model from our data. In a second step, we will simulate a cohort and its monitoring, using estimated quantities as parameters. Finally, we will use this simulation, varying different parameters, to answer our main questions of interest.

Modeling - The different parameters described earlier will be modeled and estimated from the cohort data we will have at hand, using a Bayesian approach. The two most important parameters for our work are δ, the time before visit has been recorded in a database, and l, the time between an appointment and the actual visit.

$\delta_{v,i}$ can be modeled as a Gamma distribution $\mathrm{G}(\alpha, \beta)$, with mean $\frac{\alpha}{\beta}$ representing the mean time to data entry of a visit form in the EMR. A Gamma distribution allows for a very long tail on the right, which will allow us to include data loss ($\delta \to \infty$)

$l_{v,i}$ will have to be estimated using a mixture model, to take into account the multimodal nature of the l. We will also have to consider the hypothesis that the the multimodal lateness distribution results from unrecorded shorter term appointments, and if this is the case we may need to use a long tailed distribution as for $\delta_{v,i}$.

Simulation - Using the parameters estimated in the previous step, we will simulate an HIV patients cohort. This simulation will be made using the Cost Effectiveness Analysis Microsimulation (CEAM) framework developed at IHME to simulate epidemiological cohorts.

In a second step, we will simulate the data entry process, for any given month, by drawing a δ for any visit that has been generated (initial or returning), and then computing the date of data entry for the information related to this visit.

As a result of this simulation, we will have all the information needed to estimate retention and measure of retention for the cohort. Varying selected parameters, we will be able to measure the quantities of interest for our study aims.

Quantities of interest - This simulated data will then be used to estimate our elements of interest :

1. Measuring data quality impact We can simulate $p(X = \mathrm{o}|\theta_\delta)$ based on different values of the parameters of θ_δ. Different scenarios will be considered for data quality, varying both the mean and variance of δ. Perfect data quality will be compared to situations with long delays of data entry, and situations with important data loss (high variance of l). The resulting variation in p will be described as the impact of data quality on the measure of retention.

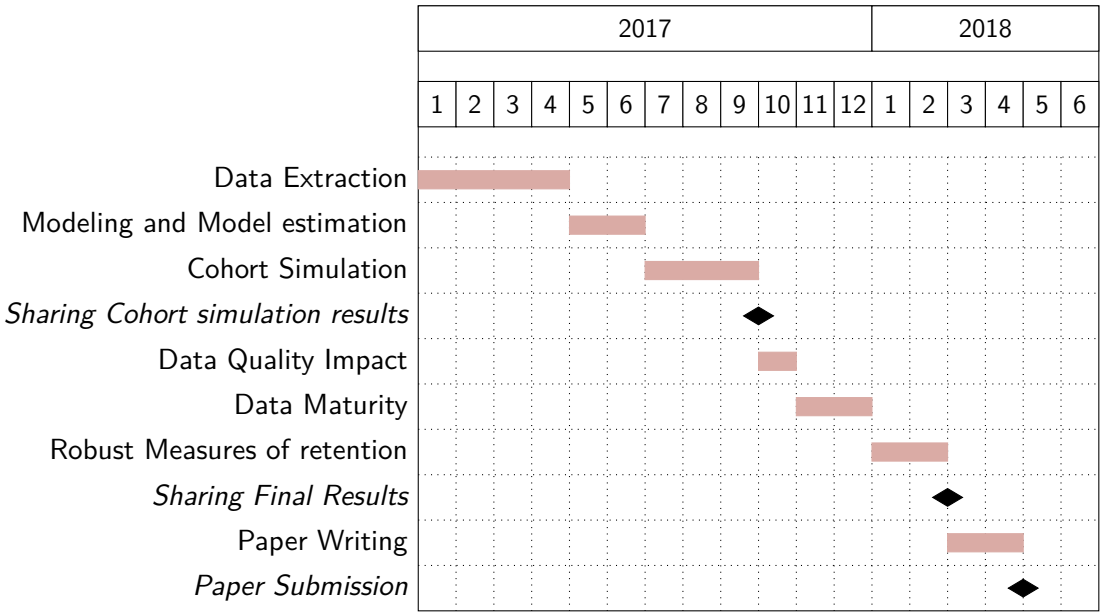

Figure 7: Gantt Chart for Aim 1

2. Data maturity As data is being entered in the EMR, or as missed visits are being made again, the data for a given period will get completed, and patients actively on care are more and more considered so. As data maturity grows in the EMR, the data quality induced error is lowered. Varying T_close can thus have an impact on the measure of retention of a patient on a given date. We will carry out the measure of retention using different closing dates for the database, and only using the data recorded before the closing date. These measures will allow us to define and test a Data Maturity metric, based on a combination of $\bar{f}$, l and δ that will allow us to identify the optimal minimum date of analysis to estimate retention rates in a program, and the optimal grace period G_0 to use for different levels of maturity.

3. Robust measures of retention Finally, we will consider more robust metrics that can be considered good proxies for retention. These metrics will include :

    - The ratio of the corrected average number of registered visits on the expected number of followed patients
    - The ratio of new to returning patients in the facility
    - The probability that the rate of LTFU is higher than a given threshold

For each of these metrics, we will evaluate their capacity to measure retention in the cohort, by comparing with the reference measure of LTFU measured with perfect data. We will also evaluate the sensibility of these metrics to data quality and data maturity.

2.3.1 Timeline

I am still hoping to obtain additional data for this aim. I anticipate starting to work on the estimation of the model parameters from this data in April 2017. Based on these parameters, I will be able to implement the cohort and data entry simulation and will have first results to share on this simulation in September 2017. Based on this simulation, I will estimate data quality impact, data maturity impact and I will test robust measures of retention during the last quarter of 2017 and the first quarter of 2018, and I plan on having final results by February 2018. Figure 7 summaries this timeline.

3 Aim 2 - Data hybridization for population mapping in Niger

Our third and final project pertains to the combination of data sources from outside the health systems to produce relevant information on populations in developing countries. If the low quality or even the lack of existence of good data on populations size and locations is well known in low resource and developing countries, there is a high quantity of data source, sometimes openly accessible, that can help documenting where people live, and who they are.

This project is exploring an innovative approach to mapping of populations in resource-limited settings. Using voters registration lists, to our knowledge a data source seldom used in demography, we will offer a map of population in Niger that will be callable and usable by different actors intervening in Niger. To do this, we will challenge current practice in population mapping, and will aim at producing a point map, more adapted to daily usage than raster surfaces.

3.1 Mapping Sahel populations

In countries that were formerly part of the French colonial empire, investments necessary to produce geolocalized data on population have seldom been done. Paul Pelet's 1902 very first *Atlas des colonies française* did not include a lot of information outside of topographic data[90]. Additionally, there was a radical choice made to use spellings for places in colonies that were adapted to metropolitan French rather than to local languages[90]

Meanwhile, In contrast to geological data or natural features, population is non continuous in space, and is changing fast. In 1935, Fawcett discerned three facts one may want to describe in a population map [91]:

1. The actual number of the people within given areas
2. The density of the population
3. The grouping, or arrangement, of the population.

Each of these facts require a different mapping and require different amounts and nature of primary data, and different computational approaches. The latest advances in population mapping are geared towards the production of density surfaces, presenting a continuous description of where populations live on a territory[41]. This new approach is made possible by the availability of large datasets for land use, and other usable covariates and the computational ability to interpolate these different data sources for population distribution[42].

Meanwhile, this approach presents two main problems that make its result of little use in country like Niger. First, the output format if these maps, a raster of population distribution, is of little use at a local level, where actors typically use place names and not GPS coordinates. Second, in countries with little urbanization, and poor population data, these rasters end up displaying an overlay of covariate layers more than they present a credible distribution of populations. Moreover, if this top-down approach is useful to provide macro-level perspectives on population distribution, it is not useful for local level use. Local actors typically think in terms of places names, more than in terms of GPS coordinates. Additionally, the attractivity of urban centers for rural population is hard to model through macro level covariates, as it often depends on such factors as tradition, habits or administrative border drawing, as is evident in Figure 8.

To offer more useful maps for local actors, I will use an approach supported by minimal modelling of primary population data distribution, and geared towards the anchoring of population in callable localization names.

3.2 Data

Voters list as a demographic Datasource A data source that is, to our knowledge, seldom used to inform population mapping for public health purposes, is voters registration lists. There is meanwhile

Figure 8: Mapping of Niger population from AFRIPOP

a case for the use of voters' registration data to estimate size of populations. By definition, voters' registration should aim at being as complete as possible a register of adults in the nation. Moreover, in most democracies, some form of national elections are held at least every five years, leading to an update at least partial of voters' registrations. In sub-Saharan Africa, between the years 2015 and 2016, 27 countries were supposed to hold national elections, leading to a theoretical registration of more than half of the adult population of the continent. Finally, for transparency and accountability reasons, electors registries are usually supposed to be accessible. [92]

Due to the sensitive and political use of these data, the quality of voters registries are often described as not being trustworthy. On other hand, for the same sensitivity reasons, voters registries are receiving a high level of scrutiny from different actors, and are audited sometimes multiple times before validation. This level of scrutiny before validation is much higher than the attention given to a lot of studies or other often used data sources.

The Niger 2016 elections voters registry In Niger, presidential and parliamentary elections were held in February 2016. Voters lists were updated during the second half of the year 2015, under the supervision and control of a mission of the Office International de la Francophonie (OIF). The operations for registration of voters were conducted during the third quarter of 2015[1]. A first version of the voters list was published on December 21, 2015, tallying 7,569,172 voters, out of 8,569,309 that were expected based on the 2012 census[2]

Final lists were validated in early January 2016 after being corrected for some incoherencies noted by the supervisory body[3]. A final report on these lists was published in may 2016[4]. The Comission Electorale Nationale Independante (CENI) later made these lists fully available on its website, from

[1] http://www.ceni-niger.org/article-region/#more-24

[2] http://www.iinanews.org/page/public/news_details.aspx?id=98929&NL=True

[3] http://www.nigerinter.com/2016/01/le-fichier-electoral-du-niger-valable-sous-reserves/

[4] http://www.nigerinter.com/2016/05/remise-officielle-du-rapport-du-fichier-electoral-au-ministre-detat-a-linterieur-par-le-cfeb/

which I extracted, anonymized and formatted the lists.

RENALOC and RENACOM The *Répertoire National des Localités* (RENALOC) is a geolocalized repertory of all localities in Niger. The 2012 version was downloaded as a pdf file from the *Institut National de la Statistique* (INS) website. The tables were extracted in bulk from this file using the Tabula Package, and then processed in Python to recompose the geographic structure of the document. The final data consists in 34507 localities, for which the INS provides the number of inhabitants, by gender, as well as the number of households, and the number of agricultural households. For most of the localities, a GPS coordinate is recorded, as well as the type of locality (neighborhood, village, camp, water well, hamlet).

The 2006 version, named RENACOM, was retrieved in tabular format directly from the INS website.

OpenStreetMap Additional geolocalization method will be extracted from OpenStreetMap (OSM), using the python API for OSM.

3.3 Methods

This project has three main components.

3.3.1 Name Matching

Due to the history of the creation and administration of the Nigerien territory, different spellings are in use for most localities in Niger. There are no obvious reasons to prioritize one spelling over another for this project. To the contrary, I want users to be able to use whichever spelling of a name they prefer to query their results.

In collaboration with a student in the department of Computer Science, I am designing a matching algorithm for different spellings of the same locality names in Niger. Our approach relies on the use of a mixture of standard string matching algorithms. We use these algorithms for each pair of data sources and define a heuristic to combine them and select best matches. We also enrich these heuristics by defining patterns and features that allow a first classification and simplification of names to improve matching performance. These patterns may be data source specific to reflect specific explicit or non-explicit conventions used in each data source.

After this first round of unsupervised matching, we will manually confirm some of the matches with the help of members of the OSM community in Niger. Using this validated training set, we will fit supervised algorithms to improve our previous matching approach.

As a result of this step, I will have a consolidated list of localities in Niger, with different possible spellings of names for each of them.

3.3.2 Locality mapping

The three data sources that include GPS coordinates (RENALOC, RENACOM, OSM) have GPS coordinates for different subsets of localities in Niger. It appears that RENALOC GPS coordinates are biased, and that OSM coordinates are sometimes rough estimates of exact locations with a rounding factor. I will design an algorithm to attach, for each identified locality, the most probable GPS localization.

1. Get RENACOM GPS coordinates for localities where they are available.

2. Fit some models to correct GPS coordinates in RENALOC using localities with both RENALOC and RENACOM GPS coordinates. Use the best performing approach, as evaluated with cross-validation, to correct RENALOC coordinates

3. Fit some models to correct GPS coordinates in OSM using localities with both OSM and RENACOM GPS coordinates. Use the best performing approach, as evaluated with cross-validation, to correct OSM coordinates

For steps 2 and 3, different linear models will be tested, as well as Machine Learning approaches allowing for different local corrections. For localities with RENALOC and OSM coordinates but no RENACOM, I will evaluate if the results 2 or 3 or a combination of both performs best, using localities with GPS from the three data sources as training set.

As a result of this step, I will have the most complete and accurate map possible of named localities in Niger.

3.3.3 Population estimation

Finally, I will model Niger population using its voters list by precinct as a main data source. I could not source an example of using voters list as a source for demographic estimation. Meanwhile, in a country like Niger where elections are held much more regularly than censuses, using voting lists, a quasi complete enumeration of the population, to estimate population size and structure, does not seem unreasonable.

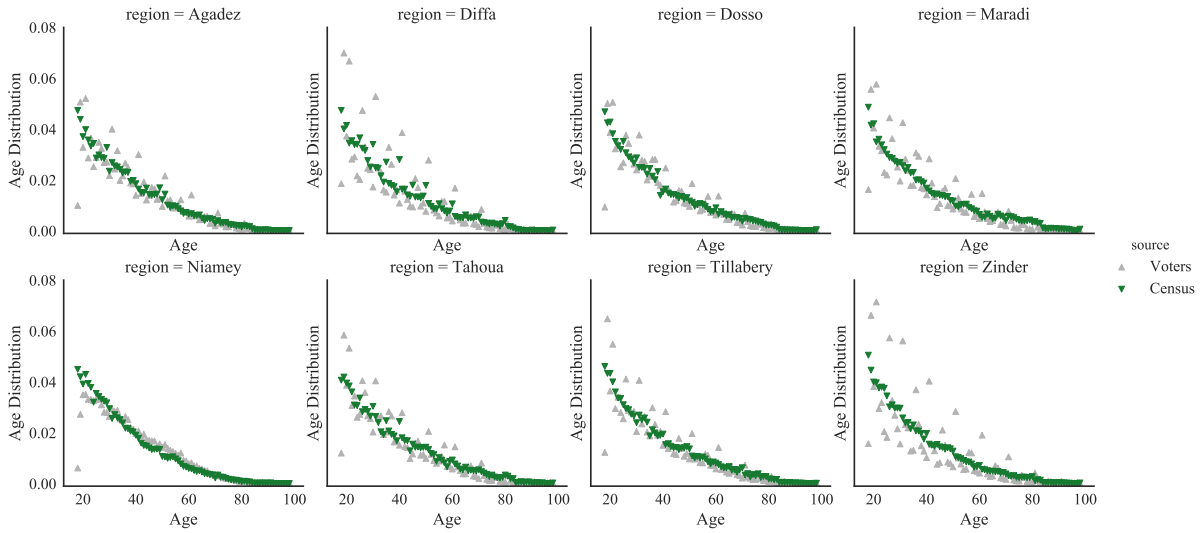

Figure 9: Comparison of standardized adult age distribution between the 2012 census and the 2016 voting lists

A specificity of the voting list is that it does not include children under 18, as they are not allowed to vote. Additionally, the completeness of the data is not perfect, and I should assess and correct voters lists counts to correct this. Finally, as voting lists are very local, I will need to determine the most appropriate level of aggregation to get a meaningful estimation of the population age and gender distribution. Figure 9 compares the standardized age distribution of adults in the 2012 census and in the 2016 voters list at regional level. We can see there is more variability in the voters lists age structure than in the census. Concordance between the two age distributions seems to vary between regions.

We will model population size and age and gender distribution, using a life table method, using different life tables. Our gold standard will be the results from the 2012 census. We will compare performance of our approach applied at locality level, Health Zone level and regional level to choose the best performing approach.

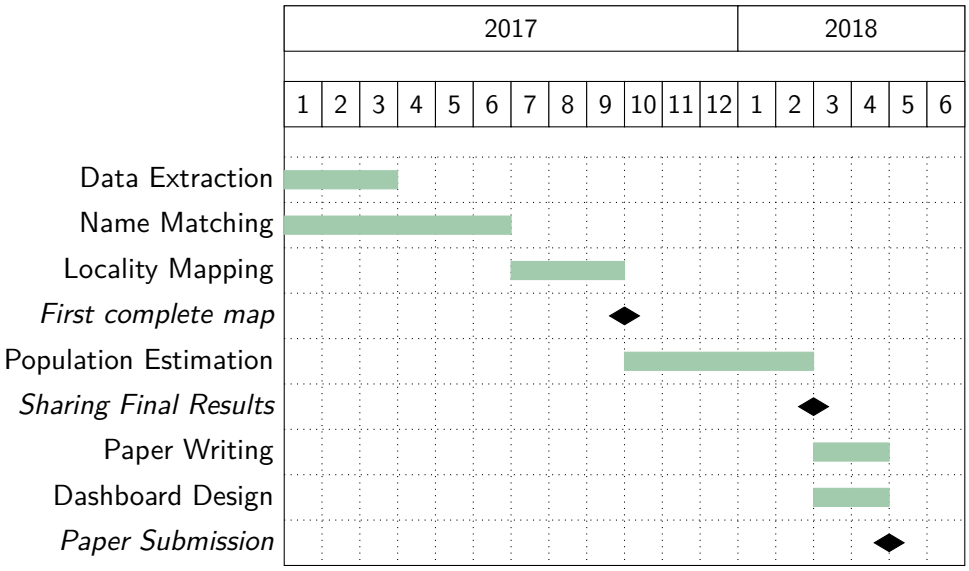

Figure 10: Gantt Chart for Aim 3

3.4 Output

The output of the project for the quarter will be to produce a dashboard, allowing display of our results for local practitioners. This dashboard will have the following feature :

1. An interactive map of Niger localities, selectable by clicking, or panning for multiple selection
2. An estimation of the population in the zone selected on the map
3. A histogram representing the age structure of the population in the localities selected on the map
4. A search box through which the user will be able to search for a given locality. Every name linked to a mapped locality will be searchable and will return the different matching localities in a hierarchized way.

3.4.1 Timeline

I am currently trying to obtain more detailed census data from Niger Census. Meanwhile, the name matching and locality mapping work is already well advanced as we have a first set of matched names from the unsupervised approach, and I have already explored approaches to GPS correction for RENALOC. I anticipate three more months on the name matching and one month to confirm the locality mapping and the overlay with other *adhoc* layers such as health services and health administration map, and should have completed mapping data by September 2017. I plan 5 months of work for the population estimation, and should have my final results by February 2018. Figure 10 summaries this timeline.

[

Data Monitoring]Aim 3 - Health System Data Monitoring and Screening

The second project will be aimed at exploring methods for screening and monitoring of data collected in health systems to inform and orient supervisions. Specifically, we will consider data collected in Result Based Financing programs. Results Based Financing (RBF) is a mode of financing of health systems based on the ex-post payment of health facilities by a national financing body or program. This mode of financing alleviates the burden of planning for coordinating bodies, but transfers it to increased reporting needs for facilities. In order to receive their payment, facilities have to report monthly on a set of indicators on which this payment will be based.

In a RBF system, understanding and monitoring results is thus important on two main levels. First, Program managers want to have an accurate evaluation of the activity they should be paying for, as the accurate evaluation of this amount is key to the sustainability of the program at local and aggregate level. Underfinancing facilities endangers their ability to operate in good conditions. Meanwhile overpaying some facilities may be detrimental to the overall sustainability of the project. Second, being able to measure and compare facilities performance is essential to identify weakly performing facilities, and to start implementing correcting measures.

In Bénin, the Programme de Renforcement du Système de Santé (PRSS) has been launched in 2011 by a consortium formed by the Beninese government, the World Bank, the GAVI Alliance and the Global Fund. As part of this program, a comprehensive RBF program has been implemented in all 34 health zones of the country. To allow the management of RBF reporting data, the software OpenRBF, developed by the Belgian startup Bluesquare has been implemented.

In systems using OpenRBF, data is collected in facilities for indicators contracted in the RBF program, and are reported at district level on a monthly basis. The District administrators are in charge of entering the data in the OpenRBF database. This monthly data is then aggregated, and checked on a quarterly basis for quality. Data quality check is made through a field visit made by project managers in facilities, which will then check the quality of primary data collection in facilities (reports, charts) and the quality of reporting, by comparing collected primary data and reported numbers.

This system allows to improve the confidence and exactitude of reported numbers, on which payments to facilities depend. Meanwhile, it is costly and does require regular field visits by program managers, in order to identify on average XX data problems per month, leading to savings of YY$ by month.

This system has proved its worth in allowing RBF program managers to access credible data on facilities performance. Meanwhile, in a program managing close to 800 facilities, it is increasingly unceasingly difficult to validate data, and to monitor service quality in facilities. We will develop an approach to screen indicators reported by facilities, to help program managers making decisions. The decision framework in which we operate is quite simple, and has two main outcomes : validate data or not, raise a service quality issue or not. These two outcomes are not independent, and all depend on an evaluation of the normality of reported data when compared to previously observed data.

3.5 Research questions

This project will be aimed at developing and validating a generic framework for screening and validating data reported by facilities in the Bénin RBF program. We will develop this framework in four specific objectives.

Data screening In a first step, imputed distributions will be compared to reported data. We will develop and validate a set of rules and visualization to guide and inform decisions makers to validate data, and to judge quality of services based on reported data.

Classification

Program Management Finally, we will simulate different strategies to prospectively collect data in facilities, so as to allow an optimal performance of imputation models at a minimum cost.

3.6 Data

OpenRBF has been implemented in Bénin since March 2012, and has been rolled out in every departements of the country. Data is collected and validated monthly for both the *Minimum Activities Package* (PMA). As of January 2017, the data consists in 16131 facilty/months of PMA data in 671 different facilities. In each report, a median of 75% of indicators are correctly reported.

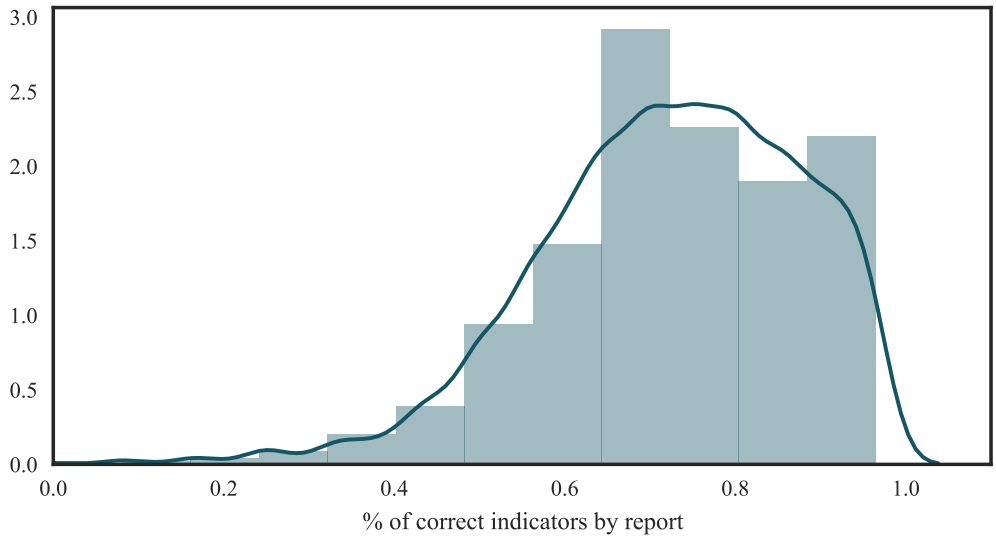

Figure 11: Distribution of the percentage of correct indicators by report

3.7 Methods

Each month, each facility sends a report, composed of indicators. Each indicator I has a unitary cost C. Thus, on month t, facility f will receive a payment of the amount :

$$P_{t,f} = \sum_i I_{i,t,f} C_{i,t,f}$$

When taking into consideration a monthly report from a facility, we want to measure the marginal and joint probabilities of two events Q and D, where :

1. $Q = 1$ if the quality of care in the facility appears in accordance with the quality in other facilities.
2. $D = 1$ if the data appears of sufficient quality to base payment of the facility on it.

We are thus most interested in three distinct joint events :

- $D = 0$ the data appears to be of insufficient quality to draw conclusions
- $D = 1 \cap Q = 0$ the data appears sufficient but quality of service seems poor
- $D = 1 \cap Q = 1$ the data appears sufficient and quality of service seems good

The definition of D results from a budgetary arbitrage. A report is considered of insufficient quality if the expected monetary value of the payment made to facility based on this report is too severely affected by data quality. We are then interested in the difference between the payment based on reported data ($\bar{P}$) and the expected payment based on all validated information available (P^*).

I will approach this problem in two steps. I will first test multiple approaches for process monitoring, to detect and spot unlikely data patterns. I will then define a approach to classify detected abnormalities as either $D = 0$ or $D = 1 \cap Q = 0$.

3.7.1 Data Screening

Methods for continuous data inspection and screening come from the industrial statistics domain and are increasingly applied for healthcare monitoring [93, 94]. Spiegelhalter et al. provided et nice overview of how these tools can be used for health systems, for three main functions of interest : rating, screening and surveillance [69]. These methods are based on the standardization of data distributions, and the analysis of observed data to detect values diverging from their expected distributions. This second stage, geared toward hypothesis testing, can be made using visual tools based on adaptation of classical charts like Shewart charts, Cumulative Sum control charts (CUSUM) or Exponentially Weighted Moving Average charts (EWMA). I will compare and combine three approaches to this data screening question.

Syndromic Surveillance A first approach is to define the expected distribution of a given series based on its past values. This approach is widely used in syndromic surveillance, and builds on a model-based CUSUM approach, where the expected count of cases for a given period is modeled based on historical data, and the CUSUM is updated at each period using the forecasting errors [95]. Fricker writes a general version of model-based CUSUM as monitoring $S(t)$ where :

$$S(t) = \max(0, S(t-1) + x(t) - k)$$

where $x(t) = \frac{Y(t) - \hat{(Y)}(t)}{\sigma_\epsilon}$ is a standardized prediction error for $Y(t)$ on σ_ϵ the variation of the model error, and k is a tuning parameter that will have to be optimized to obtain detection characteristics for our model.

A reference implementation of this approach was developed by Farrington et al. [66] and updated by Noufaily et al. [67], and is implemented in R. I will implement this approach to test its ability to detect and differentiate between data quality issues and regime changes for certain indicators series. I may also use the Z-Score aggregation approach described in [96] to aggregate multiple indicators result for a given facility month.

Hierarchical Modeling A second approach defines expected values from a facility based on a hierarchical model including all facilities. Using bayesian hypothesis testing strategies based on multiple sampling from the posterior distribution, this approach allows me to spot unlikely numbers for a given facility as well as facility level unusual performances for a given indicator[70]. A hierarchical Poisson model for each I_i, in a facility f can be defined as :

$$I_{i,t^*,f} \sim \text{Poisson}(\exp(\alpha_f + \sum_{i,t<t^*} \beta_i I^v_{i,t,f}))$$

$$\alpha_f \sim \text{N}(0, \sigma^2_\alpha)$$

$$\forall (i,t,f), \beta_{i,t,f} \sim \text{N}(0, \sigma^2_{\beta_{i,t,f}})$$

For time t^*, $\tilde{I}_{i,t^*,f}$ will be simulated by first simulating parameters α_f and β_i and second drawing from the corrsponding Poisson distribution using the different parameters.

Profile Monitoring Finally, we want to be able to detect pattern variations in reports. Indeed, the methods we described until now are targeted at monitoring univariate series for which desirable variations are clearly identified. In in-control situations, number of cases of monitored diseases are expected to stay low, and mortality rates are supposed to stay low. In the monitoring of RBF data, meanwhile, there is no clear denominator to construct rates, and there is little sense of what an "in control" situation should look like for individual indicators. Profile monitoring is an increasingly popular research area[94], and has many trends and applications, but I couldn't find any application in the healthcare sector. Its main idea is to monitor how indicators in the monitored process are related by a functional relationship, instead of monitoring individual indicators themselves. This relationship can be specified in parametric[97] or non parametric ways[98], and I will explore the options offered by the latter approach for the type of data we have.

For each of these approaches, I will need to define thresholds to define unlikely data. This threshold will be a combination of analysis of the deviation of the observed indicators from the expected distributions, and will also incorporate an element of financial risk for. We noted the constraints of the RBF, which should aim at spending their budget efficiently, but ensure facilities have sufficient budget to operate their basic activities. I thus define the threshold of data credibility from a financial perspective as :

- For the upper limit, we want to identify the risk that the cost of bad data for the system exceeds a certain threshold. This can be defined as

$$\bar{P} - P^* > \eta_1 \Rightarrow D = 0$$

with $\eta_1 > 0$.

- For the lower limit, we consider the risk of underfunding the facilities, if the payment claimed is significantly smaller than the expected payment. This can be defined as

$$\frac{\bar{P}}{P^*} > \eta_2 \Rightarrow D = 0$$

with $0 < \eta_2 < 1$.

For any given pair of thresholds (η_1, η_2), for each report computed in month t for facility f, I am thus interested in evaluating :

$$p(D = 0) = p(\bar{P} - P^* > \eta_1 \cup \frac{P^*}{\bar{P}} > \eta_2)$$

$$p(D = 0) = 1 - p(\bar{P} - P^* < \eta_1 \cap \frac{P^*}{\bar{P}} < \eta_2)$$

This will be made by sampling the posterior distributions of each $I_{i,f}$ and applying the correct tariff.

For any given month t^* in the data, I will sequentially evaluate each approach in this section using validated data from previous periods $t < t^*$. I will be able to evaluate the ability of each approach to identify low quality data, or data that is too different from expected its values.

3.7.2 Risk Classification

The second step of this work will be to describe the risk associated with the reported data. As described earlier, I want to provide an indication of two different types of risk : a data quality risk (D) and a quality of care risk (Q). For any indicator or report spotted as behaving in an unexpected way, I will want to understand if the problem detected can be linked to data quality issues or to a modification of the conditions of care in the facility.

This classification will be made using the results of each methods used for data screening and combinations of their results as features for classification methods. Using the confirmation data, I will be able to train various supervised learning approaches for classifying data as diverging from the expected distributions.

3.7.3 Validation and Operational fine tuning

Performing algorithmic verification comes with a risk of creating reinforcing errors. Since we fit the expected distribution of I_i using only the data that was previously validated on the field, the periodic creation of such validation data points for every facilities is essential to ensure these expected distributions are still in line with reality. Meanwhile, in facilities that demonstrate good measured data quality, data will be verified less frequently than previously. This holds potential risks for our approach to be able to detect variations in performance. The question we know ask is thus, what is the minimum of validated data that has to be available in a facility to allow algorithmic validation to perform well ?

The question at stake here is to find a best performing arbitrage between data verification costs and benefits of verification. To identify a best performing data validation strategy, we will compare four strategies :

1. **Reactive validation only :** On site data validation is only performed in facilities were data quality issues have been suspected algorithmically.
2. **Reactive and yearly validation :** On site data validation is performed in facilities in which data issues have been suspected, but every facility has to be visited at least once per year.
3. **Reactive and bi-annual validation :** Same as the previous scenario, but every facility has to be visited at least once per semester.
4. **Reactive and quarterly validation :** Same as the previous scenario, but every facility has to be visited at least once per quarter.

The comparison will be made by simulating progressively the implementation of each strategy on the available data. We will be describing the performances of each approach in the same way we described the performance of the full model in section 3.7.

3.8 Timeline

The data for this aim is already available and has been partially cleaned. I envision needing four months to implement the different data monitoring approaches, and four months for risk classification and operational fine tuning.

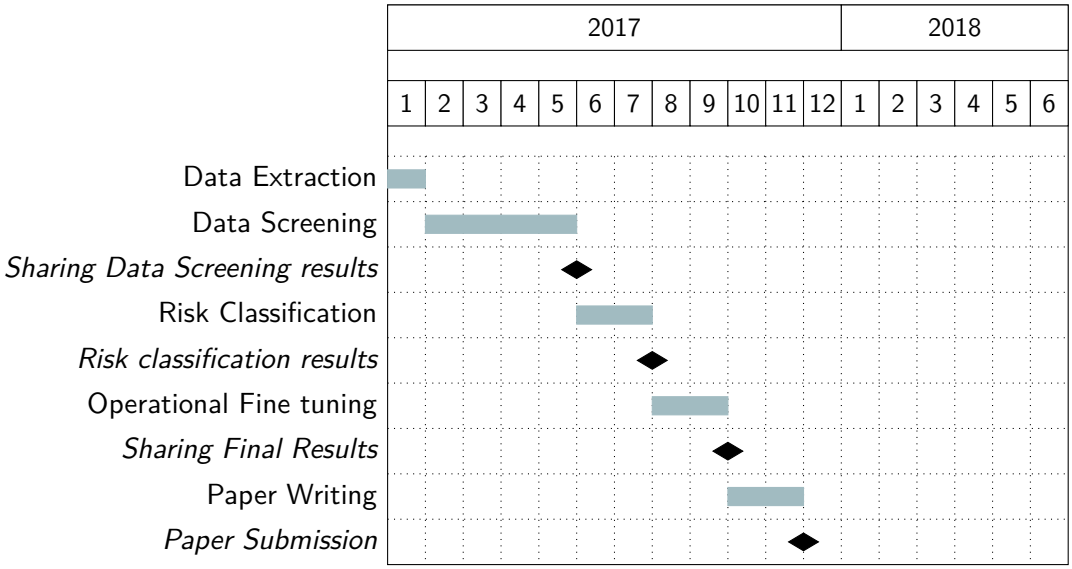

Figure 12: Gantt Chart for Aim 2

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