PhD in Global Health

Metrics Track

Local Practice or Global Norm ? Exploring the border between local and global Health Metrics

Grégoire Lurton

IHME
Institute for Health Metrics and Evaluation

Abstract This proposal defines a project for a doctoral research into data processing and analysis methods adapted to Health Information Systems (HIS) in developing countries. My research explores the relationship between local and global levels of analysis in Global Health Metrics.

I concentrate on three important dimensions of this relationship. First, I define an approach to local indicator definition. Using EMR data from HIV care in different countries, I show how the most common metric used for patients retention in HIV care is impacted by data quality and local characteristics, and I explore robust alternatives to this metric. Second, using widely available data from Niger, I implement a data-hybridization strategy to produce an actionable map of Niger population. Finally, I develop an analytical framework to understand the relationship between health metrics and the political and social systems in which they are used.

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 data in low-resource settings. Finally, it will contribute to the STS field by offering a framework the analysis of how quantitative methods in health systems are affected by the structures in which they are used, and how they can in return impact these structures.

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Acronyms

ART Antiretroviral Treatment. 6

CEAM Cost Effectiveness Analysis Microsimulation. 10

CENI Comission Electorale Nationale Independante. 14

DHIS2 District Health Information Systems. 2, 4, 15

EMR Electronic Medical Records. 3, 4, 6, 8, 10, 11

GBD Global Burden of Disease. 1, 2

ICT Information and Communication Technologies. 4

INS Institut National de la Statistique. 14

LTFU Lost To Follow Up. 3, 6, 8–11

M&E Monitoring and Evaluation. 2

OIF Office International de la Francophonie. 14

OSM OpenStreetMap. 15, 16

RENACOM Répertoire National des Communes. 14–16

RENALOC Répertoire National des Localités. 14–16

SNIS Système National d'Information Sanitaire. 15

STS Science and Technology Studies. 4, 19

1 Introduction

1.1 General Overview

Research in Global Health navigates between different levels of relevance. A global level, that aims at understanding global phenomenons and trends pertaining to the health of populations, and a local level, in which policies are designed, implemented and evaluated. The articulation between these two levels is essential, and gives Global Health its coherence and its specificity. Funding for local policies are defined by global institutions, using highly aggregated Health Metrics. In the meantime, global priorities are also informed by the results of local experiences, that are translated into generalizable practices.

A challenge for Global Health Metricians is to create and disseminate information that will be relevant at each of these levels. Defining metrics and approaches that will have global relevance and comparability seems to be a different work from creating actionable actionable evidence on which national and local deciders will be able to base their own decisions.

This challenge is not merely a technical one, but also a structural one. The field in which this information is produced is indeed not level, but bears the mark of historical and political structures, heritage from centuries of scientific development and nations building. The result of this history on public health expertise is described by Bergeron and Cassel as "a network involving many different actors, structures and tools, concepts and spatial and institutional arrangements" (Bergeron & Castel 2014).

Isn't the will to define a global research agenda to understand such complex and local equilibria the fundamental paradox of Global Health ? This question often finds technicist answers. The ability of statistics to offer rational basis to make decisions (Desrosières 1993, Porter 1996), allied with progresses in data collection and analysis techniques haved fostered enthusiasm and hope in the ability of governments and other actors across the world to design and implement public health policies based on strong evidence (Abou-Zahr & Boerma 2005, Shibuya et al. 2005, Bambas Nolen et al. 2005, Mutemwa 2006, Boerma 2013). Better data, allied with better methods should offer the basis to produce strong evidence, both at local and global levels.

In this regard, Global Health Metrics as a field has emerged as a set of tools and concepts to improve the quantification and comparison of health for every populations around the globe. Murray and Frenk described the field as unifying in its purposes as well as in its methods(Murray & Frenk 2008). The vision they delineate is one of standardized data, tools and methods, shared results and synthesized knowledge. Global projects such as the Global Burden of Disease (GBD) have demonstrated the success of this approach in fostering international cooperation and offering unified, comparable results on Global Health issues across time and space.

There is thus a pull towards norming and standardization in the production of Global Health knowledge, which is often understood as a technical necessity. Meanwhile, critical works in the field of global measurement have warned on the oversimplification provided by global indicators, and have questioned the ability of this approach to provide locally relevant information(Merry 2011, Rottenburg et al. 2016). These critics should lead Global Health researchers to question the political assumption hidden in the methods we use, and to look into ways to mitigate their most stringent limitation. How can a global framework serve local action? In which conditions can a local metric be useful at a global level.

My work explores ways in which locally relevant health metrics articulate with global norms. I question this issue looking at different levels:

Critical Framework My work relies on a critical approach to measurement in Global Health. I want to question measurement strategies that privilegy external validity and global comparability of metrics over local usability of the results. The main stake here is to provide a description of how the structure of Global Health as a political, economic and academic field heavily influences quantitative methods, by giving a higher priority to a global level over a local level. My goal is

to offer a framework holding together the technical and the political characteristics of a Global Health measurement approach.

Development As a Global Health Metrics researcher, my main tool is the development of data processing and analysis methods that can be used to better understand data produced in low resource Health Information Systems. I question current methods and structures by looking at their limit of validity, and looking into how different approaches could yield better results.

Implementation Finally, the goal of this work is to be offer tools that could be used by practitioners in the field of Global Health. I work on the development and implementation of tools for daily usage. In the scope of this dissertation, this component will not be carried out, but each methods development has a potential future implementation as an end goal.

This variety of concerns in this dissertation is relevant as each dimension informs the others. By disentangling the technical necessity from the political expediency in measurement practice, I identify structures and practices that can be amended, once they are acknowledged. In the meantime, when developing new methods, I keep an eyes on how these methods can be used, and how they will be implemented.

1.2 Work hypothesis

My main work hypothesis relies on the distinction between a *top-down* approach and a *bottom-up* approach to measurement for health. The precise description of the characteristics of these approaches is one of the aims of this dissertation. In first intention nonetheless, I can describe *top-down* methods as methods that are defined and standardized at global level, and later rolled out in different settings. This description fits most HMIS design recommendations for building Health Information Systems in developing countries. (Lippeveld 2000, RHINO 2003, d'Altilia et al. 2005, Health Metrics Network 2008). Moreover, it is the foundation of the Monitoring and Evaluation (M&E) field. Guidelines such as those of Global Health agencies like the Global Fund have important influences on the organization of health information systems 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 (The Global Fund 2014). The limitation of these approaches is that the asymetric relationship between global and local actors leads to a *reductio ad M&E* of information systems, that are built to answer imposed norms but do not create their own logics, cultures and traditions.

A contrario, *bottom-up* methods are geared towards an aggregative approach of evidence. They rely on the use of data locally collected in *ad-hoc* ways. Most of the technical data work in this approach is dedicated to the upward movement of data aggregation, for example to produce national or international level analysis. This type of approach is *de facto* used in health systems with a diversity of actors, for example when international NGOs use data systems that are different from the national Health Information System. It is often considered ineffective and dysfunctional, because of the difficulty to compare results from different local systems, and because of a perceived deficiency of health information systems that do not abide to validated international standards. Meanwhile, they have the benefit of fostering the development of local data culture, local data usage and ownership.

Of course, most projects do not fall completely in one of these categories. A project like the District Health Information Systems (DHIS2), for example, aims at providing standardization of data at Health District level. Part of the theory behind this tool is that district level is the right level of standardization, to offer flexibility at facility level. On an other level the GBD as a project has some of the aggregative characteristics of a *bottom-up* approach, with some globalizing and standardizing characteristics of a *top-down* project. Finding the right theoretical framework to make this classification operative will be one of the tasks of the third aim of this dissertation.

1.3 Aims

The principal aim of this dissertation is to test and describe the differences between *top-down* and *bottom-up* approaches to producing statistics in low resource health systems, and to explore the respective benefits of each approach. I address this principal aim through three specific aims. The two first aims will be concrete examples of analytic questions I will use as examples of the difference between the two perspectives. The third aim is to provide a generic framework justifying the relevance and the usefulness of differentiating between these two approaches to build more relevant health information systems.

Flexible Standards Defining categories based on which people are going to be counted is an essential piece of the statistical work (Desrosières 1993). 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 on Metrics like the Disability Adjusted Life Years, to unify description and measurement of health across the globe, and allow comparison and benchmarking (Murray 2007, Murray & Frenk 2008). 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, and efforts have been made to track measure to inform strategic planning and programs evaluation (The Global Fund 2014). Meanwhile, the measure used in most settings to track patients retention, namely the proportion of patients that are considered Lost To Follow Up (LTFU) after a certain time in care, is problematic. The high variation of LTFU rates between programs and the low specificity of this metric leads researcher to question the way Loss to Follow Up is defined and measured globally (Chi et al. 2011, Yehia et al. 2012, Grimsrud et al. 2013, Forster et al. 2008). Using Electronic Medical Records (EMR) data, I will model how the measure of retention is affected by local contexts and data quality, and I will explore more robust ways to measure retention in HIV care.

Data Hybridization Unavailability of reliable data on population geographical distribution in a large number of countries is a well known issue (Mahapatra et al. 2007, Mikkelsen et al. 2015). 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 lighting imagery (Linard et al. 2012, Stevens et al. 2015). 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 second 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.

Framework for Information Systems critique To understand how the distinction between *top-down* and *bottom-up* methods can help build Health Information Systems in low resource settings, we need to build a critical framework to understand the *Information Infrastructure* (Bowker et al. 2009) of these systems. I will offer an overview of the influences and assumptions that structure current health information systems in developing countries, and I will describe the enabling and limiting aspects of these systems, linking their technical characteristics to their political implications. Using results from the two first aims as well as other project I am working on, I will explore the relevance of the vertical classification of health information systems. Finally, I will delineate a framework in which practitioners can think the mix of methods they use in Health Information Systems, to serve their varied needs.

1.4 Novelty and scientific contribution

My dissertation is contributing to three main areas of research surrounding Health Information Systems. One is mostly investigated by the Information and Communication Technologies (ICT) community 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 inform decision making. The last domain of contribution will be more related to the Science and Technology Studies (STS) field, and will endeavor to integrate results from this field with applied statistical work.

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 presided to the design and development of the DHIS2 remarks that "the top-down and all-inclusive approach to standardization [is] common among ministries and central agencies" and pleads for *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" (Braa et al. 2007). The need for local adaptability of Information Systems is seen as a key issue of ICT in developing countries (Macfarlane 2005, Walsham & Sahay 2006, Walsham et al. 2007, Jacucci et al. 2006) and thus some ICT solutions have been designed and explored in the forms of tools like DHIS2 or standards like the Open Health Information Exchange initiative.

Aims 1 explores ways in which standards for indicators definition or for the evaluation of data quality can be adapted to specific contexts. An extension of this work could also be the definition of methods for aggregation and comparison of metrics defined and measured using flexible standards.

1.4.2 Imperfect data Usage

Health Information Systems data is often underused, or not used at all by its intended users(Health Metrics Network 2008). This underuse is often blamed on the perceived bad quality of primary data that would make it unfit for statistical analysis (Ronveaux et al. 2005, Makombe et al. 2008, Heunis et al. 2011, Gimbel et al. 2011, WHO 2011, Hahn et al. 2013, Kihuba et al. 2014, Glèlè Ahanhanzo et al. 2015). Approaches to solve this issue have mainly focused on improving primary data quality to improve data use (Braa et al. 2012, Mutale et al. 2013, Ledikwe et al. 2014, Nisingizwe et al. 2014), but some authors have also pointed to the possibility to use even imperfect routine data to answer specific public health questions(Gething et al. 2006, 2007, Wagenaar et al. 2016). 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 offers 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 1 and aim 2 also examine methods to enrich data, 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 Internal Critic for health statistics

Most of the critics made on the use of statistics to inform and manage public policies comes from a post-modernist perspective, with a tendency to put an emphasis on the shortcomings of statistical systems, and their hidden political agenda. Statistical tools are considered over-simplifying, biased, or sometimes just inadequate (Merry 2011), and when used for Monitoring and Evaluation of public

policies, they are considered too prone to enforce power relations instead of offering knowledge (Desrosières 2014, Gaudillière 2016). My approach, as a statistician, will not be to try to prove or disprove these claims. Building on Latour's suggestion for a productive critic (Latour 2004), I create a framework for the co-construction of a technical object and its critic. I will be exploring the relationship between social structures and analytical tools through the exploration of the technical limitations of these tools, and looking how their adaptation question current structures.

Aim 3 offers a framework in which to critically understand different approaches to health information systems, and anchors the development of new tools in this framework.

1.5 Timeline

Aims specific timelines are explained in more detail in sections 2.4, 3.4 and 4.3. 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.

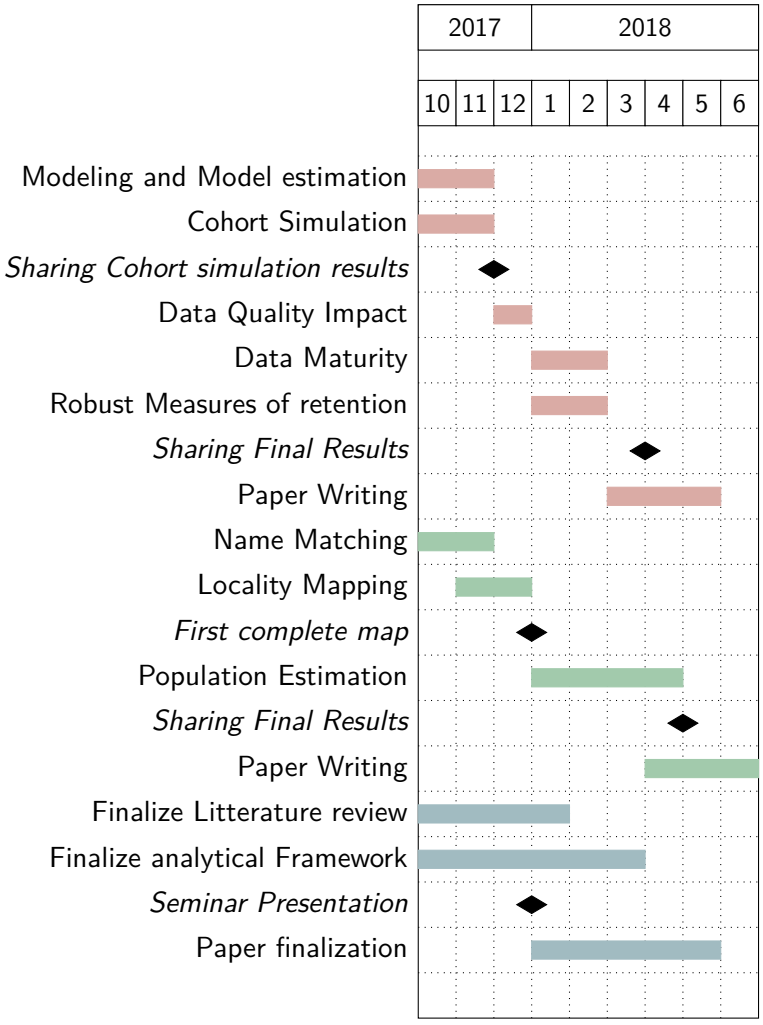

Figure 1: Dissertation Timeline

2 Aim 1 - Flexible Standards for categories definition

The measure of retention of patients under Antiretroviral Treatment (ART) 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 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 how and why patients remain in care on the long term (Ioannidis et al. 1999, Lebouché et al. 2006, Moh et al. 2007).

Initiating treatment programs, HIV practitioners used the categories that had been developed and used in clinical trials to categorize patients outcome. This definition 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 (Kwong-Leung Yu et al. 2007, Dalal et al. 2008, McGuire et al. 2010). 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 (Yiannoutsos et al. 2008, Geng et al. 2010, Tassie et al. 2010), or by fitting correcting models (Brinkhof et al. 2010, Egger et al. 2011, Van Cutsem et al. 2011, Henriques et al. 2012, Verguet et al. 2013). Finally, some authors started paying attention to how the very metric used to measure patients retention could heavily impact the evaluation of HIV programs performance (Chi et al. 2010, 2011, Fox et al. 2012, Mugavero et al. 2012, Yehia et al. 2012, Grimsrud et al. 2013, Shepherd et al. 2013).

An important underlying hypothesis of the use of the LTFU metric as a proxy for retention 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 (Lebouché et al. 2006) but it can be problematic in developing countries, where data quality in care setting is often difficult to guarantee. In these settings, the delay between a visit and the time of data entry will be important, mechanically inflating the number of LTFU (Lurton 2012). 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 seldom made.

With the development and rollout of 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 through three specific aims :

Impact of data quality on the measure of retention I will model the path through which data quality impacts the measure of retention, and will simulate the results metrics 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 period improves over time. I will define a metric of data maturity to describe the ability of a database to measure retention for a cohort. This measure will be tested and validated on the simulated cohort.

Robust Retention Metrics Building on the insights gained in the previous aims, I 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 Theoretical Framework

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 2 shows the distribution of l_v^i in our data. Unrecorded appointments are handled by dividing the time between scheduled appointment and actual visit by 28, and considering 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.

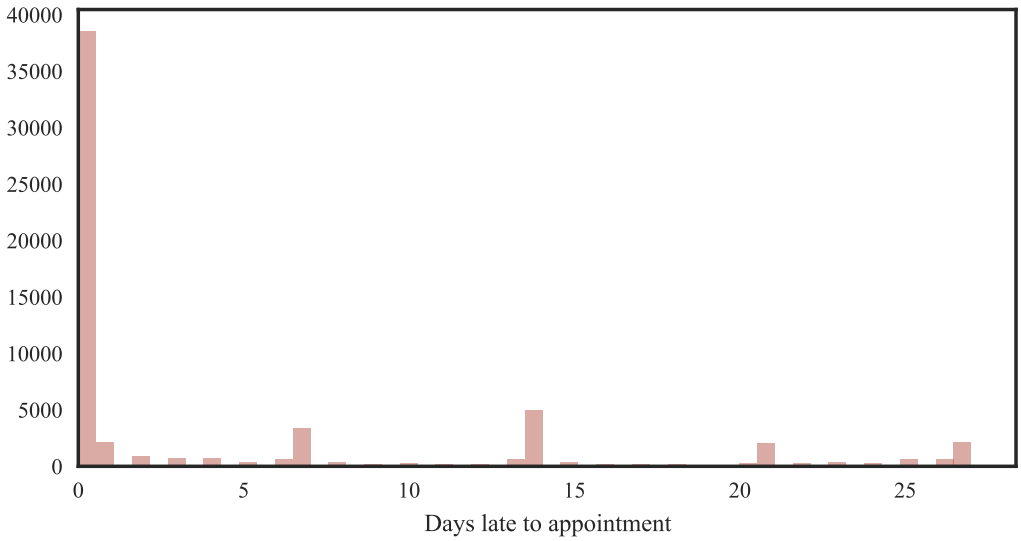

Figure 2: Distribution of l_v^i in our data.

The time elapsed between a visit and the next scheduled appointment is set by the national norms regarding the frequency at which HIV 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 follow-up and no complications. We note (f_v^i) 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 (cf. *supra*). Figure 3 shows the distribution of f_v^i in our data.

We can finally express the time between two visits as :

$$V_{v+1}^i - V_v^i = f_v^i + l_v^i$$

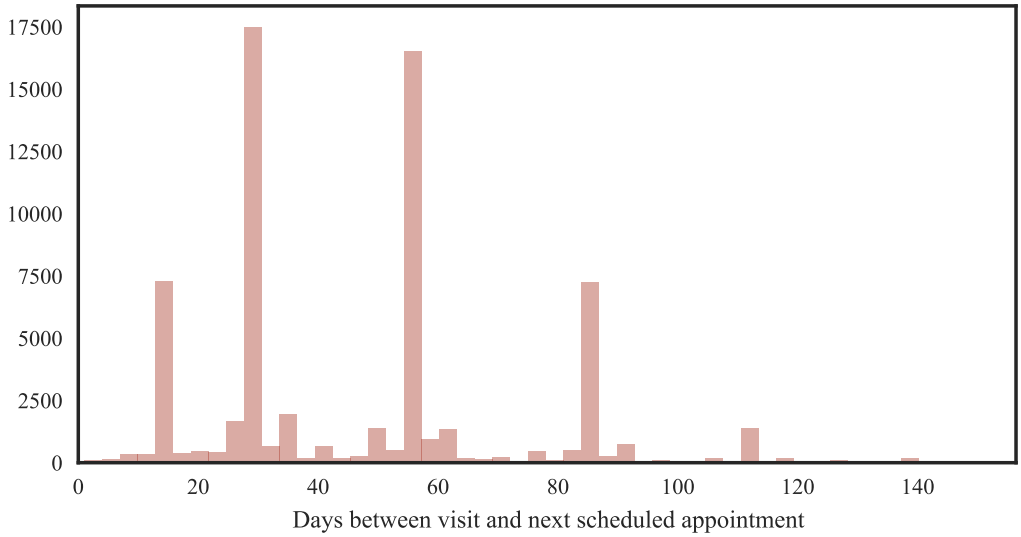

Figure 3: Distribution of f_v^i in our data. We see the visits are scheduled mainly 7, 28, 56 or 84 days after the previous visit

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 :

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

δ may vary in a facility, depending on the workload, staffing or other factors. In some cases, the visit has not and will never be recorded. I will note this situation as $\delta \to \infty$. Figure 4 shows the distribution of δ in our data.

Finally, data entry is interrupted at 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 5 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_0.

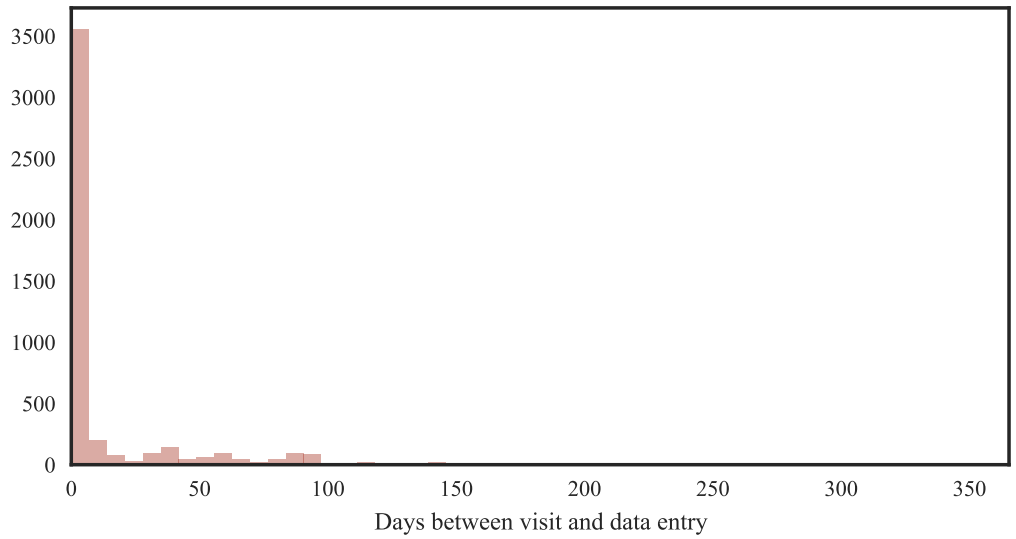

Figure 4: Distribution of δ_v^i in our data. Most of the data is entered in the first week following the visit, but we see some data can be entered much later

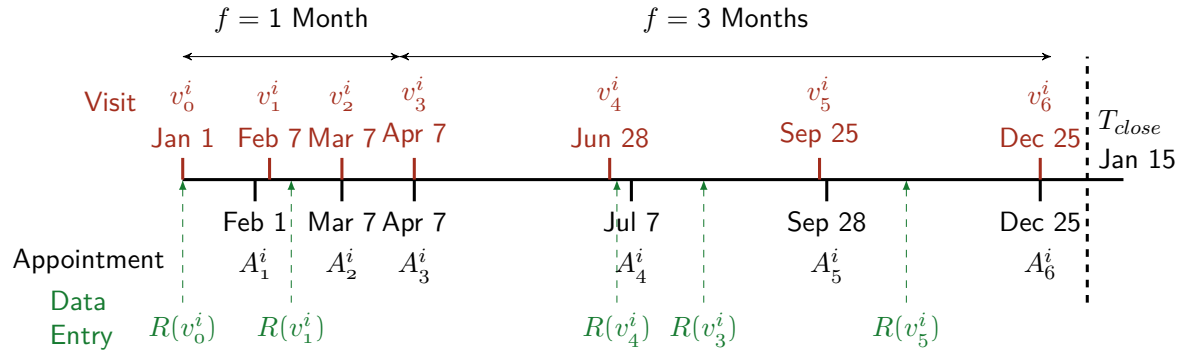

Figure 5: Individual follow-up and data entry process

A patient i is considered LTFU if he is late to his latest scheduled appointment for more than G_0 days.

$$l_{v^*}^i > G_0$$

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

1. $l_{v^*}^i \to \infty$: The patient is LTFU and will never come back to the facility.
2. $\infty > l_{v^*,i} > G_0$: The patient is late to his appointment but will come back in the future.
3. $\delta_{v^*+1} > G_0$: The patient came for his visit $v^* + 1$ but data entry took longer than the grace period and the visit was not entered at the time of database closure.

Using this definition, we can express the probability that a 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 $X = 0$ the event that the patient is LTFU. We can get $p(X = 0 | l_{v^*}^i \leq G_0)$ as the combination of elements we can measure :

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

We can understand $\infty > l^i_{v^*} \leq G_0$ as an intrinsic myopia of the health system, who can not predict the future, and $\delta_{v^*+1} > G_0$ as a data quality measure. 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 aim are EMR database obtained from the HIV programs. I currently work with an EMR from Kenya, and part of IHME's ABCE study. 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 two additional EMR databases. The ISanté EMR, used in Haïti, and multiple implementations of the FUCHIA system, developped by Médecin Sans Frontières and used by the national HIV program in Niger. 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. If scheduled appointment dates are missing, they will be imputed using observed f^i_v in the data. I will also use the metadata collected in the EMR, especially the dates of data saving, to estimate data quality by measuring δ distribution.

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

2.3 Methods

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

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

A first approach to modeling these parameters is to express δ 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 could be modeled using a mixture model, to take into account the multimodal nature of the l. I will also have to consider the hypothesis that the multimodal l distribution results from unrecorded shorter term appointments, and if this is the case we may need to use a long tailed distribution as for δ.

Simulation - Using the parameters estimated in the previous step, I 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 which I will feed draws from the posterior distributions of the previously estimated models.

In a second step, I will simulate the data entry process, for any given month, by drawing a δ for each visit that will have 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, I will have all the information needed to estimate retention and measure of retention for the cohort. Finally, varying the relevant parameters, I will be able to measure the quantities of interest for my study aims.

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

1. **Measuring data quality impact** : From the cohort simulations, I will measure the LTFU rate using different distributions of 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 δ). The resulting observed variation in the LTFU rate will be described as the impact of data quality on the measure of retention.

2. **Data maturity** As data is being entered in the EMR, or as missed visits are finally being made, 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. I 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 me to define and test a Data Maturity metric, based on a combination of 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_{o} 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, I will evaluate their capacity to measure retention in the cohort, by comparing with the reference measure of LTFU measured with perfect data. I will also evaluate the sensibility of these metrics to data quality and data maturity.

2.4 Timeline

I have obtained the data I need for this aim and have made a first set of microsimulation and started the estimation of relevant parameters in my data. 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 March 2018. Figure 6 summaries this timeline.

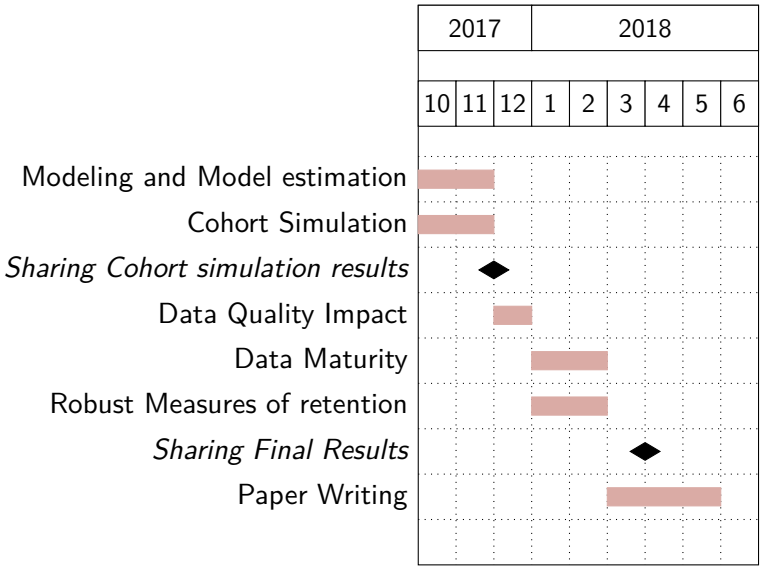

Figure 6: Gantt Chart for Aim 1

Figure 7: Mapping of Niger population from AFRIPOP

3 Aim 2 - Data hybridization for population mapping in Niger

In 1935, British geographer Charles Fawcett defined three phenomenons that could be described on a population map (Fawcett 1935):

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

Each of these elements is important to design public health programs, to plan infrastructure development or to implement quick emergency response (Bambas Nolen et al. 2005, Thieren 2005). Meanwhile, the lack of good quality data on populations size and locations in low resource and developing countries is well known (Mikkelsen et al. 2015). As a consequence, most current approaches to population mapping rely on models aimed at mapping density surfaces (Linard et al. 2012). This approach makes best use of the availability of large datasets for land use and other usable covariates, and of the computational ability to interpolate these different data sources for population distribution(Stevens et al. 2015). As is evident for Niger in Figure 7, in countries with little urbanization, and poor population data, these methods end up displaying an overlay of covariate layers more than they present a credible distribution of populations.

Mapping the density of the population is useful for descriptive purposes, and the production of density rasters can be essential to the spatial modeling of diseases and other population phenomenons. Meanwhile, these maps do not display actual numbers of people, nor a comprehensive display of populations groupings. Moreover, being able to query places by their name is an essential feature for managers. The information needed to produce a precise and actionable map of population in Niger can be found scattered in different unrelated data sources. This project is exploring an innovative approach to provide a population map in Niger, through the hybridization of multiple data sources and the use of Bayesian models for administrative data.

3.1 Data

Voters list as a demographic data source A data source that is, to my knowledge, seldom used to inform population mapping for public health purposes, is voters registration lists. This low usage can be linked to concerns regarding the completeness of this data in settings where only subsets of the population are eligible to vote, to issues regarding the regular update of this lists, or to the political purported use of these data, that could favor non-random missingness in data in some situations.

There is meanwhile a case to be made for the use of voters' registration data to estimate size and the spatial distribution 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 supposed to be accessible.

Due to the sensitive and political use of these data, the quality of voters registries are often described as not being trustworthy. On the 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 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 2001 version of this database, named Répertoire National des Communes (RENACOM), contains similar information. Meanwhile, the number of places identified varies, and for places identified in RENALOC and RENACOM, some names spelling vary. I retrieved the RENACOM in Excel tabular format directly from the INS website.

[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/

OpenStreetMap OpenStreetMap (OSM) is "a free, editable map of the whole world that is being built by volunteers largely from scratch and released with an open-content license"[5]. Its API allows an easy query of its content, from which we can retrieve places names and community generated GPS coordinates. This data can provide additional precisions on where some localities are, but is much less complete than both RENALOC and RENACOM.

DHI2 The Niger Système National d'Information Sanitaire (SNIS) is currently implementing DHIS2. The portal to DHIS2 already makes available some limited geolocalization data, regarding the health districts divisions, and some health facilities coordinates[6].

3.2 Methods

To make the best use of this data, I will implement an approach based on a minimal modelling of primary population data, and geared towards the anchoring of population in callable named localization. To achieve this, my project has three main components.

3.2.1 Name Matching

Due to the history of the creation and administration of the Nigerien territory, multiple different spellings are in use for most localities names 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 Fahad Pervaiz, a PhD student in the department of Computer Science at UW, 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 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.

3.2.2 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 of very low quality, 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 glsrenaloc using localities with both RENALOC and RENACOM GPS coordinates. Use the best performing approach, as evaluated with cross-validation, to correct RENALOC coordinates

[5] http://wiki.openstreetmap.org/wiki/About_OpenStreetMap
[6] http://www.snisniger.ne/dhis-web-commons/security/login.action

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 non linear 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 grid possible of named localities in Niger.

3.2.3 Population modeling

Finally, I will model Niger population using its voters list by voting 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.

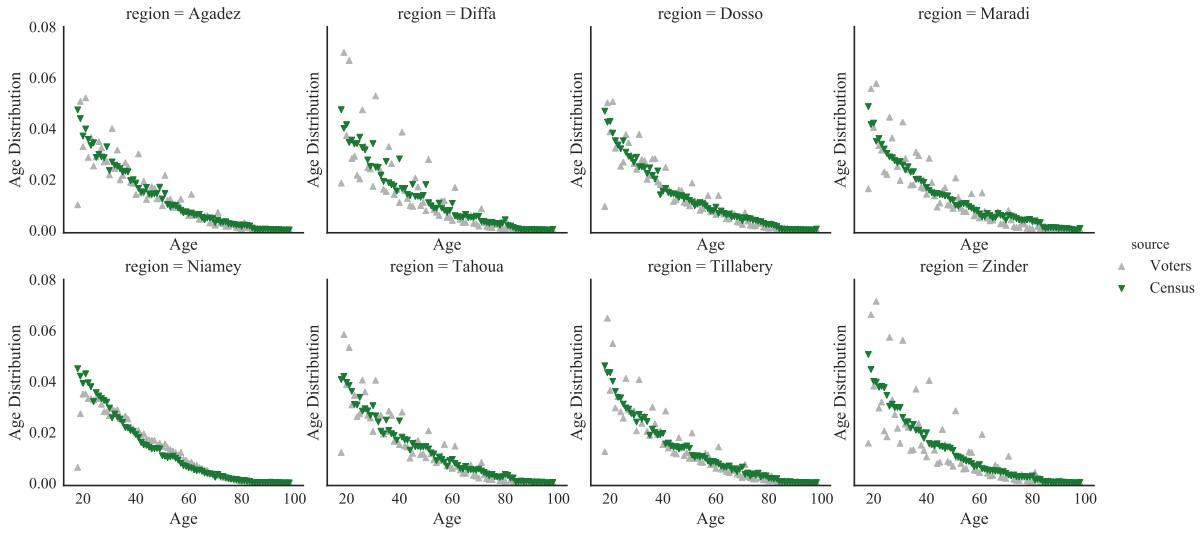

Figure 8: Comparison of standardized adult age distribution between the 2012 census and the 2016 voting lists

A specificity of the voting list is that it does not include children under 18, as they are not allowed to vote. Additionally, I listed in section 3.1 some issues that can be raised regarding the quality and completeness of voters lists, and I should assess their quality and correct their count to match the census results. 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 8 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.

I will model population size and age and gender distribution at regional and health zone level, using the electoral lists as input data, and the 2012 census regional distributions of population by age and gender as validation data. A simple approach will be used to keep this part of the project tractable, and easily reproducible locally. Age distributions from the voters lists will be aggregated at the regional or health zone level, and a number of children will be computed using widely available life tables. I will use multiple life tables to get an estimation of uncertainty on this estimation. The

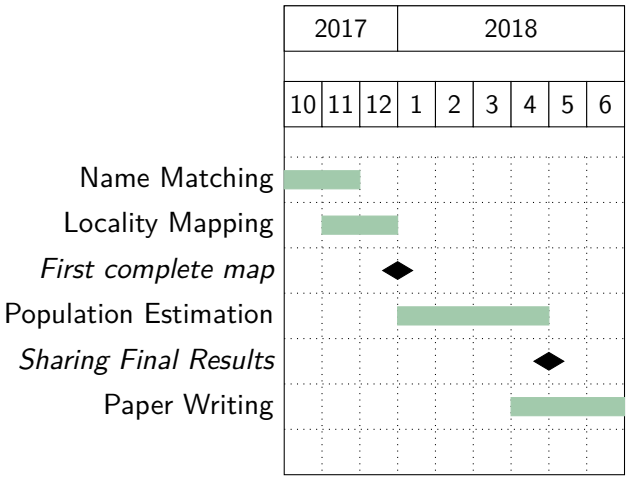

Figure 9: Gantt Chart for Aim 2

total population numbers will then be modeled in a linear regression framework, using the 2012 census numbers as validated results.

3.3 Output

The output of the project will be an interactive map, allowing the query 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 with different spellings. Every name linked to a mapped locality will be searchable and will return the different matching localities in a hierarchized way.

3.4 Timeline

I anticipate two 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 december 2017. I plan 3 months of work for the population estimation, and should have my final results by February 2018. Figure 9 summaries this timeline.

4 Aim 3 - Understanding information - what a bottom up appraoch is

4.1 Objective

As a field, Global Health has to navigate between different levels of relevance. A Global Level, that aims at understanding global trends and phenomenons, and a local level, in which policies are implemented. In this regard, one of the challenges of Global Health is to create and disseminate information that will be relevant at these different levels. The difficulty in doing this is not merely a technical one, but also a political and structural one. The field in which this information is produced is indeed pre-organized by historic and political structures, that are not adapted for this multi-level adaptation of knowledge. National Statistical systems, for example, are the products of the larger systems they are designed to serve. As such, Health Information Systems are the results of the Health Systems in which they are created, and are influenced by the administrative cultures and the political context they are supposed to inform (Bergeron & Castel 2014).

This relation between local and global levels of Global Health is nonetheless asymmetric. As a scientific field, Global Health is essentially a hierarchical organization, where political, academic and economic institutions situated in high resource countries world offer guidance and validation for the methods and results used to measure health over the world. As a result, the field has to find an equilibrium between a downwards *standardization* of information and an upward *aggregation* of locally produced data.

The social background in which this equilibrium is sought is important and has its roots in the origins of health information system in developing countries. Whereas European statistical systems development was led by social activists who guided the design of the first modern welfare systems (Desrosières 1993, 1997), colonial statistical systems were geared towards efficient land administration and economic exploitation (Rambert 1922, de Martonne 1931) with little attention to local population. The development of these statistical systems can indeed be traced to the enforcement of a specific mode of administrative control by colonial powers in the XIXth century (Appadurai 1996, Cordell et al. 2010, Gervais & Mandé 2010). Colonial statisticians, often weakly skilled or trained (Kateb 1998, Cordell et al. 2010), nonetheless set the nomenclatures and conventions around how land and populations would be described and analyzed (Rambert 1922, Gervais & Mandé 2010). Enumeration and its categories did not emerge to describe local complexities and specifities, but were on the contrary simplifications aimed at creating a uniform colonial subject, to which a standard colonial rule would apply (Said 1979, Appadurai 1996).

This historical background can be prolonged after the decolonizations, and can present some continuities with the way public health statistics are produced in developing countries today. Understanding how this longstanding history affects the way people involved in Global Health Metrics think about the production of quantitative evidence is important for practitioners of Global Health Metrics to understand the limits of their work, and the improvements they can bring.

The aim of this paper will be to provide a clear understanding on how the structure of the field of Global Health can have an influence on how health metrics are produced, and how they are being used, or not used. Providing this framework on the conditions for designing quantitative evidence in Global Health is essential to design useful methods and metrics that can help shape public health policies at local and global levels. I will then use this framework to show how it can help understand and bring into context the results of my applied work.

4.2 Method

This paper will build on the work and results of the two previous aims as well as on other work I have done in the field, to understand the conditions in which a *bottom-up* approach to health metrics can be defined and put into practice. The methodological challenge of this to work is to enter the domain of critique from within my own field (Latour 2004). Most of the critical work on the use

of quantitative evidence in health policy indeed comes from researchers that are not practitioners of Global Health Metrics (Merry 2011) . In this regard, even the most nuanced critique suffers the temptation of an overwhelming challenge to the possibility of quantitative work(Latour 2004).

I will thus offer a framework and examples for an internal critique of this work. Using the opposition between a downward, normative movement and an upward, aggregative movement of methods and data, I will offer a simple explanation of how power relations that structure Global Health Metrics can be found in the methods that are used, and I will show how understanding the limits of these methods can help challenge this power structure, to reequilibrate the relationship between local and global actors of Global Health.

This work will be built in three main parts:

1. Provide a description of how a top-down approach to Health Metrics differs from a bottom-up approach.
2. Delineate how the structures in place in Global Health can influence which of these approach will be used by Global Health actors.
3. Describe the comparative benefits and shortcomings of each approach, and how they can be combined.

The main methodological challenge of this paper is to make a common reading of literature from STS, Colonial Studies and Global Health Metrics. This diverse corpus will be used to test the hypothesis made in other projects in this dissertation, as well as other projects I am involved in. I organize this project in four steps:

1. Explore the literature in STS and Colonial Studies pertinent to the opposition *bottom-up* vs *top-down* of statistical methods.
2. Identify the themes and concepts relevant to the Health Metrics field in this literature.
3. Identify features relevant to these themes in my applied work, and build a critical framework in which to read this my projects.

4.3 Timeline

I have already made most of the literature review for this work. A first paper on this work has been accepted for presentation in a workshop at the Ecole des Hautes Etudes en Sciences Sociales. Another presentation of this work for social scientists interested in Data Science should be held at the UW in december. This will allow me to get feedback and to complete my analytical framework. Most of the remaining work for this aim is to include the results from the two other aims and to situate them in my analytic framework.

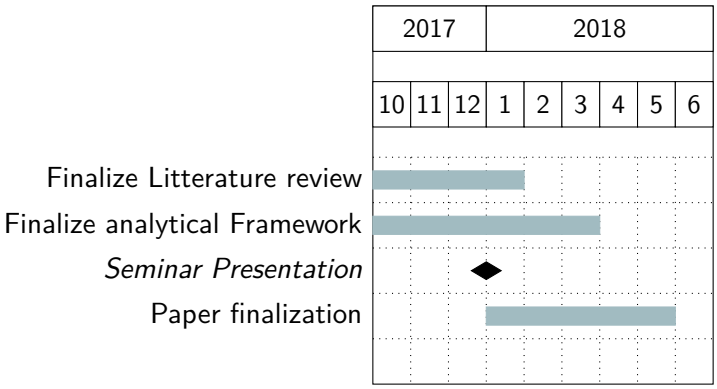

Figure 10: Gantt Chart for Aim 3

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