Understanding Conditions of Uncertainty in Disease Surveillance and Response in Burkina Faso

An inquiry into the sociological aspects of health information construction and use

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Abstract

Through an interpretive, social constructivist approach, the research explores the production and use of information in the public health care domain of a low and middle-income country (LMIC). The research shows that taking action for health is as much about finding ways to deal with various forms of uncertainty or incomplete certainty as it is about producing better and more data.

Theoretically, the research considers the relationship between Information Systems (IS) and knowing. This is a long-standing yet contemporary theme in IS research and development as new enhancements in data-producing technologies stimulate an increasing demand for data globally, for example reflected in the debates around big data. Concepts from the domains of sociology of science and technology and from medical anthropology are drawn into the IS and HIS domain to develop a theoretical lens that takes into account the diverse contextual, situated and material character of how health workers and managers acquire knowledge and take action in the process of providing and administering care in the context of disease surveillance and response. These processes are conceptualized as multiple, cross-disciplinary, epistemic practices where uncertainty plays a key role.

Empirically, the thesis explores how information about the detection and transmission of two diseases (meningitis and dengue) are represented and acted upon in the context of disease surveillance and response in Burkina Faso. The ethnographically inspired case study of data use practices in the domain of disease surveillance and response in the health sector of Burkina Faso explores how health managers and workers create and use health information for the purpose of preventing and controlling contagious diseases. The study highlights how their work includes accounting for, rather than avoiding, different types of uncertainty.

The contributions of the thesis lie both in the sociological conceptualization of how knowledge about a disease is produced and used in the context of disease surveillance and response as well as in the articulation of different aspects of uncertainty and their relation to the understanding of how we know about a disease.

The articulation of uncertainty as not just a barrier to knowing but also a driver of action, helps supplement IS and HIS theory concerned with knowing. Uncertainty is introduced as something that should be considered an important element to action rather than an element that must be avoided and eliminated through the formal IS or HIS. In this sense the findings invite us to flip the context for IS research and reflect further on what IS research can learn from LMICs instead of narrowly focusing on what we as IS researchers and practitioners can bring to this context.

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Contents

List of figures

Lists of tables and images

Abbreviations

ANT	Actor network theory
CSF	Cerebrospinal fluid
CSPS	*Centre de santé et promotion sociale* (primary health facility)
CSCW	Computer-supported cooperative work
DHIS2	District health information system (version 2)
ENDOS	*Entrepôt national des données sanitaires* (national health information data warehouse)
GIS	Geographical information system
HIS	Health information system
HISP	Health information system program
ICT	Information and communication technology
ICT4D	Information and communication technology for development
IDSR	Integrated disease surveillance and response
IHIA	Integrated health information architecture
IS	Information system
LMIC	Low and middle income country
MoH	Ministry of health
NTD	Neglected tropical diseases
RDT	Rapid diagnostic test
SCOT	Social construction of technology
SST	Social shaping of technology
TLOH	*Télégramme lettre officielle hebdomadaire* (weekly epidemiological bulletin)
WAHO	West African health organization
WHO	World health organization

Prologue

“Laafi?”

“Laafi bala”

This short sequence of words is exchanged several times a day in the Central Region of Burkina Faso. It is a greeting in Moré – the most widely spoken language in this region – and it is exchanged in a similar way as ‘How are you?’ ‘Fine thanks’ is exchanged in many Anglophone societies. In Moré, however, *Laafi* does not just mean fine, it means health. Being well thus has strong connotations of being healthy. While such a connection between health and well-being is probably true in most societies, it has a profounder meaning in a country such as Burkina Faso, where there is neither a free public health service nor affordable health insurance to rely on in cases of encounters with different diseases. For the ordinary citizen there is inherent uncertainty in accessing health care, whether it is through the public or the traditional system. For health workers and managers in the public health system there is inherent uncertainty in providing health care. They deliver health services under conditions of uncertain funding and constrained human, diagnostic and therapeutic capacity. Unexpected developments of potentially epidemic diseases and limitations in the tools to foresee and spot these developments generate further uncertainty.

When Health Information Systems (HIS) are introduced under these circumstances it is often with the aim of increasing the availability of information that can reduce uncertainty and improve health service delivery, for example identifying and tracking new cases of potentially epidemic diseases to support the making of data-driven decisions. However, the production and use of health data is often underpinned by imprecision, leading to partial uncertainty and in some cases complete uncertainty.

Through an ethnographically inspired case study of data use practices in the domain of disease surveillance and response in the health sector of Burkina Faso, this thesis considers how health managers and workers create and use health information for the purpose of preventing and controlling contagious diseases. The study highlights how their work includes accounting for, rather than avoiding, different types of uncertainty.

From an HIS perspective I argue that these insights should inspire a shift of focus from the production of more and more precise data to considering how to accept uncertainty as part of decision-making processes, which in turn would raise the question of how to represent uncertainty in the HIS. The study suggests that this includes paying attention to both the multiplicity of diseases as well as the related practices of health information construction and use where other technologies such as telephones and Excel spreadsheets complement the electronic web-based HIS.

> *"Because in our country, if we have to wait until everything is confirmed, that will be after the death of many patients."*
>
> *(Health district manager, Ouagadougou)*

Chapter 1 Introduction

In this section, I provide an outline of my research project on the sociological aspects of health information construction and use. The project considers the production and use of information in the public health care domain of a low and middle income country (LMIC). Empirically, the thesis explores how information about the detection and transmission of two diseases is represented and acted upon in the context of disease surveillance and response in Burkina Faso. Theoretically, concepts from the domains of sociology of science and technology and from medical anthropology are drawn into the IS and HIS domain to develop theoretical concepts that take into account the diverse contextual, situated and material character of how health workers and managers acquire knowledge and take action in the process of providing and administering care. These processes are conceptualized as multiple cross-disciplinary epistemic practices. Taking action for health is shown to be as much about finding ways to deal with various forms of uncertainty or incomplete certainty as it is about producing better and more data.

1.1 Motivation, research aims and questions

Data has been in high demand during the past decades, and this demand is still growing. It is claimed, for example, that data has surpassed oil as the world's most valuable resource (*The Economist* 2017). Such claims are partly nourished by technological developments within computing, the internet and social media, which have enabled data collection and processing at an unprecedented scale and pace. Other factors, however, are also at play when considering how data is put to effective use. One is the political will to govern by what can be measured, something that requires quantification of phenomena, including social ones. This trend has been promoted by the new public management agenda, exemplified in the saying 'what gets measured gets done.' Another enabling condition is a widespread confidence in data-driven decisions. Within the health care domain, this is exemplified by the use of rigorous clinical trials aimed at producing evidence about best clinical practices, making evidence-based medicine the de facto gold standard for making decisions about health improvements. However, as Alexander and Lyytinen (2017) point out, it is all too easy to overestimate the value of big data as a reliable and objective resource for decision-making in organizations without taking into account the human capacity to process the data and make sense of it.

An important related factor concerns the process of knowing. The availability of data and techniques of data mining and machine learning has been celebrated as enabling new ways of knowing about the world that may lead to the 'death' of analytical professions such as epidemiology and financial analysis (Sahay 2016). However, it has also raised questions about the "avalanche of numbers" generated by these systems and whether these numbers provide clarity in knowing, or if they instead threaten to limit local initiatives needed for creating and maintaining good lives (Appadurai 2013, p. 299). In other words, the argument is that our ability to envisage better futures and facilitate social change does not rely solely on data and information. It is also linked to more fundamental human questions concerning how to handle uncertainty, which have been made almost invisible amid Western ideas about modernity and progress (Appadurai 2013). How we handle uncertainty, however, is deeply relevant when it comes to our ability to deal with life as it evolves rather than as it has been planned (Whyte 1998) and, more specifically, to doctors' ability to diagnose and treat patients (Fox 1980; Timmermans and Angell 2001).

Information Systems (IS) are vehicles for the collection, analysis and dissemination of data, making them intrinsic to discussions concerning data as a driver of change, and of knowing and doing (Orlikowski 2002; Suchman [1987] 2007). IS are often introduced with a promise to deliver more and more data to enable organizational and social change. However, the IS literature has provided many examples showing that this promise remains partially or fully unrealized (Sahay et al 2017) and that it can lead to other unanticipated changes. Such initiatives always carry tensions arising from the interplay between technology on the one hand and human and institutional practices on the other hand (Orlikowski 2007). This tension is magnified when data is seen as a commodity, or as an output in isolation from the enacted practices that produce it (Walsham 2001). However, despite these tensions, the quest for enhancing the production of data is continuous, in both research and practice. These tendencies are especially evident in the domain of HIS in the context of LMICs, the focus of this thesis, where resources are limited and data in high demand.

This thesis takes a deeper look at the dynamics of health information production and use in the context of disease surveillance in an LMIC. It considers the work that goes into the production of information about health and the way this information circulates and is used by health workers and managers at different levels of the health sector in their daily work. The study conceptualizes these dynamics not as a consequence of information or information technology in itself, but instead as a social phenomenon comprising the interplay between technology and situated practices. Health information construction and use is enabled by the web-based HIS and other technologies, but it is the everyday practices involving both manual and computer-based work that shape how the information is used, for what purpose and by whom. Such a conceptualization requires a shift in focus from information as an input and output of the HIS to how a phenomenon (e.g. a disease under surveillance) is represented through the system, and how these representations lead to the construction of varying meanings to different actors. These varying meanings are conceptualized as ‘interpretive flexibilities’ and ‘multiplicity of representations.’ More specifically the thesis is about understanding how knowing about diseases is made possible in the health system of an LMIC, and how this knowing is intertwined with the practices which produce it and with those it informs. This broad approach is seen to reflect the sociological aspects of health information construction and use where the tools, technologies, materials and practices that go into producing knowledge and taking action hang together in a social environment.

The empirical setting for this theoretical development is the disease surveillance and response system in Burkina Faso. Disease surveillance and response is an area of vital importance to human well-being as it is concerned with preventing outbreaks of contagious diseases through early detection and response mechanisms. The work that goes into disease surveillance and response is heavily reliant on different types of information, ranging from early notification about potential cases to laboratory confirmed results detailing the more exact nature of the disease in question, and the resulting interventions based on this information. The devastating 2014-2015 Ebola outbreak in West Africa showed that disease surveillance and response is an area of global concern and that it is not only highly dependent on hard facts but also requires a functional health system that can support the interpretation of a plethora of information, including when it is inadequately confirmed or unconfirmed.

There is an ongoing degree of uncertainty surrounding the production and use of disease surveillance and response information. This uncertainty is particularly pertinent in LMICs, which operate under conditions of inadequate resources and infrastructure and frequent disease outbreaks. However, despite these uncertainties and inadequacies of available information, ‘the show must go on.’ People must be treated and epidemics controlled. This thesis seeks first to understand how such practices unfold in context, and second to discuss how this invites us to think about how uncertainty can be better represented in IS and HIS design and research.

The thesis aims to contribute to discussions around the role of data in human action and social change. I conceptualize the relationship between the production of knowledge and its use for action in the domain of health service delivery in LMICs as a social-technical phenomenon that involves data, technology, people, and their physical and organizational settings. To do so, I take the view from sociology of science and science and technology studies, which emphasize that both knowledge and technologies are socially constructed (Bijker, Hughes, and Pinch [1987] 2012) but still represent reality (Latour 2005, 1999; K. D. Knorr Cetina 2009). Specifically, I draw on the insight that knowledge about diseases can be constructed differently, with the implication that diseases are multiple as objects (Mol 2002; Moser and Law 2006). I furthermore combine these concepts with the notion that medicine is also about handling conditions of uncertainty (Whyte 1998; Cooper and Pratten 2014; Timmermans and Angell 2001; Fox 1980).

I have drawn these concepts together into a theoretical framework outlining the sociological aspects of health information construction and use. This framework acts as a theoretical vehicle for conceptualizing health information construction and use as a social process that does not inject a dichotomy between the mental and the physical worlds, but instead articulates the idea that what we can know – about a disease, for example – is intertwined with how we come to know in different settings and situations. Furthermore, the framework is designed to help us consider uncertainty not only as the absence of information, a gap that needs to be filled, but also as a driver that motivates us to ask further questions and thereby obtain more information. In other words, the theoretical framework proposed here assumes that obtaining information and knowledge about diseases is embedded in practices of handling uncertainty. The main research question is:

How can the concept of uncertainty inform our understanding of the challenges to health information construction and use in the context of low- and middle-income countries (LMICs)?

The concept is applied to an analysis of the empirical case of the disease surveillance and response system in Burkina Faso, and for this purpose the following empirical research questions have been applied:

- *What are the networks of people, technology, and materials that enable knowing in disease surveillance and response?*
- *Which conditions of uncertainty affect production and use of information in disease surveillance and response?*

Through the development and application of this framework for studying sociological aspects of health information construction and use, I hope both to provide a critique of the current data-centric approach to IS and HIS design and implementation and to outline an alternative to it. This study aims to provide a constructive critique that both deconstructs knowledge processes and offers inspiration for how to deal with the future as it is emerging in other ways than by numbers (Ortner 2016; Appadurai 2016).

1.2 Empirical setting and research approach

I have explored the research questions through an in-depth longitudinal study of health information construction and use in the health sector in Burkina Faso with a particular focus on its disease surveillance and response system. I have used an interpretive approach where the focus is on understanding why actors do what they do, and where the production of thick descriptions is emphasized as a tool to convey this understanding (Walsham 1995). Methodologically, I have been inspired by ethnography, which has helped me to develop thick descriptions of the construction and use of health information in disease surveillance and response.

The fieldwork was conducted over a three-year period within the health sector in Burkina Faso. During this period, I lived in Burkina Faso and was affiliated with the IT directorate of the Ministry of Health as a 'stagiaire', which literally translates to intern, but in practice meant that I was considered a staff member of the directorate. From this position, I was able to do an in-depth interpretive study of work practices in the health sector in a West African country.

The research was done in affiliation with the Health Information Systems Programme (HISP) network. The HISP network is a research program working on strengthening health systems through the development of the free and open source software DHIS2, strengthening of public health informatics capacity in LMICs as well as conducting research on HIS-related issues. In 2013 members of the HISP network assisted the Ministry of Health in Burkina Faso with the implementation of a national HIS database with DHIS2 as the core. Fieldwork for this thesis began in late 2014 after the system had been put in place, which means the research took place in the post-implementation phase.

Both the theoretical approach and the empirical methods are concerned with understanding how health managers and workers work with both information and absence of information. A key focus is on the social shaping of knowledge construction in the clinical setting as a means to understand both the content and processes of HIS. Theoretically, I conceptualize this as 'epistemic machinery' consisting of people, tools, and materials. The thesis aims to understand how this machinery works, including under conditions of uncertainty, which entails organizing based on both structure and improvisation.

1.3 Papers and research contributions

The papers that constitute the basis for this thesis are listed below. They all focus on lessons learned through a practice-based perspective on health information construction and use. The first three deal specifically with the case of disease surveillance and response, whereas the last paper has a broader focus on health data use and planning in general. Each paper deals with different aspects of the main thrust of the research: the construction and use of health information in disease surveillance and response in the health sector in Burkina Faso. The papers are listed below with an indication of their publication status.

1) **Practices of disease surveillance and response in Burkina Faso**
   Rasmussen, SL (2017). In Proceedings of the 14th IFIP WG 9.4 International Conference on Social Implications of Computers in Developing Countries, Yogyakarta, Indonesia, May 22-24, 2017 (pp. 333–344). Springer, Cham.
2) **Information and substance as defining elements of the epistemic cultures for meningitis surveillance and response in Burkina Faso**
   Rasmussen, SL and Sahay, S. Under review by The Information Society (status: revise and resubmit).
3) **Disease surveillance and response in conditions of uncertainty: The case of 'palu dengue' in Burkina Faso**
   Rasmussen, SL and Sahay, S. Under review by Information and Organization (status: revise and resubmit).

4) **Plans and “off-plan activities”: exploring the roles of data and situated action in health planning in Burkina Faso**
Rasmussen SL (2018). Electronic Journal of Information Systems in Developing Countries. 2018;e12049. https://doi.org/10.1002/isd2.12049RASMUSSEN 9of9

Paper one adopts a practice-lens to look at the characteristics of practices under the Integrated Disease Surveillance and Response (IDSR) and the use of their supporting guidelines. It shows that surveillance and response have two different sets of practices and there are challenges in keeping them connected. Surveillance is well grounded in practice and similar to routine HIS data collection, while response is often unexplored in practice and therefore more challenging to incorporate into existing HIS.

Paper two develops a sociological lens for health information construction and use in order to trace its epistemic practices, including the translations involved in producing representations of meningitis that support its surveillance and response. Meningitis is a critical disease to control in Burkina Faso, with relatively well established practices. The paper shows that the ability of the health staff to know relies on more than one epistemic practice, significantly defined by whether the material origin of the information is record or substance. Viewed in this perspective, integration of HIS becomes a challenge of integrating different epistemic practices.

Paper three explores the conditions that contribute to uncertainty in the case of an outbreak of dengue, a neglected tropical disease (NTD)[1], in Ouagadougou, the capital city of Burkina Faso. The analysis uses the perspective of multiple rationalities to discuss how what we do not know can be an asset to compensate for lack of prior experience, inadequate resources, ill-designed protocols and institutional constraints, which all contribute to creating uncertainty. Health workers deal with these uncertainties by relying on improvisations such as making exclusions, exchanges through social relationships, and structuring practices informally. The

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[1] NTDs are a diverse group of diseases that persist in poor and marginalized communities although they have largely been eradicated elsewhere. They affect many people but measures to control them often remain unprioritized. Source: http://www.who.int/neglected_diseases/diseases/en/
This means they are often overlooked, and that when they appear it is under conditions of uncertainty.

paper argues that while the formal HIS does play a key role in conveying information, it is not well equipped for informing practices faced with conditions of uncertainty.

Paper four focuses on how health managers and workers use the concept of ‘off-plan activities’ to organize health activities in an uncertain context where local plans are often overruled at short notice by requirements from higher-level, unexpected developments in diseases, or sudden possibilities of funding. HIS data is conceptualized not as a tool to discipline local practices but rather as one of the elements that can guide individuals in their daily work.

As seen in these brief summaries, I have used slightly different theoretical lenses in each paper to bring out different aspects of the overall thesis, as each contributes a different facet of a sociological understanding of health information construction and use. Taken together, the papers constitute the empirical basis for the theorization of this perspective, which I elaborate on further in the thesis.

The findings I present in this study highlight that uncertainty is inherent to disease surveillance and response. In supplement to general IS and HIS theory it is shown that uncertainty is not only due to poor data quality or lack of information. Instead, it is seen as inherent in the conditions of health service delivery in general and in the production of knowledge about diseases as it is made visible first in the individual patient and later in the population. The findings also show that in LMICs, where resources are scarce, uncertainty is also seen in the lack of control over funds and health agendas. Furthermore, contrasting dengue and meningitis – two quite different diseases – shows that some types of uncertainty are more present in a disease such as dengue, which is not on global agendas, whereas with meningitis, which receives considerable attention from the international health community, these uncertainties are less prevalent when it comes to the construction and use of health information. On the ground, health managers and health workers creatively employ different practices to handle uncertainty. Concepts such as off-plan activities, and use of technologies such as mobile phones and spreadsheets, are used to make the data construction and use flexible so it supports everyday action by the health staff.

On the basis of these findings I outline the two main contributions of the thesis, which are:

- A sociological conceptualization of how knowledge about a disease is produced and used in the context of disease surveillance and response; and
- An articulation of different aspects of uncertainty in disease surveillance and response and their relation to the understanding of how we know about a disease.

The first contribution is mainly practical as it serves as a map of the different information requirements across the health sector in disease surveillance and response. It can be applied as a model to inform future HIS design aiming to strengthen disease surveillance and response. It furthermore highlights that collaboration is not achieved through sharing the exact same information throughout the health sector, which lies at the heart of current integration efforts. A disease consists of multiple objects and their different representations through the HIS are situationally created and used in different ways by health managers and health workers.

The second contribution is theoretical as it describes variations in uncertainty and articulates it as not just a barrier to but also a driver of action. This articulation supplements IS and HIS theory concerned with knowing by introducing uncertainty as an element that should be considered important to action rather than as an element that must be avoided and eliminated through the formal HIS. This insight entails questions of how to represent uncertainty in HIS and IS.

Focusing on the sociological aspects of health information construction and use emphasizes the interplay between practices within different social conditions. It entails seeing this process of construction and use as embedded in everyday practices, as consisting of chains of translations, as concerning objects that are multiple but not fragmented, and as containing uncertainty that does not necessarily have to be avoided. It treats the link between data and action not as a linear sequence of practices but as a bundle of situated practices. This perspective has the advantage of showing that there is an order in practices even though they may appear random and untidy at first sight. It helps to explain that these practices can actually be quite well appropriated to enable action in conditions of uncertainty where knowing cannot be taken for granted.

1.4 Structure of the thesis

The thesis is organized as follows:

In Chapter 2 on the context of the research, I position the research theme within different aspects of providing health data for action in LMICs. This extends HIS research in LMICs as it includes the health situation in Burkina Faso, global health agendas and recent efforts in disease surveillance and response globally and in West Africa.

In Chapter 3 on related literature I present the theoretical readings that I draw on to develop an understanding of the sociological aspects of health information construction and use. Next, I discuss social shaping as an approach to Information Systems, as well as the concept of multiplicity of representations. Finally, I introduce the idea of uncertainty leading to an ethics of possibility as an alternative to the ethics of probability.

In Chapter 4 on methods, I describe the methods used as being interpretive and related to the theoretical reading through a practice-based approach inspired by ethnographic work-place studies. I also provide an overview of the data collection and analysis processes.

In Chapter 5 on the analysis, I present a brief overview of how disease surveillance and response is done in Burkina Faso before I analyze two contrasting cases of disease: a neglected tropical disease and one that has recently received close attention from the global health community. In analyzing the material, I develop the two main ideas. The first is that epistemic practices are not shaped only by multiple rationalities but also by the multiplicity of the object that needs to be understood in order to be accounted for in an HIS. The second is the idea of uncertainty as a resource for the production of social order and aspirations for the future.

In Chapter 6 on contributions, I discuss how these findings contribute to current discussions in the HIS literature, including how they might be extended to the broader IS literature. This includes a discussion on the practical and theoretical implications of these insights as well as perspectives for future research.

Chapter 7 closes the thesis with some brief concluding remarks.

Chapter 2 Context of the research

This chapter presents the context of the research and the challenges with health information construction and use that it aims to address. I begin by introducing the site where the fieldwork was undertaken, namely the health sector in Burkina Faso, with a focus on the current HIS situation there. Next, I broaden this focus to discuss HIS in developing countries more generally with a particular focus on the development of the free and open source software DHIS2 by the HISP network, which is the platform used for the national HIS in Burkina Faso. I end the chapter with a view on the broader context of global health through a brief discussion of some current trends in this field, underlining that there are different expectations around the HIS in general and disease surveillance and response in particular.

2.1 Burkina Faso: uncertainty and hope

Despite some recent turmoil, Burkina Faso is a politically stable country. The former president, Blaise Compaoré, managed to steer the country free of other conflicts in the wider West African region. In 2014 his 27-year rule came to an end due to a successful popular uprising motivated by his intent to change the constitution in order for him to serve yet another term. The uprising led to his resignation and ultimately peaceful democratic elections a year later in 2016. This change in the political landscape has spurred optimism on one hand, as it has become a pan-African example of the power of populations to drive political change (Hagberg 2015). The new government, however, has been challenged as the political instability and insecurity in the neighboring country of Mali has started to spill into Burkina Faso. Areas along the Malian border particularly are affected by small but frequent extremist attacks on public services such as police stations and schools, leading to great insecurity and uncertainty among the population in these areas about their future. The situation has led to a large number of internally displaced people. The capital of Ouagadougou has seen three large terror attacks in the first two and a half years that the new government has been in power. As two of these attacks were directly targeting Westerners, they have affected tourism and foreign investments adversely, leading to loss of employment and business opportunities. Taken together these events contribute to general uncertainty about the future, lined with both hope and worry.

2.1.1 Public health

With up to 40 percent of the population living below both national and international poverty lines Burkina Faso is among the ten lowest ranked countries in the UNDP Human Development report (UNDP 2016). The human resources for health are quite limited; for example there is one medical doctor per 15,836 inhabitants (Ministère de la Santé Burkina Faso 2016). In contrast there are between three and five medical doctors per 1,000 inhabitants in most European countries (WHO 2017). The health sector is highly donor dependent, which creates a culture of planning that on the one hand targets the most urgent health needs, but on the other hand is constantly being reshaped by these external funding mechanisms. The extensive external funding entails quite some coordination and negotiation when it comes to financing and delivering health services.

In general, public health systems in developing countries are characterized by uncertainty as living conditions and delivery of health services are influenced by poverty, risk of armed conflict, variability of infrastructure, and weak governments and public sectors (Farmer et al. 2013). Burkina Faso is not an exception. Health workers have to deal with multiple contingencies, not just those directly related to care provision, but also in emergency situations where measures to protect health workers are not in place, as was the case during the 2014-2016 Ebola outbreak that unfolded in countries close by (Østergaard 2015). Patients are seldom sure that health clinics can deliver what they need, and "*caring for a sick child becomes a routine based on uncertainty*" (Østergaard, Bjertrup, and Samuelsen 2016). Often health seeking behavior entails a multitude of strategies of swapping between the formal and traditional components of public health care delivery (Samuelsen 2004).

One health area that has gained significant attention following recent large-scale epidemics in the West African region is on strengthening disease surveillance and response capacity of the health system. Located in the middle of West Africa, Burkina Faso has borders with six other countries, making it vulnerable to communicable diseases that are easily spread over the borders. This threat is enhanced by the fact that there is substantial migration aided by extensive travel between the francophone West African nations (in ECOWAS). Burkina Faso has responded to these threats by adopting both the international Integrated Disease Surveillance and Response (IDSR) guidelines as well as being committed to the Global Health Security Agenda, emphasizing the 'one health' approach (CDC 2016). These commitments have led to a number of national and regional initiatives, including some to strengthen the national HIS capacity to support disease surveillance and response.

2.1.2 Health system, national HIS and DHIS2

The health sector in Burkina Faso is organized at three levels: national, regional and district. The national level is in charge of strategic development of the health sector, including the development of clinical guidelines and coordination of national health initiatives such as vaccination campaigns. The regional level is an administrative level that oversees and assists districts in health service delivery. The district level is operational and is in charge of managing health care delivery through the health facilities in the district. This includes implementation and local coordination of national initiatives, monitoring of quality of services, and administrating drugs and medical equipment. In 2016 there were 13 regions, 70 districts, and approximately 1,760 health facilities (CSPSs) across the country, each serving on average 10,000 patients (Ministère de la Santé Burkina Faso 2016). There are a number of hospital-like clinics, as well as regional and national level hospitals, but the CSPSs are the primary entry point to the health sector for most of the population. There are some private clinics but mainly in the capital of Ouagadougou, where more people can afford to pay for health services. Laboratories share premises with a clinic or a district but in some cases they are managed independently.

The national HIS in Burkina was strengthened in 2010-2013 through the development of a strategic HIS plan and the installation of the DHIS2 platform for the collection of routine national data. This work was assisted by a team from the HISP program at the University of Oslo (Braa and Sahay 2012). Since 2013 the District Health Information System software version 2 (DHIS2, https://www.dhis2.org/) has been in use as the backbone of the national HIS in Burkina Faso, including for the IDSR programme. The Ministry of Health is now working with limited support from the HISP network with maintenance, redesign and adaptation of the system. In terms of content the database covers most of the national health programs when it comes to routine health information collection. Data entry is done at health district level, as there are no computers at the health clinics. There are data managers employed at the district, regional and national levels, but not at the CSPSs.

2.2 HIS in LMICs and the HISP network

The research is part of the global Health Information System Program (HISP), which is engaged in strengthening of HIS in LMICs (Sahay, Sundararaman, and Braa 2017; Braa and Sahay 2012; Braa, Monteiro, and Sahay 2004). Over a 20-year period, HISP has gone from being a small-scale, bottom-up development project initiated in South Africa to becoming a large global player encompassing a vast organizational network delivering and implementing a software program that supports routine national registration of public health data in more than 70 countries. This expansion and globalization means that the HISP network is now also engaging in more top-down global agendas of data-driven development and standardization. While the expansion is due to the ability of the program to solve many challenges concerning the quality of HIS, new challenges are also arising due to the scale of the program and the ensuing complexity (Sahay, Sundararaman, and Braa 2017). In this thesis, I focus on one of those emerging challenges: the one of health information construction and use in the context of disease surveillance and response in Burkina Faso.

2.2.1 Creating a better world (with information for action)

The HISP program adopts a comprehensive approach to information systems. There are three core components: action and research around the design and development of the free and open source software DHIS2 (see dhis2.org for more details), the promotion of an integrated health information architecture (IHIA), and capacity building on public health informatics in countries. The DHIS2 software is designed specifically to serve the district-based health systems of many LMICs, while the IHIA promotes a way to streamline the fragmented landscape of databases, lab systems and electronic health records in LMICs (Braa and Sahay 2012). The capacity building in public health informatics is done through various means including hands-on training in use, implementation and administration of the DHIS2 software, enrolment of PhD and Master’s students, and continuous action research activities.

In recent years, HIS has specifically been adopted in LMICs in order to support the provision of health information to facilitate health systems strengthening. This increase in adoption has on the one hand been made possible through technological advancements such as cloud computing and mobile phones (Adaletey, Poppe, and Braa 2013; Asangansi and Braa 2010). At the same time, it has been aligned with a global demand for more data and indicators, creating a strategic and financial push to strengthen health data collection as a key element in improving health systems (AbouZahr and Boerma 2005; Lippeveld 2001; Sahay, Sundararaman, and Braa 2017).

It has always been central to the work of HISP that the health information collected through the DHIS2 software should benefit countries by empowering health managers at all levels to make better decisions in their endeavors to improve health. An early slogan of the HISP was ‘information for action,’ which has also been reflected in partnerships with for instance the Health Metrics Network, which advocates HIS strengthening under the slogan ‘better information, better decisions, better health.’ This slogan gained global momentum with the introduction of the Millennium Development Goals and now the Sustainable Development Goals as the idea behind these agendas was to create globally aligned indicators against common goals for the world and enable the measurement of development progress.

However, as the introduction of HIS expands beyond the pilot stage in many countries, a paradox is emerging: even as these HIS are becoming more stable and providing more comprehensive and timely data on a national scale, the use of this data remains limited (Sahay, Sundararaman, and Braa 2017). This is especially the case when it comes to the peripheral levels of the health sector, where significant amounts of time are spent on data collection while feedback is seldom, if ever, given.

Within the HIS literature, traditional explanations are given for low data use which are prone to assuming a rational, linear relationship between data and its use (Braa and Sahay 2012). The idea behind this approach can be summed up in the illustrative but not so flattering saying ‘garbage in, garbage out,’ meaning that if low quality data is entered into an HIS, only low quality information can be extracted. This dynamic leads to a vicious circle where poor data leads to lack of trust in the information, which leads to lack of use, which in turn lowers the incentives to collect the data and so forth (Sahay, Sundararaman, and Braa 2017). Such types of explanation are sound and they do address part of the challenge with low data use. However, they still imply that if data is collected, it will eventually be analyzed and used as a basis for action. This precludes an understanding of how people act under conditions of uncertainty.

Until recently, these challenges were mainly approached in a rationalistic way that focused on the provision of better and more data as the main key to improve use of health information.

However, the provision of useful information involves being more specific about who needs what information, under which circumstances and for what purposes (Sahay, Sundararaman, and Braa 2017). For example, it has been pointed out that taking action based on an HIS requires translating data into relevant knowledge (Lewis and Sahay 2009). Further efforts to reposition the formulation of data use in the health domain include seeing decisions in health as based on conversations that matter, rather than on hard evidence only (Kelly, Noonan, and Sahay 2013). This idea was recently explored in a paper that drew a distinction between data use practice being 'authoritarian-bureaucratic,' on the one hand, and 'dialogic' on the other (Kelly and Noonan 2017). In all these examples data use is closely linked to the kind of practices that go beyond mere production of data.

By being part of the HISP research initiative, this research project stands on the shoulders of much of the previous and ongoing HISP research, while it also engages in one of the new key topics, information use, to help drive the movement towards its goals of contributing to better health for the populations in LMICs. It is a move that requires a turn to public health informatics, which Sahay, Sundararaman and Braa (2017) describe as an emerging paradigm in the public health domain within the context of public health.

2.3 Global health and disease surveillance and response

Global health can be seen as a collection of health problems, addressed through the development and delivery of technologies (Farmer et al. 2013). It is more an agenda than a field, as its main focus is to engage in solving global health challenges through interdisciplinary efforts rather than through one discipline only. In this sense, it is similar to public health, although it differs in that it addresses both prevention and clinical care provision to individuals while public health mainly addresses health in the population (Koplan et al. 2009). Within global health it is recognized that it is important to provide not only clinical solutions to worldwide health challenges, but also solutions that address structural inequalities, poverty and unequal access to health care. The reasons that health services are not universally accessible to populations in countries around the world are often related to poverty and structural or economic constraints. For example, who should invest in developing medicines for people who cannot afford to pay for them? How can poor states finance the delivery of health services that are accessible for all regardless of socio-economic status? These are some of the questions that underpin global health efforts, and they require both technical and structural solutions, including those concerning their HIS.

The year of 1978 was a milestone for global health. All countries of the world agreed on the Alma-Ata declaration, which was the first unified statement to secure health for all as a fundamental human right. However, the vision behind the Alma-Ata declaration suffered during the 80s and 90s as a result of financial crises and structural adjustment policies promoted by the IMF and the World Bank, leaving limited space for the investments needed to promote a 'health for all' agenda (Farmer et al. 2013). The politics of these years resulted in weak health systems that did not have the capacity to provide the services needed to achieve health for all. International organizations thus had to develop alternative interventions at lowered costs that were easy to implement and that could demonstrate effective results. United Nations International Children's Emergency Fund (UNICEF), for example, successfully employed selective primary health care on a large scale to fight child mortality and malnutrition through delivery of simple measures such as growth monitoring, oral rehydration treatment, breastfeeding and immunization (also referred to as GOBI). The results on global child mortality were impressive and the strategy functioned in spite of health systems being unable to deliver all basic services. However, financial support eventually dried up and exposed the weaknesses of this approach. Without funding, it was not sustainable as it did not target strengthening the health system in itself. Similarly, a new turn in health service delivery in LMICs is the involvement of large global nongovernmental organizations (NGOs) that exclusively target a specific disease. This yields impressive results in the targeted disease, such as HIV/AIDS, but again neglects to strengthen the overall health system in the country and as a result, standards of treatment remain low for other diseases, such as NTDs and respiratory illnesses. As it favors projects at the expense of a holistic sectoral approach, this approach has been labelled projectification of health services (Prince 2013; Meinert and Whyte 2014).

To the projects and donors who measure targets focusing on the diseases they address, this might not matter so much, but to the people who seek health services, it can be difficult to understand why there is treatment for some diseases while not for others. This is illustratively summarized in the statement 'I wish I had AIDS' made by groups of patients in Uganda (Whyte

2012). AIDS was at the forefront of the then global health agenda and received considerable funding and attention.

This approach leaves local doctors with a range of ethical dilemmas around where to work and how to treat people equally when the means to do so is not equal (Prince and Otieno 2014). Another dimension to take into account when it comes to data for global health is the purpose of the data collection. Crane has observed how HIV/AIDS treatment in Uganda has been transformed over a period of ten years from a “local clinic to a global research site” (2013, p. 181) feeding new types of data on clinical trials to a global community of researchers. Along these lines it has thus been argued that global health has become framed as a series of technical problems that need technical solutions, which furthermore marks a shift away from the public health priorities of securing health service delivery for everyone (Crane 2013; Prince 2013).

The potential consequences of the lack of focus on health sector strengthening became evident in the wake of the 2014-2015 Ebola epidemic in West Africa. The big question emerging from this event was how it could develop to such an unprecedented scale when outbreaks of the same disease in Central and Eastern Africa were usually quickly contained. One key explanation was to be found in the weak capacity of the health systems of many West African countries as they had been severely underfunded for many years (Gostin and Friedman 2015).

Providing health information in the context of global health is a matter of balancing multiple interests and agendas (Sullivan 2017). In particular, there is a tension between, on the one hand, generating data on projects that easily show results because they are easy to measure, and on the other hand generating data to monitor long-term improvements in the health system itself. These are more difficult to measure and the definition of indicators is not as straightforward. For example, it is uncontested that high quality research data is needed for the development of better technology and medicines to improve health globally, but doctors and nurses across Africa are working hard to make ends meet at clinics and hospitals, and global agendas also need to prioritize improving conditions for their work.

2.3.1 Information for disease surveillance and response

A theme central to contemporary global health priorities is the prevention of communicable diseases and especially those at risk of spreading across borders and becoming pandemic. It is a theme that recurs frequently on international agendas (Zacher 1999). Large outbreaks of lethal diseases have been known throughout history. Due to advancements in medical science during the 19th century a trust in medication was summarized by the slogan 'one drug for each bug,' and attention to disease surveillance waned more generally until the 1990s (Zacher 1999). Around this time there were large outbreaks of known diseases, such as cholera, but the appearance of new threats such as HIV/AIDS also sparked tremendous worries about the potential for uncontrollable outbreaks on a global scale, resulting in a renewed focus on disease surveillance and response (Zacher 1999). As mobility across and within borders continues to increase and new diseases continue to develop, it is clear that these diseases cannot be contained through medication and restrictive measures on movement only. Instead, rapid detection and efficient deployment of control mechanisms is now seen as the key to cope with these new threats (Zacher 1999; Lakoff 2017).

In recognition of these challenges the member states of the World Health Organization's African branch (WHO AFRO) adopted a resolution on IDSR in 1998 (CDC 2015; Kasolo, Roungou, and Perry 2010). The main idea behind the IDSR framework was to transform disease surveillance into a cross-sectoral undertaking instead of a task of each individual disease program, which had proven ineffective. This was envisaged through the standardization and streamlining of the technical guidelines down to each individual disease. There are two kinds of guidelines in the IDSR framework: general ones and individual instructions for more than 45 diseases. Further, when a country adopts the standard IDSR guidelines, they also contextualize them by making their own country-specific guidelines, including identifying which particular diseases to include. In Burkina Faso, the guidelines were adopted in collaboration with the WHO.

The IDSR framework has quite a number of objectives (Kasolo, Roungou, and Perry 2010). Those of most interest when it comes to supporting IDSR through HIS are to "*integrate multiple surveillance systems,*" "*improve the use of information*" and "*improve the flow of surveillance information.*" (Kasolo, Roungou, and Perry 2010, pp. 7-8). Doing so involves improving different data streams and acquiring surveillance data for early tracking of new diseases. Improving the use of information implies generating relevant evidence to strengthen action for both surveillance and response.

Surveillance has to do with collection of information while response is about taking action, including being prepared to fight disease outbreaks. Surveillance refers to all the mechanisms put in place to detect the first cases of contagious diseases. This involves diagnosing and identifying potential cases as well as enabling health workers to diagnose – or at least know when to suspect – such cases and refer them appropriately to relevant health facilities. This could be about both putting in place rapid diagnostic tests and improving laboratory capacity. However, for some diseases such tests are not easily available and diagnosing might instead be done clinically, supported by diagnostic guidelines. Surveillance also involves raising awareness in the population so that people know when to seek medical assistance. In any case surveillance also involves the rapid and efficient dissemination of information about suspected cases of potentially epidemic diseases through the health system.

Response is about all the different types of action that can be taken based on the information about an emerging outbreak or a new threat. This also involves effective control mechanisms of verification, so that it can be confirmed whether the suspected case is indeed a real case. There are several such mechanisms in place in the health system but the final controlling body should be an independent organization, as countries might have too many economic interests clouding their decision on whether an emerging outbreak should be made publicly known or not (Zacher 1999). However, the response time of international agencies has also been hotly debated, with criticism for being both too slow to announce and too quick on the trigger (Lakoff 2017).

Again the 2014-2016 Ebola epidemic in West Africa has highlighted all too well that although the IDSR guidelines have been adopted in many African countries, there is still a need to improve disease surveillance and response efforts in this region (Phalkey et al. 2015). Some of the information related challenges that were identified after the Ebola epidemic were difficulties to diagnose fast enough, to provide up to date and accurate information to the highest levels, to coordinate among the many actors involved in the response, and to inform populations about the protective measures to take (Dahl et al. 2016; Gostin and Friedman

2015; Moon et al. 2015). In addition, the data on the effectiveness of the response was not sufficiently reliable to support further action (Cancedda et al. 2016).

In short, disease surveillance and response is about monitoring communicable diseases in order to identify new cases and controlling the transmission of these diseases before they spread and develop into epidemics. Ideally, this should generate information that can be used for public health action (Kasolo, Roungou, and Perry 2010). Interestingly, this is very close to the vision of 'information for action' that tends to underpin the HISP agenda around HIS design, and supposedly there should be mutual benefits in supporting IDSR data collection through established countrywide HIS. Frameworks such as the IDSR guidelines are providing standards and high-level descriptions of how work should be done. While on the one hand the guidelines are a gift for efforts to strengthen HIS, on the other hand they bring some challenges, especially concerning their adaptation to existing conditions in individual countries. They still need to be contextualized, and the guidelines are silent on how this contextualization should take place.

2.4 Health information for action: a challenge of knowing and doing

Based on the readings in this section, the challenge to health information construction and use appears to be a practical, contemporary challenge to the public health domain. However, the readings show that there are further challenges. These concern determining how information leads to action, as well as how to produce information for action that is relevant for stakeholders across the spectrum in the health sector. As HIS are tools to provide relevant information, they are inevitably implicated in such work. However, there are significant challenges when it comes to supporting meaningful data use beyond just routine reporting. This question has mainly been approached as a data quality issue; in other words, the assumption is that better data would lead to more action. On the other hand, I argue that the question of health information use for action is also a question of how to collaborate in multidisciplinary settings where the character of action is diverse, which affects the nature of information required by different stakeholder groups. Furthermore, the tools to produce information are constrained. It is a challenge of knowing and doing under these circumstances as much as it is of data production. Such topics of knowing and doing have been of interest to the IS field, and it is with this in mind that I now turn to a discussion on how to approach these challenges theoretically.

Chapter 3 Related literature and analytical lens

The research considers construction and use of health information in LMICs, which concerns questions of how we know with a particular focus on the role of technology in the production of knowledge. The question of ‘how we know’ relates to both ontology and epistemology because it involves reflecting on what is accepted as knowing as well as defining how an understanding of this knowing can be obtained. As IS are tools for the production of knowledge, questions of how we know and share knowledge are longstanding and important to the IS research field (Hirschheim and Klein 2012; Alavi and Leidner 2001; Walsham 2001; Orlikowski 2002; Land 2014). These questions have also been considered in domain-specific subfields to IS, such as health informatics (Berg 2003) and HIS (Sahay, Sundararaman, and Braa 2017) as well as other health-related fields such as medical sociology (Timmermans and Angell 2001; Mol 2002; Moser and Law 2006). Much of this research shares a social constructivist approach to the question of how we know by seeing knowledge not as something existing independently in the minds of people but instead as ideas shaped by their social environment – including organizations, ideologies and work practices – and by the tools to produce and store knowledge such as paper, microscopes and computer-based technologies.

In this chapter, I discuss in more detail theoretical foundations for studying the relationship between IS and knowing. My approach to this topic is social constructivist and it is grounded in the sociology of technology and social shaping approaches, which in turn have developed from the sociology of knowledge and sociology of knowledge and science (Latour 1999; K. D. Knorr Cetina 2013; Stehr and Meja 2005; Swidler and Arditi 1994). Social shaping approaches provide a framework for an integrated study of facts and artifacts (Pinch and Bijker 1984) including both the nature of knowledge itself and the tools and systems used to create and represent this knowledge. These approaches have been used in the IS field particularly to theorize the IT artifact (Aanestad and Olaussen 2010), and also the content and processes of IS development and use (Howcroft, Mitev, and Wilson 2004; Williams and Edge 1996). My research focuses on the latter.

This chapter is organized as follows: in section 3.1, I discuss literature on the social shaping of technology, with a focus on IS development and design in the West as well as in LMICs. In section 3.2, I detail my analytical understanding of an HIS as epistemic machinery, including the key analytical concepts that I draw on in this regard. These concepts include interpretive flexibility, translations, circulating reference, multiplicity and situated action. I supplement this with a discussion in section 3.3 on uncertainty, a concept I draw from material within the sociology of health and from anthropology, which in my case is relevant for understanding health information for action. Last, I summarize these multiple concepts as part of my integrated analytical framework to guide my empirical and theoretical analysis.

3.1 Social shaping of technology and IS

Social shaping approaches have been instrumental in assessing a wide range of aspects within IS. As opposed to viewing technology as a neutral driver of change, researchers in this tradition view it as socially shaped and consequently reflecting the structural and political circumstances of its development and implementation (Howcroft, Mitev, and Wilson 2004). Some have argued that these circumstances should be accounted for if technology is to be successfully designed for and adopted by organizations and society. At the same time, this strain of research has provided theoretical and philosophical insights regarding the positions and meanings technology is given in society (Bijker, Hughes, and Pinch [1987] 2012).

Although it is beyond the scope of this thesis to give a full account of the history of social shaping approaches, I briefly discuss some of its roots. Social constructivist approaches to both scientific knowledge and technology are rooted in the sociology of knowledge, which in turn focuses on the social aspects of knowledge and knowing (Stehr and Meja 2005), including how people and societal institutions produce, use and react to knowledge. A key focus is on understanding the nature of knowledge and questions of what truth is and how it is generated. This line of thinking has its roots in the works of sociologists such as Marx and Mannheim, who engage with understanding human ideas and how these were shaped by society and its institutions rather than being a result of pure intellectual activity (Stehr and Meja 2005; Swidler and Arditi 1994). Marx was occupied with ideology and how different positions in society, such as social class, shape our worldview, including our comprehension of truth within a societal framework. Mannheim took this thinking further, arguing that while ideology builds on the past and serves to conserve the present, the notion of utopia builds on the future and thereby aims to move beyond the present. Developing from this sociological base, the sociology of science or scientific knowledge has matured into its own distinct domain, occupied with questions of the social shaping of knowing in science, while focusing on the social rather than the natural determinants of knowing in the natural sciences (Pinch and

Bijker 1984; K. D. Knorr Cetina 2009). The sociology of scientific knowledge is largely inspired by the work of Thomas Kuhn, who argued that scientific knowledge is shaped less by objective criteria than by shifting paradigms of what is considered valid or not (Stehr and Meja 2005; Swidler and Arditi 1994).

In IS research, this approach has been applied to implementation (Orlikowski and Gash 1994), organizational learning (Pentland 1995), and social consequences of new technologies such as a Geographical Information Systems (GIS) (Sahay and Robey 1996). Different variations of these approaches, such as social shaping of technology (SST), social construction of technology (SCOT) and actor network theory (ANT) have been developed, all of which counter the technological determinism argument by arguing that the technology-social relationship instead is mutually constitutive, heterogeneous and indeterminate (Howcroft, Mitev, and Wilson 2004). Ethnographic fieldwork and empirical case studies have been important tools for the development of these new theoretical insights (Aanestad and Olaussen 2010).

Ideas from social shaping approaches that draw on the sociology of science in the tradition of SST and ANT have gained wide recognition in the IS research field because they offer tools for conceptualizing technology (Orlikowski and Baroudi 1991; Orlikowski and Iacono 2001; Hanseth, Aanestad, and Berg 2004). There was a need for such tools, as theorizing technology was a recurring topic in sociologically informed analyses of IS (Howcroft, Mitev, and Wilson 2004). From an ANT perspective, technology was regarded as an actant in a sociotechnical system, exemplified in the statement "*B-52s do not fly, the U.S. Airforce flies*" (Latour 1994, p. 35). The point here is that the capacity of the IS should not be viewed as an isolated instance but rather as the sum of a sociotechnical network comprising people, technology and their interactions. An important but also controversial aspect of this approach was that this actant could hold agency in the network, just like people could. Thus, while the approach solved one problem, it was criticized for doing so at the cost of narrowing the human (Appadurai 2013) and for taking an amoral stance (Walsham 1997).

Various other theoretical concepts within social shaping approaches have been used in IS research to understand the context and the content of the technological. One example is the concept of 'boundary objects,' which refers to an object or instance that can be understood as a common point of reference by different communities of practice that might be in disagreement (Star 2010). Puri (2007) drew upon this concept to describe the relevance of different types of maps shaped through negotiation processes around representations of land divisions in a GIS in India. Another is the concept of 'circulating references,' which has been used to understand what is lost and gained when software is scaled to be used in multiple contexts; a process also referred to as 'circulating translations' (Sahay, Sæbø, and Braa 2013). A third is the concept of 'interpretive flexibility,' which in turn inspired the idea of 'technological frames,' – the different understandings that members of an organization can have of the same technology (Orlikowski and Gash 1994; Sahay and Robey 1996) Pentland (1995) takes a slightly different approach, emphasizing learning processes rather than the technology itself. He argues that learning and knowledge construction are social rather than individual processes, and that a knowledge system comprises a collection of knowledge processes, namely construction, organization, storage, distribution and application. The content that needs to be stored in IS should be seen as results of these multiple processes (Pentland 1995), which consequently redefines what we understand by knowledge.

Along the same lines, social constructivist approaches to IS have received criticism for being too oriented towards the social, resulting in a neglect of the technical. A related criticism concerns the focus on micro processes in situated contexts, and inadequate consideration of the macro structure and processes at the organizational and societal levels (Howcroft, Mitev, and Wilson 2004), as well as of information infrastructures (Monteiro et al. 2013). While recognizing these limitations, I find the social constructivist perspective relevant to IS research as it enables a consideration of both the general context of the IS as well as the content and processes of the IS. But before discussing the key concepts from the social shaping approach that I draw on in my analytical lens, I want to delve into this motivation a bit further.

3.1.1 Technological and information determinism towards Information Systems

Information Systems as a distinct research field was initiated in response to a growing need to study the introduction of computers in organizations in the 1960s (Hirschheim and Klein 2012). The field grew out of other disciplines, such as computer science, accounting, management and organization theory, which were limited in their theorization of technology. IS research has its origins in the US and Europe, which each applied different theoretical strands to their research (Hirschheim and Klein 2012; Land 2014). In general, the field was dominated by optimistic assumptions about technology and rationalistic expectations of the positive effects of technology (Robey and Boudreau 1999), despite empirical evidence to the contrary (Aanestad and Olaussen 2010; Hirschheim and Klein 2012). Technology can also have unintended and even negative consequences, such as an increase in surveillance and disempowerment of users (Aanestad and Olaussen 2010). Such findings countered beliefs that users were expected to use the technology in ways that were either predetermined by physical design (Suchman [1987] 2007) or shaped by content such as clinical guidelines (Berg 1997). Despite these empirical findings, the IS field persists with a broadly technologically deterministic approach that expects positive effects on productivity and efficiency from technology (Land 2014).

A recent example that illustrates this bias from Denmark is 'Sundhedsplatformen' (the Health Platform), an integrated comprehensive electronic health record covering twenty hospitals in two administrative regions. The platform was implemented in 2016 with unrealistic expectations on how the system would ease documentation work and potentially replace the work of medical secretaries. During implementation it became evident that the secretaries did more than simply transcribe and record the physicians' notes. They also structured and organized the information, making it easier to read for other physicians and using it for secondary purposes such as health statistics (Mørck et al. 2018). This example highlights how health information use is not only about making information available on an electronic platform, but also about considering the multiple meanings ascribed to the information and the ensuing transformations to serve different purposes. Another example can be found in a West African context, where the post-Ebola environment has spurred political focus on epidemiological information sharing, including budgets for some costly initiatives. One such initiative was the development of an integrated regional data warehouse for epidemiological information sharing between the 15 ECOWAS countries (West African Health Organization 2012). While the focus has been on making the data warehouse technically operational (Poppe and Sæbø 2015), information sharing between countries is not yet effective, as the required structures, including collaboration and trust, have not yet been put in place. Again, this example illustrates that availability of information is not sufficient for putting it to use.

The above examples help build caution towards current optimism on what can be done with information derived from new initiatives involving mobile technologies, big data and machine learning (Sahay 2016; Alexander and Lyytinen 2017). It thus becomes important to critically assess the boundaries of what can and cannot be done with data, information, methodologies, and new technologies. My research is an effort in this direction.

3.1.2 Information Systems and ICT4D

An important sub-domain of the IS research field, which has evolved during the past thirty years, is that of Information and Communication Technology for Development (ICT4D) (Walsham 2017). Just as has been the case in mainstream IS, a technological determinism has underpinned ICT4D research, despite many empirical examples of unrealized potential of ICTs (Toyama 2015). A consequence of this is a number of design-reality gaps (Heeks 2002). These findings reinforce similar findings from Western contexts which have highlighted the mismatch between highly structured expectations around the IS and the messy reality of organizational practices (Berg 1997; Orlikowski 1992; Suchman [1987] 2007).

The ICT4D field has established itself as a relevant research domain, and is continuously striving to enhance its theoretical contributions (Avgerou 2017; Walsham 2017; Sahay, Sein, and Urquhart 2017). Walsham (2017) suggests several IS theories should be explored further in transdisciplinary constellations while at the same time being sensitive to local views on development. Sahay et al. (2017) suggest more specifically that we ‘flip the context’ and discuss what insights ICT4D research can bring to mainstream IS. Having done my research in an LMIC, I find the latter proposal highly relevant as it invites me both as a researcher and as a private individual to reflect critically on my own baggage and the value of it in a country that in so many ways is fundamentally different from my own country, Denmark. Professionally, I find that the idea of flipping the context invites us, as Westerners involved in research or development work, to take some distance from our implicit role as do-gooders who are often heavily supported by donors. It is a role that can easily have us focusing too narrowly on what we bring to these LMICs rather than what we can learn, either through listening or with more balanced collaboration.

In summary, my research is situated in ICT4D as a sub-domain of IS research, and aims to contribute to two lines of discussion. The first is about how IS can support the creation and use of knowledge to take action in the context of health care. The second is the question of theorizing from an LMIC context.

3.2 HIS as epistemic machinery

For the purpose of defining the content and the processes of one of the key elements of my study, a web-based HIS, I draw on work from within the sociology of scientific knowledge by Karin Knorr Cetina, who has approached the subject of truth – and specifically the creation of scientific truth – through extensive empirical studies of laboratory work. Drawing from her ideas around epistemic cultures, I build my conceptualization of HIS with a particular focus on the network. This concerns specifically the practices of handling information within it rather than just the actants.

Knorr Cetina (2009, 2007) argues that there is a need to shift our focus from *what* we know to *how* we know. Having changed the perspective from a knowledge culture to an epistemic culture, Knorr Cetina defines this culture as the machinery of knowledge construction and points out that such machinery comprises not only humans; things also have roles in knowledge construction processes. This focuses attention specifically on the internal processes involved in generating knowledge.

Knorr Cetina's work is part of the social studies of scientific practices carried out by a range of sociologists of science in the 1980s. Through in-depth laboratory studies in the 70s and 80s, they challenged the dominant rationale that scientific practices were purer than those in the disciplines of humanities because they were derived through rational procedures aiming to create a uniform body of knowledge that would be similar across scientific domains (Knorr Cetina 1991; Knorr Cetina 2007; Stehr and Meja 2005). The sociology of scientific knowledge showed that there were indeed many social and cultural facets to the production of scientific knowledge. Knorr Cetina's work draws on material from two ethnographic laboratory studies – one in experimental particle physics and one in molecular biology – to explore the different ways of reasoning in different scientific cultures. From these studies she demonstrates that in the natural sciences also, epistemology as a method is a process that involves reasoning along the way, rather than strictly following a fixed set of rules of argumentation (Knorr Cetina 1991).

This shift from knowledge culture to epistemic culture might seem subtle, but in the context of this research project, such a conceptualization will make it possible to focus on HIS-supported knowledge creation. It is not concerned with knowledge in the sense of what is to be found in the minds of people, but rather with the content and processes involved in knowledge creation. It accounts not only for the software component but also inquires into the techniques and practices around its use and the creation of knowledge it supports. Analyzing an HIS as an epistemic culture – that is, its '*epistemic machinery'* grounded in the exploration of epistemic practices – will open up a space for analysis of how the functions and meanings of such practices contribute to knowledge shaping within a certain domain. Below I discuss in more detail some concepts to support such an analysis.

3.2.1 Constructing facts through interpretations and translations

The social constructivist approach to IS research emphasizes the meanings people ascribe to technology and how this shapes how they will adopt and use it. Two concepts, interpretive flexibility and technological frames, have been used to account for this type of mechanism.

One of the most commonly used examples of an object that has interpretive flexibility is a map, which for some people might give directions to a specific point of interest, such as a campground, whereas for others it describes the topological qualities of the landscape or animal habitats (Star 2010). This can be seen as a quality of maps, and in this perspective interpretive flexibility is not necessarily considered bad. Instead, it reflects the relatively open properties of objects or information, which are not intrinsically natural but shaped by social interpretations and practices (Pinch and Bijker 1984; Bijker 2017). Interpretive flexibility thus accounts for the variations in how social groups define problems and solutions, which in turn helps to explain why these objects often function differently in practice than how it was anticipated (Howcroft, Mitev, and Wilson 2004).

In other cases interpretive flexibility can create tensions. Based on a study of biogas in India, Bijker (2017) analyses how interpretive flexibility around biogas allows different social groups to assign different meanings to it. There is 'biogas as solution' promoted by Western agencies who sees it as a way to combat environmental challenges. In contrast, there is 'biogas as burden,' which is how the local farmers see it because instead of simply burning the straw in their fields they now have to collect it and transport it to the biogas plant. This example is also an instance of multiple rationalities (Avgerou 2003) reflecting ongoing discussions and contestations between the technical/rational and more interpretive social perspectives (Avgerou and McGrath 2007). Often the Western rational approach tends to dominate, and instead Avgerou (2003) argues the need to consider and negotiate the multiple rationalities in play. This contextualist position has been used in HIS research to show how health programs are shaped by different interests, which in turn can affect HIS integration (Chilundo and Aanestad 2005). These findings emphasize that achieving HIS integration is not only a question of managerial instrumental rationality, but requires contextualized understandings about the nature of diseases, work practices of health staff, and processes of patient care (Chilundo and Aanestad 2005). The idea of interpretive flexibility has inspired more IS-specific concepts, such as technological frames, which refers specifically to the different ways people think differently about technology and its context (Howcroft, Mitev, and Wilson 2004; Orlikowski and Gash 1994). Varying technological frames in terms of knowledge, assumptions, and expectations of the technology have implications for the implementation outcomes (Orlikowski and Gash 1994).

In the context of this research, these notions are interesting as they address the variations in requirements there might be of the information the HIS should hold. The concept of interpretive flexibility is relevant in a multidisciplinary field such as health care, where knowledge is collaboratively produced across professional boundaries in a number of different physical contexts and with a range of different tools. The idea of interpretive flexibility can help understand the differences in understandings of, for example, a diagnosis by a patient, a doctor or an epidemiologist.

At the same time, knowledge is not only a product of the tools and epistemologies we use to define it. It is also a product of reality, experienced both physically and intellectually. To communicate about this reality, we use representations, which can be in the form of words, categories or other placeholders for information. These provide a language to talk about reality and transport these understandings from one setting to another. The notions of representations and translations help to understand such processes of circulation (Latour 1999).

Latour describes the myriad steps involved in turning a research site, the Amazon rain forest, into a site for the production of scientific knowledge about forest degradation (Latour 1999). He follows the work of a multidisciplinary team of botanists, pedologists and geographers in the Amazon and traces how they turn the empirical material, soil samples, into written text: a report which then circulates across time and space. Latour analyzes the gap between the words we use to talk about the world and the world in itself – in other words what is reality? To show that our representations of reality and reality itself are indeed connected rather than separated, he develops the concept of 'circulating reference,' which refers to the multiple transformations the soil samples undergo during the work undertaken by the expert team putting the world into words: making a reference. Latour argues that scientists can only construct representations of the world as it is impossible to have a 100 percent accurate description of how something occurs in nature using a laboratory setting.

Latour furthermore states that "*the sciences do not speak of the world but, rather, construct representations of it that seem to push it away, but also bring it closer*" (Latour 1999, p. 30). Putting the world into text entails a trade-off between particularity and relative universality, where the richness of the physicality of the research site is successively reduced as the soil samples circulate, while at the same time other characteristics are amplified, as the soil samples from different contexts are increasingly standardized and made comparable. Latour describes this dialectical process of simultaneous reduction and amplification as 'chains of transformation,' reflecting different connections between a real-life phenomenon and their representations across time and space.

I draw upon this concept to interpret the process by which data is collected and circulated across the different aspects of the health system. At the point of clinical care, diagnostic data is collected through various methods and tools (inscriptive devices) and recorded in the registers of the facility. This becomes the starting point for the continuous circulation of these clinical references through the national health system: they contribute to statistical reports which later return to facilities and thence – though in a different form – help treat the patients who were the source of the samples. Understanding the specificities of how this works serves as a prerequisite for HIS design: in the process of gaining universality, the local is increasingly lost.

3.2.2 Disease as a multiple object

To supplement these discussions on representation, I introduce the notion of multiplicity. This refers to the idea that what we usually think of as one object can in practice appear as more than one, though not in the sense of different interpretations; instead, as different physical presences (Mol 2002).

The concept of multiplicity aims at articulating differences in objects that are the same and yet appear different. Take, for example, a disease. It is present in the human body – in the blood, perhaps, or in other tissues – but how do we know it is there, and how can we represent it with precision? Anne Marie Mol (2002) explores these questions in her ethnography of a disease, atherosclerosis. She specifically looks at how multiple professional groups in a Dutch hospital collaborated on treating patients with this disease. She was able to articulate how they worked together without sharing a unified version of this disease. Visibility of atherosclerosis was made possible because of multiplicity, thereby referring to the idea that one body, or one disease, takes on multiple forms. For a pathologist atherosclerosis is enacted like this: "*'Look. Now, there's your atherosclerosis. That's it. A thickening of the intima. That's really what it is.' And then he adds, after a little pause: 'Under a microscope'*" (Mol 2002: 30). From this statement, Mol builds an understanding that a disease can be enacted, or performed, by different professionals in different settings. To patients, atherosclerosis is pain while walking; to the clinical doctors it is tangible signs such as a lack of pulsation in the leg; to the pathologists it is the thick intima they can see on the vessel wall under the microscope, while for epidemiologists it represents a cause of death in a statistical report. It is only when these groups meet that they need a shared point of reference to refer to 'atherosclerosis.' In such cases, they use the term 'atherosclerosis,' which then becomes a 'coordinating mechanism': co-existing, but yet relatively independent of each other.

Mol distinguishes between the clinical and the pathological sections of the hospital and argues that while they do collaborate on the diagnosing of atherosclerosis, they also work relatively independently. This division of work is also seen in an LMIC context, although the reliance on laboratories for diagnostics is more limited (Street 2011; Moser and Law 2006).

In a HIS-perspective, multiplicity is usually seen as something that should be normalized, or aligned, for purposes of standardization and aggregation. For example, a division between the clinical and pathological sections can lead to tensions around integration in terms of balancing the different representations of the disease. Chilundo and Aanestad (2005) describe a multiplicity of information flows for malaria originating from disease surveillance, laboratory management and the routine facility reporting system in Mozambique. This multiplicity creates challenges around ownership of data and registration workloads, as the data needs are not the same everywhere in the health system. In contrast Mol provides a more consensual perspective on this issue through the notion of multiplicity, which emphasizes the different values, needs and interests of the same information for different social groups. Mol's ideas help us to understand that multiplicity should be considered necessary for different people in the health system to make decisions even when they work on treating or responding to the same disease. I will use this concept to discuss how to represent multiplicity in an IS or HIS.

3.3 Uncertainty – or when there are no facts

While social constructivist and sociologically informed approaches provide rich insights into how we know, and how technology supports knowing, there is less guidance on what to do when we cannot know. Although the perspective on knowing is contextualist, most often the topic of inquiry is how knowledge in some form can be produced. Likewise, being rational implies some state of knowing and ability to be reasonable. Reality, however, is often quite different, and sometimes knowing might not be possible; in other words, people may have to operate under conditions of uncertainty. In this section, I draw on work from medical sociology and anthropology to explore different ways of thinking about what people do under such conditions of uncertainty. The focus is not on trying to eliminate uncertainty, but on helping to imagine the future more positively.

In anthropology, the indeterminate nature of everyday life has been an important topic of study as it characterizes an essential part of the human condition (Cooper and Pratten 2014). Even though we cannot be sure what tomorrow brings, we continue to make plans to go on with our daily activities. Doing so requires different strategies for dealing with uncertainty.

In an LMIC context, uncertainty as a condition of living is dominant when there is a limited state social security net and health insurance to rely on in conditions of severe illness or loss of a job (Cooper and Pratten 2014). Susan Whyte has studied adversity, and how people deal with uncertainties in life, amongst the Nyole people in rural Uganda (Whyte 1998). She reflects on how insecurity and contingency reflects the unforeseeability of life in rural Uganda.

Uncertainty is defined as a state of mind, insecurity as a social condition, and contingency as being interrelated or dependent on others (Whyte 2009).

> *To be contingent upon persons or happenings that cannot be fully foreseen is to lack control and be subject to uncertainty. But to try to create contingencies in the sense of making connections to possible forces for improving security is to attempt to move an uncertain situation towards greater confidence.*
>
> *(Whyte and Siu 2015, p. 20)*

Uncertainty and its relationship with human practice has also been widely dealt with in medical sociology (Fox 1980), and it has been applied in different global contexts (Street 2011; Whyte 2009, 1998; Timmermans and Angell 2001). Managing uncertainty is part of the medical residents' training program: through practical situations in the clinical setting young doctors learn to develop their clinical judgment by handling knowledge gaps between the largely theoretical concepts studied in medical school and the unexpected developments of daily doctoring (Timmermans and Angell 2001). New concepts, such as evidence-based medicine, aim to reduce uncertainty through the provision of more facts and knowledge. Although they do succeed in reducing some types of uncertainty, such as the risk of overlooking vital signs, they also introduce other uncertainties, especially concerning the validity of the evidence. Consequently, introducing evidence-based medicine should not be seen as a replacement of but rather a supplement to clinical judgment (Timmermans and Angell 2001).

In her study of Malawian medical students, Wendland (2010) observes a gap between the technology the medical students learn about in their textbooks and what they find available and functional when engaging in clinical practice. What makes this gap even wider is that the textbooks come from America and the hospitals in Malawi are not equipped to the same standard. She discusses how this shapes the students' approaches to doctoring by comparing it to the approaches of American students. While they tend to become more scientific, mechanistic, and reductionist during their resident period, the Malawian medical students draw upon different values of social engagement, such as service to the community, or pursuing a collective rather than individual good. As they encounter conditions that are very different from what they have read about in their textbooks, they tend to employ some kind of activism. This enables them to navigate in spite of minimal resources.

Uncertainty, coming from a complete lack of information and a state of not-knowing, is often experienced in settings where both resources and diagnostic capacities are severely limited (Street 2011). Based on empirical work in hospitals in Papua New Guinea, Street argues that despite such conditions of uncertainty, basic principles of Western medicine are in fact followed but diagnoses are not considered strictly necessary to the treatment of patients (Street 2011). In this setting knowing and not-knowing become interdependent and interchangeable processes as both are seen as valuable resources in the provision of care.

Lack of diagnostic capacity has also been observed to lead to more practical means of diagnosing (Mol and Law 1994; Steven Feierman 2011). European doctors who had worked in countries across Africa found laboratory capacity to be inadequate, and they learnt from their local colleagues, for example on how to rely on practices of clinical observations of paleness to diagnose anemia (Mol and Law 1994). The authors note *"the clinical gaze doesn't create sharp numbers. But it certainly produces diagnoses"* (Mol and Law 1994, p. 654). Such an approach, quite a common improvised practice in many LMICs, has been referred to as functional diagnosing, as opposed to technological diagnosing (Steven Feierman 2011). While such approaches may appear messy and imperfect, they might be necessary in order to take action to treat a patient. However, these local practices may create tensions when creating comparable aggregate statistics of data from multiple sources (Mol and Law 1994).

Other sources of uncertainty are lack of attention given to a phenomena, such as emerging diseases like cancer, which are not generally expected in a specific context (Livingston 2012). When knowledge resources are limited, both in the medical domain and among patients, strategies to handle such diseases are built on improvisation (Livingston 2012).

These studies of uncertainty in different contexts emphasize the different conditions under which uncertainty occurs. These include living conditions, degree of practical experience with a topic and availability of resources to achieve knowledge. In summary, uncertainty is both an existential condition and an institutional one, and both result in unforeseeability. As they are hard to avoid completely, strategies for acting under these conditions are required, which I elaborate on below.

3.3.1 Uncertainty and situated action

To place this discussion of uncertainty in the context of IS research, I will connect it to the notion of situated action observed by Lucy Suchman. Through her work on how users interact with a so-called self-explanatory photocopier, Suchman (1987) challenged research in Artificial Intelligence (AI) by exposing the weaknesses of our tendency to rely on plans in defining how humans interact with technology. Suchman was interested in the claim that computer interfaces and technological objects could be designed to be intuitive and self-explanatory and that human-computer interaction was an important topic to study (Suchman [1987] 2007; Suchman et al. 1999). Together with colleagues she did detailed studies of how people interacted with a modern photocopier, which was designed to be intuitive to use. They observed that the troubles people had in operating the photocopier were due to their unfamiliarity with the machine which, unlike humans, lacked the resources to engage in sensemaking (or making up for a lack of understanding) during the course of interaction (Suchman et al. 1999). The study highlighted that action is not defined by predefined structures or rational plans, but instead based on assessments of what it is rational to do in a given situation. Suchman articulated this finding through the concept of 'situated action,' emphasizing multiple rationalities for different situations shaped by the social and material properties of the world that surrounds technology.

Suchman is careful to point out that action is not random, although it cannot be fully predetermined. She also uses the analogy of the differences in how European and Micronesian sailors navigate. The European sailors use maps and charts to navigate at sea, and the Micronesian make use of the signs they meet as they move, such as the wind or the waves, and adjust their sailing to these contingencies as they experience them. Her point is that while this might appear random to a European sailor, who thinks of a map as the key to guide action, they do not act randomly. They have a vision for their journey, but they let situational contingencies guide them forward rather than predefined plans and maps.

In their studies of how West African states deliver services, anthropologist Oliver de Sardan and colleagues have similarly observed that practices are not irrational just because they do not follow the official rules of the public sector (Bierschenk and Olivier de Sardan 2014). They argue that the bureaucrats take a rational approach to the contingent circumstances of internal and external hierarchies in which they have to conduct their work. Instead, they apply ‘practical norms’ to their work. In West Africa, public services are usually co-delivered, which means that bureaucrats need to interact with a range of other actors, such as donors, who might subscribe to other modes of governance than those of their own governments, thereby introducing another layer of accountability.

Within the health care domain, there are often gaps between formal rules and local practices. For example, there might be criteria for documentation based on national policies and plans, but actual registration is affected by informal constraints and priorities at the point of service delivery, where care is seen as being more important than reporting (Piotti, Chilundo, and Sahay 2006). Formally, there is a demand for an increased volume of information from the health clinics to register data, and this follows the introduction and rapid expansion of certain health programs. However, in clinics registration may not be prioritized because it is not believed to be of highest priority. Piotti et. al. thus argue for a need to take informal work practices into account or “*the installed base—comprised of* [sic] *the existing situated rationalities of the work practices, donor influences, and the particularities of the diseases*” (Piotti, Chilundo, and Sahay 2006, p. 106).

The concept of situated action, or requiring improvisations based on the contextual factors (Suchman [1987] 2007), appears to be linked to the concept of uncertainty. As such, contextual factors are contingent and might be changing, and this means that situated action will always have an element of unpredictability or uncertainty. It could be to a smaller or larger degree but nevertheless, uncertainty is there. It follows that agency is not based only on information, but also on lack of information and incomplete information. With this perspective in mind, we can begin to reflect on what people do as having an inherent logic, even though it does not follow a predetermined pattern based on, for example, managerial rationality. Thus we can discard the idea that in practice, when work is messy or seems random, it is not rational. Supporting this work with an IS then ceases to be about aligning work practices to the IS and becomes about finding ways to represent uncertainty so that it can be incorporated into the HIS and support situated action.

3.3.2 Uncertainty as a resource

In spite of insights such as those made by Suchman and others, it appears that information system design and implementation continues to happen under assumptions of rationality, both when it comes to the problems they can help solve and the practices they should support. One reason for this persistence could be that while it is easy to challenge managerial and rationality assumptions for being narrow and insufficiently descriptive, it is far more difficult to develop alternatives. Social anthropologist Arjun Appadurai (2013) helps to identify such alternatives. In his view, we need to replace the monopoly of rationality, which he sees as defined by a Western conception of modernity and exemplified by rational-choice theory, with an approach that instead is based on what people aspire to rather than what they calculate. This is necessary, he argues, if we want to navigate the future rather than study the past.

On a related note Wendland (2010) critiques how the identification of conditions of uncertainty due to inadequate resources can lead to conclusions of people living in the past. Instead, she argues, we should focus on reimagining the underlying practices of how we do knowledge work in settings that constitute everyday reality. Uncertainty, she concludes, should be embraced as a driver of change, and understood by inviting people to reflect on questions related to managing their experiences of misfortune. These reflections help to identify alternative approaches to deal with and leverage on emerging uncertainty.

Whyte (1998) looked specifically at ‘cultural resources’ for managing uncertainty, and provides a concrete example of such approaches. She identifies two common phrases/idioms used to deal with uncertainty: the symptomatic, and the explanatory. While the symptomatic is concerned with treatment using both pharmaceutical and local medicines, the explanatory is concerned with asking questions and forming an understanding. This includes visiting diviners to help identify the source of misfortune. To describe how the Nyole dealt with uncertainty, she developed what she calls a ‘*pragmatics of uncertainty*.’ It emphasizes that the Nyole are not helpless in an uncertain world; rather they engage with it by asking questions. This is a strategy that seldom eliminates uncertainty, but is “*a characteristic of both the experience of misfortune and the process of dealing with it*” (Whyte 1998, p. 19). Since uncertainty reflects the unknown or unexplainable it makes us wonder and ask questions, and therefore it can be seen as a driver for imagining the future.

In the book “The Future as a Cultural Fact” Appadurai draws on anthropological work on city planning in India to criticize anthropology for being a science concerned with studying the past instead of the future (Appadurai 2013). Along some of the same lines as Avgerou (2003) and

Suchman ([1987] 2007), he criticizes the modernistic rationality that has been promoted by Western thinking and consequently shapes our view on progress and how to envision the future. To illustrate the limits of this approach he draws on American sociologist Frank H. Knight's ideas on how to differentiate between risk and uncertainty. According to Appadurai, Knight sees risk as associated with situations that have unknown outcomes but where there are yet recognizable factors that can be taken into account. This Knight contrasts with uncertainty, which is characterized by an absence of factors that can be accounted for. Consequently, calculations can be made to deal with risk but not with uncertainty. Therefore, Appadurai argues, risk and probability have been dominant at the expense of uncertainty and possibility.

If we apply this idea to information systems, a similar pattern might be seen. The deterministic tradition is still dominant when it comes to design and implementation of IS; where the critical, interpretive tradition has provided insights on challenges it has done so largely from a retrospective perspective, and they are limited in guidance on how to envision the future. This is also the case when thinking about software development, including for health information construction and use. The dominant assumption is that data will support the elimination of both risk and uncertainty through the production of numbers, rather than any emphasis on how work can be done under conditions of uncertainty. I see an approach that offers such guidance and insights from social sciences as especially useful in the surveillance and response to epidemics of infectious diseases, which is an area that already requires navigation in unprecedented events, and in LMICs is usually accompanied by the forced dependence on inadequate statistics and data (Farmer et al. 2013).

3.4 My conceptual perspective: social shaping approach to health information construction and use

Based on the readings in this chapter, I will now connect the analytical concepts introduced above to my conceptual perspective, which I use to assess the sociological aspects of health information construction and use. The purpose of the perspective is twofold. First, it should facilitate a theoretical discussion on the role of information in decision-making and thereby the structure of knowledge and its potential representations in IS. Second, it should facilitate the empirical study of how these sociological aspects can be accounted for to support HIS design and development.

The readings on social shaping approaches to IS design and development help to consider the content of an IS or HIS. They also help to define IS, or HIS, as a central part of knowledge-constructing epistemic machinery that does not hold only static instances of information needed to support action. This machinery is represented graphically below.

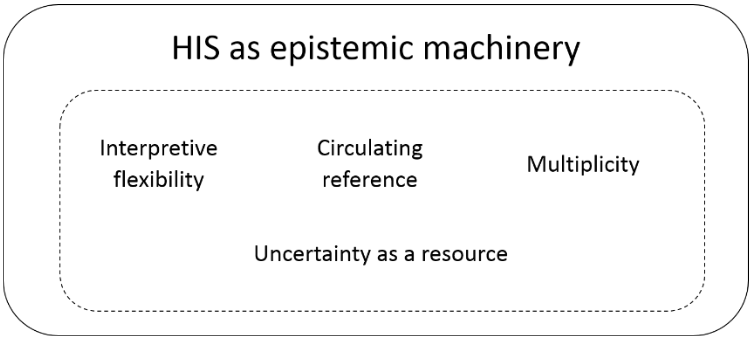

Figure 1: HIS as Epistemic Machinery

Within this framework, knowledge and meaning are generated through processes of constructing facts, relying on both interpretive flexibility and circulation of reference. Whereas interpretive flexibility refers to how different social groups understand a phenomenon, circulation of reference refers to the way physical reality is represented by words, not as a complete abstraction but as the result of carefully arranged processes of translations as well as reduction and amplification. An important point here is that of multiplicity. In interdisciplinary fields such as the medical, there is a multiplicity of such processes and, rather than creating a tension between the different professional groups, these differences are making the system work. Putting these three concepts into the framework gives a multidimensional view on the content of an IS. It nuances the question of how we know as being shaped by several social processes. Considering these, both on their own and in connection, provides insights into how knowing can be supported through an HIS.

Thus, having defined a theoretical approach to understanding HIS, I am adding uncertainty as another aspect to this framework. Although uncertainty is usually understood as lack of information, here I try to use it as a means to tackle the problem that what we know sometimes becomes too tightly confined to what we can see and describe. In my theoretical understanding of uncertainty, I draw on anthropologists' research in LMICs where uncertainty is seen as a resource that is relevant to envisioning the future, and thus as a driver of action.

The analytical lens aims to offer a view on health information construction and use that is neither IS, nor information-deterministic. Instead of viewing data use as a linear process leading from the production of information to action, it is conceptualized as a situated practice involving people and tools in the efforts to acquire knowledge, present it, and act on it. It can be a challenging view, as it is not as easily modeled as the linear, information-deterministic view.

In section 3.1, the first in this chapter, I outlined two discussions: one relating to how IS can support the creation and use of knowledge used to take action, and in this case within a multidisciplinary domain such as health care, and the other relating to how to theorize from phenomena observed in an LMIC context. In the rest of the chapter, I approached the first discussion by arguing that construction and use of information is situated, and therefore leads not only to multiple rationalities but also to multiplicity in interpretations and representations, which is an important distinction to keep in mind when designing an IS in the medical domain. I approached the second discussion by articulating different facets of uncertainty, which draw on work from LMICs and which appear to be useful to the IS domain as they introduce another way to think about lack of information or poor information. In this way uncertainty might be a valuable addition to discussions about how we know; in addition, it may provide an example of theorizing based on a phenomenon observed in an LMIC context. As uncertainty is also seen in the medical domain in general, I believe this discussion has the potential to be extended to mainstream IS research.

Chapter 4 Methods

Studying how people collect and act on information requires a methodology that can provide a grasp of the information itself as well as of how people interact with it. While the discussion in Chapter 3 was concerned with a theoretical understanding of health information construction and use as social phenomena, this chapter outlines my epistemology. I have taken an ethnographically inspired approach underpinned by an interpretive epistemology to study the phenomena in the context of disease surveillance and control in Burkina Faso.

I begin this chapter with a brief account of how I entered the field and rearranged my approach according to my initial findings and insights. Next, I provide an overview of my research design, a chronology of the fieldwork and reflections on selection of research sites. This is followed by further details of how I collected, organized and analyzed my empirical material.

4.1 Entering the field

As I began doing fieldwork in Burkina Faso in early 2015, it was only a couple of years after the DHIS2 software had been adopted as the main database of the national HIS. The database was named *Entrepôt National des Données Sanitaires,* which translates as National Database of Health Information. In daily speech, this was abbreviated to ENDOS. The IT directorate of the Ministry of Health had worked closely with the global HISP team during implementation, and were now managing the ENDOS setup on their own. As my research project was affiliated with the global HISP team, I entered the field through this directorate. During the first part of my fieldwork, I spent quite some time in the IT directorate, as it appeared to provide good access for studying ENDOS and related health information use. However, as time passed, I found that this strategy had its limitations in relation to my specific research topic as it tended to distance me from the users of ENDOS – both those who were generating the data and those using it.

While working with the IT directorate, I also joined workshops and began to make observations and notes on what I experienced. One time I joined a one-week workshop in Bobo-Dioulasso, the second largest city, which is located six hours away from the capital. Below is a snapshot from this workshop, which was carried out as group work in a conference center.

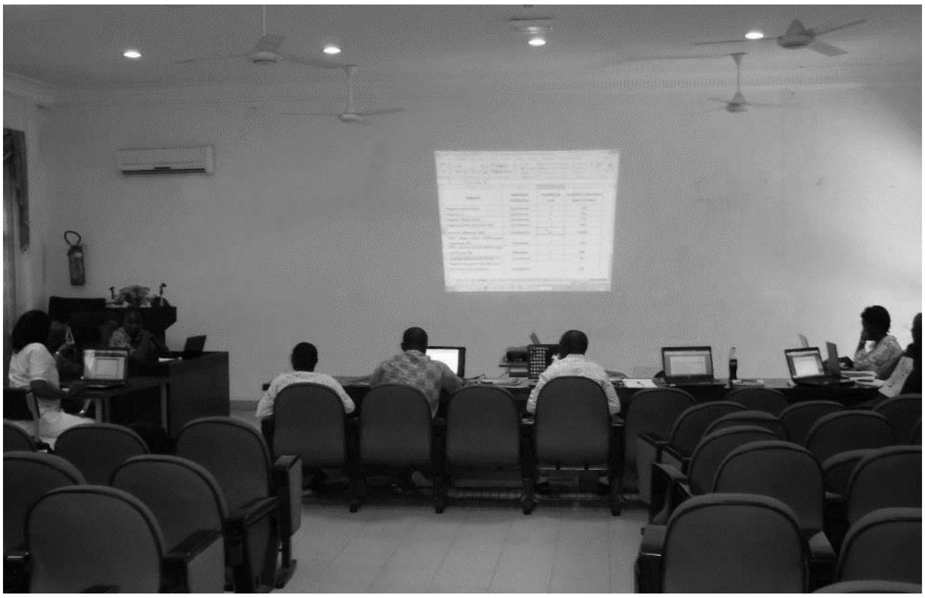

Image 1: Configuration workshop on integrating nutritional data to DHIS2

Reflecting further on what I was learning from this approach, it seemed it would have me spending hours in meeting rooms looking at projected Excel sheets, and I began to understand that I would not encounter data use this way, nor would I meet the data users. It was mainly technical staff from the Ministry of Health who attended these types of workshops and the discussions reflected a rather technocratic perspective on data use oriented towards reaching ideal data use. The reality I found was far from that; consequently, I started to think of other ways to connect more personally with the actual users of ENDOS and their practices.

This introductory account might not appear to be much about data use. However, it does highlight some essential issues concerning health information use. First, it underscores the lack of actual use of such information in IT departments. Therefore, to study this phenomenon from an IS-oriented perspective also required direct interaction with end users in order to understand their needs and possibilities for acting on data. While this might seem to be a rather obvious observation, it reflects a longstanding challenge that both researchers and practitioners face when developing and adopting rich and sensitive social approaches to understanding IS in context (Howcroft, Mitev, and Wilson 2004). In addition, the account highlights some methodological points about defining both the field site – which cannot be taken for granted (Blomberg and Karasti 2013) – and the subject of inquiry, which in interpretive research can be shaped through iterative processes of data collection and analysis (Walsham 2006).

4.2 Research approach

Qualitative research can be underpinned by a positivist, an interpretive or a critical approach (Orlikowski and Baroudi 1991; Walsham 2006). These approaches differ respectively on whether reality is understood as facts that can be observed and described objectively 'as they are'; as products of social interactions that need to be interpreted before they can be understood; or as shaped by political and social conditions and thus subjects to social critique (Klein and Myers 1999). Interpretive research views phenomena through the meaning people give to it and it focuses on human interpretations and meanings (Walsham 1995). Following a recognition of the significance of social issues to IS research, a focus on the need to apply methods suited for the study of social issues was developed, and a number of suggestions for taking up interpretive approaches were made (Orlikowski and Baroudi 1991; Walsham 1995). These approaches involve the use of psychological and sociological theories to understand some of the social aspects of IS development, implementation and use (Willcocks and Mingers 2004). Interpretive studies of the introduction of technology in organizations, for example, were applied to seek new insights into organizational and human aspects of people's adaptation to technology in organizations (Walsham 1995). Such approaches gained popularity, and over the years they have become well established in the IS field (Walsham 2006; Hirschheim and Klein 2012).

For the purpose of this study, I have adopted an interpretivist approach as I wish to explore the various meanings health information have in different professional practices across the medical domain. In the context of disease surveillance and response, this involves coordination between nurses, doctors, laboratory workers and epidemiologists, who collaborate across sites on gathering and using information on diseases prone to becoming epidemic. In this case, I view health information construction and use as an interpretive activity which relates, on the one hand, to how information is constructed and on the other hand to how health workers and managers interpret data and information to take action. As such, I argue that an interpretive approach is particularly useful for understanding how people work with information. The choice of a qualitative, interpretive approach furthermore resonates with calls made for the integration of social science methods into the domains of global health (Farmer et al. 2013; S. Feierman et al. 2010). This is especially relevant for the in-depth study of epidemics, as they often develop in new and unexpected ways or places, resulting in an urgent need to explore the role of information in that specific context (Hewlett and Hewlett 2007; Abramowitz et al. 2015).

Roughly speaking, research approaches can be categorized as quantitative or qualitative. Quantitative methods are used to describe a phenomenon through quantifiable and comparable information, such as measurements of a phenomenon collected sequentially over a period of time. Qualitative methods build on in-depth and sometimes subjective information about a phenomenon, usually obtained through techniques such as interviews and observations. This research project is qualitative because the aim is to understand use of health information from the perspective of end users across the health sector. While a quantitative measurement of data use, such as numbers in a report, does tell if the health information is processed, it does not show if the content of the reports has been used or in which ways the data has been generated. These are aspects of data use that are better assessed qualitatively. Furthermore, what counts as useful information might differ across professions and sites. For example, would an epidemiologist in the Ministry of Health need different information in order to take action than a nurse who is facing a sick person in a rural clinic. Since my focus was on understanding the variety as well as the interplay of such practices surrounding health information construction and use, I saw this being best supported through qualitative data such as observations and interviews.

4.2.1 Ethnographic techniques

In IS research, interpretive studies are usually done as case studies but ethnography and action research are also approaches that can yield rich insights into a phenomenon (Walsham 2006). Due to the extended time I could spend in Burkina Faso and the nature of my engagement with the Ministry of Health, I used ethnographic methods but with a focus on distinct cases and sub-cases. To be able to study and discuss inferences across the health system, I have also taken a multisited approach, where the research is not confined to one single location (Marcus 1995).

Ethnography evolved from a wish to understand people and their way of living everyday lives, and is based on a belief that this is best done by encountering their realities through firsthand experience (Crang and Cook 2007; Blomberg and Karasti 2013). Ethnographic workplace studies have served as vehicles to better understand the relationship between technology and organizational work in IS design studies (Blomberg and Karasti 2013; Myers 1999). In qualitative research and especially research of anthropological or ethnographic character, where the researcher spends a considerable amount of time at the site of the research among the people being studied, the researcher is the main instrument of the data gathering, which is done through written notes, interviews, and photographs (Crang and Cook 2007). In classical ethnographic research, the researcher stays at a single site aiming to understand this site in depth. However, as most people and objects are not bound to one location, Marcus (1995) proposed the idea of multisited ethnography as an approach to studying the movements of people, as well as meanings and objects, across time and space. The main idea is to follow an object – such as a thing, story, metaphor or person – over time and thereby become better able to understand the different facets of this object. Such approaches have been widely used in sociology of scientific knowledge research, where Latour, for example, has phrased it as 'following the actors' (Latour 2005).

Participant observation is a technique for gathering such types of material. It takes into account that the researcher cannot be a truly neutral and objective observer. Instead, the researcher gains insights from participating as an 'equal' member of the organization which is being studied (Crang and Cook 2007). When studying work practices, participant observation provides the researcher with an opportunity to take part in the practices and thereby gain a richer understanding of how they unfold (Madden 2010).

The use of ethnographic techniques in IS research has been criticized for being lightweight (Aanestad and Olaussen 2010), and for being used in a superficial manner that neglects the theoretical and methodological training behind the method (Forsythe 1999; Pors et al. 2002). Similarly, Ingold (2014) points to a tendency to abuse the term 'ethnographic', having seen it fashionably applied to almost any aspect of social research. These critiques are interesting and serve well as reminders to sharpen the methodological quality of ethnographic research.

On the other hand, they also tend to make this type of research an exclusive endeavor, almost positioning it as impossible for anyone other than a trained ethnographer to do rich observational, narrative studies of social phenomena. Clearly, experience with using a certain method will determine the depth of the material gathered, which shapes the nature of insights from the study. As researchers, we all have our strengths and weaknesses. Some of these include our experience with particular research methods, but it also concerns our experience or knowledge of the topic of inquiry (Crang and Cook 2007). This can include familiarity with, for example, the local culture, various ethnic groups, or knowledge of the language. It can also be familiarity with domain-specific language such as medical terminology. As I lived in Burkina Faso for a research period that totaled four years, I have been able to encounter the realities of the country and its health sector more intensely than I would through field visits of shorter periods. For the above reasons, I have selected my main methodology as an in-depth longitudinal case study of health information employing ethnographic techniques such as participant observation and a multisited approach.

4.2.2 Health information construction and use in practice

I have chosen to focus this study on health information construction and use that would primarily be represented via an HIS. However, as demonstrated in the literature review, health information is not a static matter; instead it is something that changes as it is observed, articulated, documented and circulated among different actors. With this characteristic in mind, I have extended my unit of analysis to include the practices that health workers and managers engage in to create and act on knowledge generated by health information. This unit I have confined to the domain of disease surveillance and response in the health sector in Burkina Faso.

Within the field of sociotechnical research, technology is not considered to be independent of the social world it is part of. Consequently, IS researchers have engaged in developing theoretical frameworks that can span both the technical and social aspects of technology development and use (Orlikowski and Iacono 2001; Robey and Boudreau 1999; Orlikowski 2007; Hirschheim and Klein 2012). A branch of this type of research adapted practice-based approaches grounded in anthropology and ethnography to the study of technology in organizations (Blomberg and Karasti 2013; Myers 1999; Suchman et al. 1999). The focus on practices yielded new and important insights on IS phenomena. For example, it was shown that when a technology was introduced in an organization it often became used in a variety of unforeseen ways, leading to unexpected organizational changes (Orlikowski 2000; Suchman et al. 1999; Robey and Boudreau 1999). As a reflection on this, it was argued that IS development was not only about the construction of technological artifacts, but also about the "*cultural production of new forms of practice*" (Suchman et al. 1999, p. 404). As technology is continuously developing and being applied to new fields in new ways, these challenges persist. This implies that such practice-based approaches are relevant to the study of contemporary challenges to the ICT in organizations (Feldman and Orlikowski 2011).

Feldman and Orlikowski (2011) distinguishes between three ways of studying practice: empirical, theoretical and philosophical. The empirical concerns how people act in organizations, the theoretical concerns understanding the relationship between people's actions and the organizational structure, and the philosophical focuses on how practices constitute reality. In this thesis, I take primarily empirical and theoretical approaches, using them as a vehicle for understanding how health workers and managers in Burkina Faso deal with information in their daily work practices.

Reflecting on what practice is, I have found guidance in the literature on workplace-oriented IS and computer-supported cooperative work (CSCW) studies, which focus on understanding the circumstances under which an IS has to be introduced (Schmidt 2014; Orlikowski 2000). More specifically I have taken Schmidt's conceptualization of practice as a starting point where:

> *The point is that work, when conceived of as a practice, is not reduced to mere activity, more or less regular sequences of operation, but is taken to also encompass the ways in which workers competently handle contingencies and variations, ensure orderly alignment of their distributed activities, as well as sundry intellectual activities such as envisioning the outcome, devising methods and plans, identifying tasks, preparing and allocating tasks, etc.*
>
> *(Schmidt 2014, p. 429)*

While still quite broad, this definition is an attempt to go beyond concepts such as situated action, which do not explicitly highlight observable phenomena to be studied (Schmidt 2018). While the situated aspect of action and knowledge is still acknowledged, there is the additional focus on the ordering of activities and the devices used to facilitate this ordering. It is also a perspective that acknowledges the distributed character of practices in organizational settings as well as the integral nature of the need to handle contingencies and variations. This focus on contingencies that affect practice makes it clear that it is not only knowledge and tools that determine action but also the situation itself and the learning acquired in it. This would also include the practices of making visible the phenomenon that needs to be reacted to, also referred to as performing an object (Mol 2002).

A critique that can be made of such an open conceptualization of practice is the challenge of generalizing from it. On the one hand there are some practical challenges regarding how to construct models for design, when there is no general representation of practice to lean on. On the other hand it also feeds into a more generally acknowledged critique that it produces overly detailed descriptions of unique practices, and consequently they cannot be compared. Thus it promotes practice as something unique that preferably should not be changed because it is so carefully organized (Monteiro et al. 2013). While I do recognize these challenges, I think it is necessary to attend to the details of how health workers and managers work with information; the more we understand, the more it will help us to make accurate inferences across multiple sites and worker groups. Furthermore, as Mol (2002) demonstrates, the focus in such studies of practices can be on how they support collaboration instead of how they create tensions, which is the more conventional approach to studying conflicting practices.

4.3 Chronology of fieldwork

In this section, I discuss the specifics of my research design. Next, I describe how the research evolved over three and a half years, including how study sites and topics were selected. The figure below provides a schematic overview of the research period including the major research themes and sites.

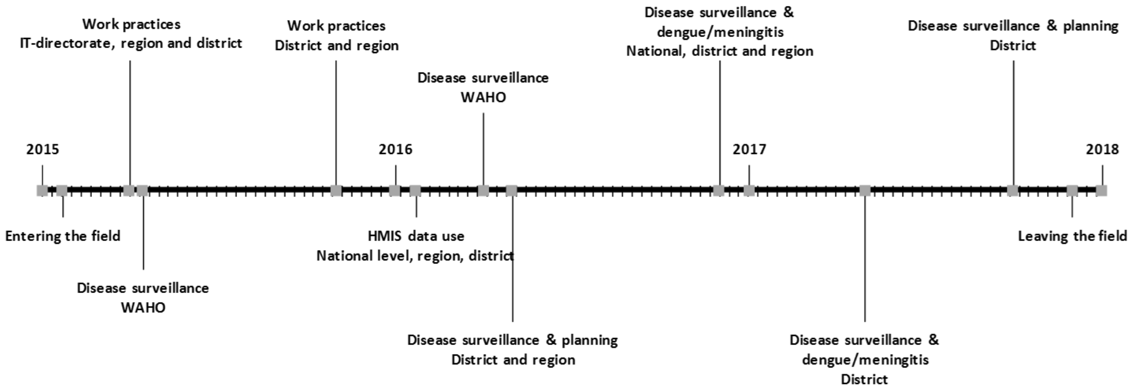

Figure 2: Schematic overview of fieldwork

At an overall level, the research was framed as a multisited in-depth case study with three sub-themes that were developed over time, shown schematically in the timetable above (Figure 1). One sub-theme concerns meningitis surveillance, representing a well-known disease with well-established funding and boasting a robust surveillance system. The second sub-theme concerns dengue surveillance, representing an emerging disease not widely seen in Burkina Faso until an outbreak occurred in 2017. The third sub-theme concerns the planning process, and it emerged during the fieldwork as I became aware of a mismatch between a stringent approach to yearly data-driven planning and the fluidity of the everyday practice of planning. Each of these sub-themes is discussed individually in three of the research papers that form the thesis.

In terms of research sites, the research took its starting point with the directorates of IT and health statistics in the Ministry of Health of Burkina Faso, circled in full line in Figure 2 below.

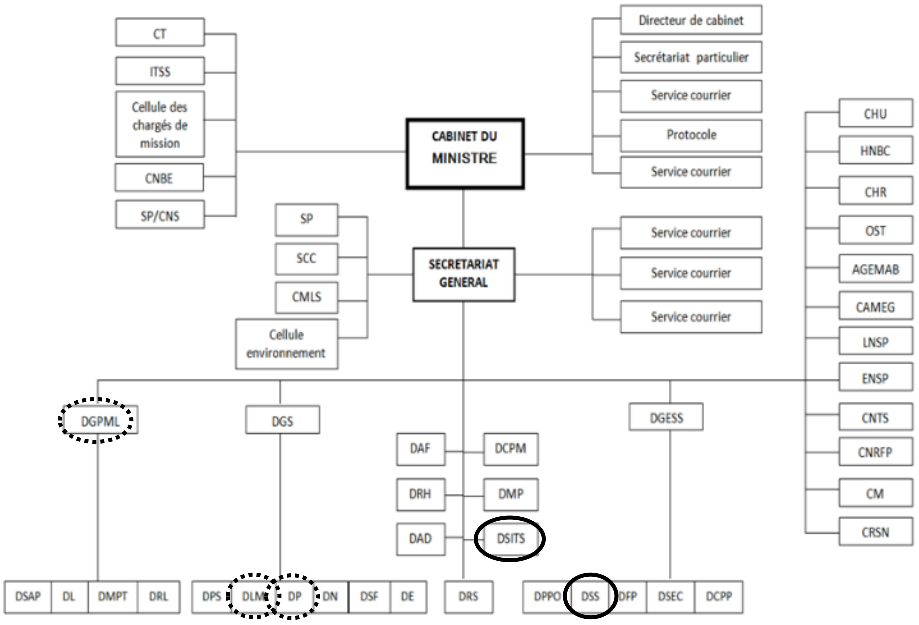

Figure 3: Organizational chart of the Ministry of Health. (Ministère de la Santé Burkina Faso 2017)

Disease surveillance and response requires a range of specialized competences across the health sector and it is thus a highly multidisciplinary task that requires a great deal of organization. While the Ministry of Health is in charge of the national disease surveillance and response, other directorates are involved as well. They are circled with a dotted line in Figure 2 above and they include the directorate for the fight against diseases and the directorate for vaccine preventable diseases. Furthermore, the directorate for laboratories and pharmacies is in charge of information from laboratories and pharmacies. To cover the whole area of disease surveillance, representatives from these offices were interviewed as well.

Furthermore, disease surveillance and response is not one process but rather a set of processes and practices that differ with what disease is under surveillance and whether or not there is an epidemic situation. Studying the practices and the data flows among these actors required a multisited approach even at the national level, but also at regional and district levels. In Table 1 below is an overview of all research sites where I did interviews, observations or both.

National	**Regional**	**District**	**Health Facility**	**Laboratory**
Directorates: IT Health statistics Disease surveillance and response Vaccine preventable diseases Laboratories and pharmacy Nutrition	Central Western Region	District CW1	Health facility CW1.A	*(Laboratory not visited)*
	Central region			National reference laboratory
		District C1	Health facility C1.A	Laboratory C1.A.lab
			Health facility C1.B	Laboratory C1.B.lab
		District C2	Health facility C2.A	*(Laboratory visited)*
			Health facility C2.B	Laboratory C2.B.Lab
		District C3	*(Health facilities not visited)*	*(Laboratory visited)*

Table 1: Research sites

As accounted for at the beginning of the chapter, I shifted from being mostly with the IT directorate to spend more and more time in the operational part of the health sector dealing with disease surveillance. In order to obtain some diversity, I had first planned to do this fieldwork in both a rural and an urban health region, selecting the Central and the Central Western Regions for my research. However, as the security situation in the country worsened after a terror attack in the capital in January 2016, possibilities for travelling solo and staying for longer periods in non-urban environments became limited. Consequently, I decided to narrow the focus even further and do a more in-depth study of only the Central region. See Image 2, which maps out the health regions in Burkina Faso, for an overview of the regions. The capital region is marked in dark grey in the center of the map.

Image 2: Map of the health regions in Burkina Faso (credit: https://commons.wikimedia.org/wiki/File:Burkina_Faso_-_Centre.svg)

This decision resulted in the limitation that the results have become very particular to the urban environment and arguably less suited for countrywide generalization. On the other hand, covering fewer sites in the research allowed for a deeper and more intimate engagement with each site, especially the two districts of C1 and C2, which became my main sites for data collection. Another advantage of this approach was that it allowed me to assess the disease surveillance system as a whole – from the health clinics to the national level, as well as across directorates in the Ministry of Health.

Initially I was also involved with an HISP project with the West African Health Organization (WAHO), whose headquarters are located in Bobo-Dioulasso, the second largest city in Burkina Faso. This project concerned the establishment of a regional data warehouse to support the collection and dissemination of regional data on epidemic diseases. Although findings from this project have not been reported individually, they are part of the research and have helped to shape my understanding, both of the disease surveillance and response domain in particular and of health information in a West African context more broadly, and therefore it is included in Figure 1.

4.3.1 Research permits

I applied for formal permission from the Secretary General of the Ministry of Health and was accepted in the Ministry as a 'stagiaire' to the IT directorate (see appendix 5). Although stagiaire translates literally as intern, officially it meant that I became part of the staff in the IT directorate and could freely participate in the work of this directorate. The general research permit I obtained from the Ministry of Health was valid for research in the two directorates of

IT and health statistics. In order for me to do interviews in other parts of the Ministry of Health, including the regions and districts, I had to ask individually for permission but via the director of the IT directorate. This process was not as elaborate as the process for getting the first permission to access the ministry. Still, it entailed writing a formal request consisting of a letter from the director including a research description, which was followed with an informal project presentation to the director. I obtained such individual permissions for studying the different national disease programs to work in the Central and Central Western Regions (which included permission to work with districts, health facilities and laboratories), and to work on the dengue outbreak (see appendices 6 and 7). Additionally, the research was registered with the Norwegian Centre for Research Data.

4.4 Data collection

I collected data primarily through participant observation and interviews, but I also collected documents and took photographs as empirical material. Table 2 below lists the number of interviews and observations I did.

	Interviews	Number of Interviewees	Participant observation
National	16	15	15
Regional	7	4	1
District	22	13	17
Clinic	13	13	3
Other	10	8	20
TOTAL	**68**	**53**	**56**

Table 2: Overview of interviews and full days of participant observation

At the national level, I did interviews with managers and data managers from six directorates in the Ministry of Health. At regional level, I interviewed regional directors, clinical directors and data managers working in the regional administration. At district level, the interviews were done with health district managers and data managers. In one district, I interviewed the district administration only, whereas in two other districts I also did observations of data collection and use. Here I interviewed vaccination officers, planning officers and head midwives. In some districts, I also did interviews with staff at health facilities and laboratories.

The interviews listed in Table 2 are those interviews that were formally conducted in a semi-structured mode. They lasted between30 and 90 minutes. Most of the interviews were conducted in French, with a few in English. In total 56 of the 68 interviews were recorded, of which 54 were transcribed. I hired an assistant to help me transcribe the interviews in French as my written French is limited. I confirmed the accuracy of the transcripts by listening to the interviews while reading the transcripts.

I obtained informed consent to all the interviews individually with each respondent. Sometimes this consent was written but in most cases oral consent was seen as sufficient. Respondents were promised complete confidentiality as quite a few respondents directly stated that they found it hard to speak freely about their work if the dictaphone was on. For this reason, I chose not to record some of the interviews and a few of those that I recorded, I did not transcribe. Most importantly, however, I used pseudonyms in the case presentation and analysis instead of real names. Similarly, I mention the health districts and health facilities only in general terms and not by their name. If time permitted, I would make notes of key points after each interview as well as of my observations concerning the interview and the circumstances it was done under.

Many of the respondents I met repeatedly, which is reflected in the discrepancy between the number of interviews and the number of interviewees listed in the table. The number of participant observations listed refers to the full days I conducted participant observation at those levels. I used interview guides for these formal interviews. The guides varied according to the sub-theme and the timing of the interview. Early in the fieldwork, they concerned work practices in disease surveillance and response in very generic terms, and later on, as I zoomed in on dengue and meningitis, they became more specific to these two diseases. In some cases, usually early in the process of looking into a new theme, I kept the interview guides flexible to enable an exploration of new aspects of this theme. Later, as my understanding of the theme became more grounded, I built more structure into the interview guides in order to discuss specific issues and questions in more detail.

I documented participant observations through written notes, which I did as soon as possible after the observation took place or whenever I had some time during the day. During participant observation, a lot of time was spent in the field talking to respondents about their work, the specific challenges they experienced, and daily life in general. Such conversations, or informal interviews, provided essential information about my research issues and I documented them in my field notes (as suggested in Madden 2010). These conversations are not listed as interviews in Table 2 above but have instead been recorded as part of the field notes.

As I visited different sites and talked to informants I would also inquire about other material such as guidelines, charts for documentation, reports, and dashboards that could support and inform my understanding of how health information is recorded and exchanged in the health sector. These materials also formed part of the analysis. I furthermore took photographs during observations. To preserve the confidentiality of respondents, I used these photographs mainly to support my own memory of sites and details regarding the nature of the health information in disease surveillance and response. An exception is the photographs taken to document and understand the meningitis information flows as discussed in the research paper *Information and substance as defining elements of the epistemic cultures for meningitis surveillance and response in Burkina Faso*.

The longitudinal character of the research made it possible for me to return to participants to follow up on details or to get confirmation of initial interpretations. I did this with three of the districts and in both regions. Sometimes I could bring material to discuss with the participants. In the case of the meningitis program, which involved an extensive mapping of the disease surveillance and response system, I did an analysis of this system, which I shared with participants in later interviews. This was extremely helpful, as not only did it serve as a tool to set the details straight but it also facilitated an understanding among participants of why I was so particularly interested in seemingly small details of their work. This was possible as the research was of longitudinal character, which allowed for data collection and analysis to be mutually constitutive.

4.4.1 My role

Participant observation is not unproblematic. For example, it can be challenging to distinguish between being an active member of the field studied and being a more critically engaged observer (Walsham 2006). In this research, I experienced this tension with respect to my role as an HISP team member and a researcher at the same time. While the objective of the HISP project is to improve but also promote the DHIS2 software, health data use, as I have argued earlier, is not confined only to the DHIS2 software.

Being a participant observer, I needed to take a role in the field. This role changed slightly with my different research efforts. In the IT directorate and at the national level, I was seen as a representative of the HISP network. In the regions, districts, and clinics where the HISP network was not known, and where I had gained access through the IT directorate, I was seen as a representative of the directorate, or simply as a researcher. At these levels, health workers and managers were more familiar with foreign public health researchers visiting for some time. I found that this familiarity helped me to engage with the health workers in the regions and districts and build expectations on my role as a researcher. In contrast, I was often seen as a consultant who could help with practical issues around the DHIS2 at the national level. At the time I entered the field, the challenges related to the DHIS2 were many, including poor internet connectivity and database hosting, as well as various organizational issues. While these issues were important, it was outside my capacity to engage with improving the internet, securing funding for maintenance, or influencing human resources decisions made in the Ministry of Health. I had to figure out the right balance in navigating these two positions, which for me became a matter of doing my own observations in two health regions and three health districts, while at the same time working with the IT directorate and the global HISP network on various DHIS2-related issues. I developed a position where, instead of acting as an IT consultant, I took on a role as a coordinator. This allowed me to be less involved in the day-to-day practical work, and instead I could act as a link between the Ministry of Health, the users of ENDOS and the global HISP community, who were in a better position to provide the necessary technical support.

4.5 Data analysis

I now elaborate on how I made sense of the collected data. One of the advantages of interpretive research is that data collection and analysis mutually inform each other during the research (Klein and Myers 1999; Walsham 2006). This helps the researcher to go beyond his or her predefined assumptions, about both the empirical context and the analytical leverage offered by one theoretical perspective over the other. Instead, themes and ideas in the research are developed through an engagement with the empirical material throughout the research process, for example through writing (Madden 2010). I found this iterative approach very useful as I was entering both a new context and a relatively novel phenomenon.

To support this interpretive approach, I specifically made use of coding, thick descriptions, and vignettes as analytical means to organize and make sense of my material.

An example of the iterative approach to data collection and analysis that helped to challenge some of my predefined assumptions was seen in my early research efforts, as discussed in the introduction to this chapter. While a post-implementation setting should be ideal for studying health information construction and use, I quickly learned that the Ministry of Health faced other challenges following the countrywide rollout of the DHIS2 in 2013. These challenges were rooted in lack of funding for this type of work, including establishing reliable internet connections, which were necessary for data retrieval from a cloud-based solution such as the DHIS2, as well as building local capacity. Although they are not the main findings of the thesis, I will briefly reflect on them here, because identifying and documenting them were part of my initial data analysis and because they constitute a contextual frame that will eventually affect the practical key findings discussed later in the thesis.

To understand the challenges in more detail, I proposed to the IT directorate that I assessed the current use of the data by key users. I interviewed managers and data managers from key health directorates in the ministry, as well as in one region and three districts. The results showed that the procedures for data entry were working and it was done in a structured manner. Data completeness was estimated at 90 percent with 80 percent timeliness. In general, ENDOS was considered a good tool for generating the annual health statistics in a timely and effective manner. However, satisfaction with ENDOS for disease-specific programs and at district and regional levels was lower due to the following insufficiencies and challenges:

- Poor internet connection in the whole country constrained data entry and retrieval;
- Insufficient procedures for sustaining human capacity to work with the database on both administrative and user levels. For example, no user training had been conducted since the introduction of the database in 2013; and
- Vertical reporting systems between health programs challenged development of shared indicators. The health programs had been promised individual forms but these had not yet been developed and integrated in ENDOS.

These challenges are rather typical of IS design; reflecting further on the meaning of them, they first helped to confirm the fact that challenges to data use are far more complex and comprehensive than the issue of making data available, and solutions require long-term efforts. Understanding these challenges from a conceptual rather than practical and design-oriented perspective thus established itself as a key aspect of my research, and I decided to follow the health information across the health sector regardless of its affiliation with ENDOS.

Another example of how initial analytical efforts resulted in a sharpening of the research focus occurred as I started to inquire about disease surveillance and response more specifically. My initial interviews on this topic indicated that while most respondents were aware of the topic of disease surveillance and response, very few had experience in practice with emergency response. It made it rather abstract and generic to talk about the topic of work practices with the health staff, and conceptually it showed that the contextual premises for knowing are very different in disease surveillance and response. These reflections are discussed further in the research paper *Practices of disease surveillance and response in Burkina Faso*. The process of writing this paper helped to move the analysis towards an understanding of knowing as situated. Practically, it prompted me to prioritize looking into the dengue outbreak, which generated actual experience across the health sector with response, thereby providing much more and much richer material to understand the response, or the action taking, in disease surveillance and response.

4.5.1 Making sense of experiences in practice

As the research evolved, I would start to experience things as a participant that could help me understand the context of the health sector. One such example of how my experiences would become part of the data collection and inform my analytical progress was in the area of planning and organizing.

When I began to work with the IT directorate, I was given a key to one of the offices and allocated a desk. I came to the office regularly, but I soon noticed that often I was the only one around. As I inquired about this, I learned that it was partly due to practices of attending meetings in other parts of the Ministry of Health or being on missions out of town. Such missions could be concerned with either supervision of staff in one of the thirteen health regions across the country, or they could be about indicator development or new registration templates for ENDOS. It would for example be quite common to do a one- or sometimes two-week workshop out of town to undertake configuration of new templates or data elements. This way of organizing work can be seen as a consequence of the external funding of the public sector in many LMICs and it has been referred to as "workshop mentality" (Smith 2003). For me it also constituted a more immediate, practical challenge; I needed to find out how I could get to know when these missions were taking place. It turned out to be not that easy as these workshops were often planned just a few days before their execution. However, as I started working more closely with one of the employees in the ministry I began to observe these planning processes in more detail, including how they worked on a system of constant renegotiation right up to the actual day of the appointment. It is quite different to what I am accustomed to in Denmark, where you make appointments by fixing a date and time one or two weeks in advance. I documented such experiences and reflections in my research notes, which constitute an initial space for ordering empirical material (Madden 2010). Experiences like this helped me both to learn how to join activities that could be relevant to my research and to gain insights on the nature of the planning processes, which I relate to data collection and use and discuss in more detail in the research paper *Plans and "off-plan activities": exploring the roles of data and situated action in health planning in Burkina Faso*.

4.5.2 From codes to narratives

Later in the research process, as my collection of material grew, I developed a more systematic analytical approach that would help me make sense of the material and distil the key findings. In ethnographic and interpretive research this approach is closely tied to writing as the written accounts often present the main analytical points through vivid, thick descriptions of phenomena (Walsham 2006; Madden 2010). To support the creation of these descriptions I made use of field notes, which already provide a preliminary organization of the findings (Madden 2010). Subsequently, the interview transcripts and field notes were taken into the qualitative software program NVivo version 11 for supporting the organization of the material through coding.

I mainly used coding to establish initial principles to order my material, which were mostly in electronic form. I employed an open-ended coding process to explore the written data. This process enables new themes to be identified based on the data itself and not on memory, and I found that such a process helped me keep an open mind towards the data. Reading and rereading the interview transcripts and coded excerpts also helped me to follow up on instinctively interesting themes noted during interviews, checking for accuracy, and drawing fresh attention to notes that may have felt trivial while recording them. I thus used the codes as tools to establish themes concerned with data use. Coding, however, is an analytical process of reduction and abstraction, which allows for exploring of patterns and themes not as individual accounts but as more general ideas. However, there is a flipside to this process: coding risks deconstructing the material to an extent where it no longer tells a coherent story, but instead consists of a number of small pieces removed from their context. According to Myers and Klein's (1999) principles for interpretive research, the micro and the macro should be related throughout the analysis. I used the codes mainly to organize statements made by informants in a way that supported the mapping of the actual health information use practices and information flows. Through this technique, the codes supported sustaining my interpretation of these information flows with empirical material such as statements and direct quotes. In this sense, the NVivo software was primarily a very helpful device to organize the interview data.

Thus, I used the codes to map the information flows, which I used in turn as a basis to create 'thick descriptions,' my main analytical tool. Thick descriptions are detailed accounts of actions or statements in context that help the researcher reflect on the often complex relationships between what people do in specific situations (Walsham 1995). In the interpretive research tradition they are an important vehicle for developing interpretations of, for example, how people interact with each other and technology in the workplace (Walsham 1993, 1995). I built my thick descriptions through the use of case vignettes supported by visual displays.

Vignettes are small subsections of a full narrative. They are rather short, illustrative descriptions of a series of events that can be used to enhance the understanding of such events (Miles 1990). They involve few actors and are usually confined to one setting and provide a portrait that is representative of everyday life (Miles and Huberman 1994, p. 81). Vignettes are vivid descriptions that bring the data to life for the reader as well as convey key messages. Using vignettes in this way helped me to build a narrative with the individual case studies on disease surveillance and response and on planning. I used them in the research papers as well as this thesis. Depending on which aspect of data use they deal with, they were crafted a bit differently.

The visual displays helped mainly to organize the narratives of my data. I visualized meningitis surveillance as an epistemological system depicting the translations of data and blood samples as they circulated through this system. This visual helped to depict the network of people, tools, practices and sites that enabled knowing and acting in terms of meningitis surveillance and response. To support this narrative, I created visual displays of the processes to show the actors, people, materials and technology involved in the production of health information as well as their connections. In contrast, I chose to arrange the case of the dengue outbreak along a timeline as knowledge was evolving over time and I wanted to emphasize the time dimension in knowing. These visual depictions were also useful in communicating my findings, both in research and practice.

4.6 Summary

In this chapter, I have accounted for my methodological approach to studying health information use in the context of LMICs. I have chosen an approach that allowed me to study health information construction and use as a social phenomenon comprising people, tools and practices across a number of sites and settings. For that purpose, I have adopted an ethnographically inspired, multisited approach, which has allowed me to follow the health information across the health sector of Burkina Faso. It is an approach that has placed its focus more on the information itself than on the different tools used for the construction of it. This has distanced the research somewhat from the technology, and especially from the detailed functioning of DHIS2 software. On the other hand, as disease surveillance and response is a rather new domain to be supported electronically through HIS, in-depth studies of information and work practices within the domain should constitute a solid base for understanding the requirements on the DHIS2 in particular and on an HIS more generally. Secondly, disease surveillance and response is an area where considerable global health effort is underpinned by data-centric approaches to data use. As I wanted to discuss the boundaries of such approaches, the chosen methodology has also been instrumental to such a discussion, as it has led to the identification of other issues, such as uncertainty as a driver of action. Essentially, the approach has helped to understand the many transitions health information undergoes as it is constructed and how these transitions matter differently to different actors according to context. In the following chapter I discuss these findings in detail.

Chapter 5 Case overview

A thesis based on papers might suffer from not providing a coherent story, as each paper in itself contains a unique contribution. Myers suggests going about this by "*treating each paper as part of the whole*" (Myers 1999). However, as the papers might draw on slightly different epistemologies or focus on different cases or different parts of the same case, they do not necessarily complement each other just as they are. Tying them together in a coherent fashion becomes a matter of uniting both their theoretical and methodological aspects as well as their contributions. In Chapters 3 and 4, I united the theoretical and methodological perspectives. Before I connect the contributions in the final chapters, I turn to the narrative that runs through the four papers; not in the sense of a chronology, but rather as an empirical whole.

In the following sections, I relate my case of disease surveillance and response to the current HIS in Burkina Faso. In the process I articulate aspects of the HIS that are related to my empirical research questions, considering the networks of people, technology and materials that enable knowing in disease surveillance and response, as well as which conditions of uncertainty affect the possibilities for knowing. I first present three vignettes, each outlining some central components of knowledge creation in relation to the existing web-based HIS in Burkina Faso. Second, I provide two vignettes outlining conditions of uncertainty as well as strategies for handling it.

4.1 Enabling knowing through HIS

(15. June 2015)

The ICP (facility head nurse) and I go outside the CSPS (health facility) to the shade of a big mango tree. He asks someone to bring out a small iron table and two iron chairs, and invites me to sit before he returns to the CSPS. After a little while he comes back with the facility register booklet and a large cardboard box full of papers. It contains copies of the reports he has submitted to the health district. He keeps them in his office, which is also the CSPS storage room. Earlier, when he showed me around the CSPS, we passed by it. It was very small and well filled with files. At the table outside, we talk about the reporting the CSPS is obliged to do. As the interview progresses the ICP reaches for the cardboard box several times. He pulls out one report after the other. There are weekly, monthly and quarterly reports. Some are just a few sheets, while others are small booklets stapled along the edge. They are all preprinted templates filled in with pen or pencil. As the reports begin to pile up, they start covering the facility register, which is lying open on the table. It is a large booklet with all patient encounters registered. It is the information in this register that feeds most of the other reports, as the three core functions of the CSPS are to provide care, do prevention through vaccinations, and offer *ante- and postnatal care. There is actually a register for each of these domains. The facility register contains all encounters made at the CSPS, the vaccination register all vaccines given but with no patient information, and the maternal register all the visits by pregnant women and women with newborn babies.*

This vignette focuses on the health facility register, which is the basis of routine health information because it contains a record of all patient visits to the health facility. In Burkina Faso, as in many other LMICs, these health facilities are the main provider of health services to the majority of the population. The facility health register contains the first instance of information concerning patients who come to the health facilities, including those presenting symptoms of potentially epidemic diseases. As such, the register plays a key role in disease surveillance and response as it helps both to spot first instances of these diseases and to monitor their prevalence in the population as a whole.

When a nurse makes an entry in the health facility register, s/he records the name and health status of a patient. This reference, or entry, constitutes the first representation of the patient in the HIS. Subsequently a process of reduction and amplification of the patient's representation takes place. Through chains of translations, the patient is reduced from being an individual in order to be made comparable to the facility's other patients and, in turn, to make representations of the population as a whole and the prevalence of diseases. Some possible destinations for this information are hinted at in the vignette. These are, for example, the national annual statistics on fertility rates or weekly reports on national meningitis vaccination coverage, which are discussed at meetings in the national committee for disease surveillance. In this sense, the vignette touches on questions related to how we know about diseases in health as well as the different stakeholders who need to know what and when.

Currently, aggregation is a manual process where data from the health facilities across the country is entered in the web-based HIS at regional level on a weekly and monthly basis. Although this process can be further optimized through electronic support at the health facilities, requesting more data will always require the health workers to make more entries in the health facility register or the other basic registers at the CSPS. As shown, there are already many reports to be compiled at the health facility level, and at the same time, the health workers in these facilities have their hands full seeing and caring for a high number of patients. The vignette also serves as a reminder that the creation of information based on patient encounters at health facilities comes at a cost.

(30. May 2016)

Madame Ouédraogo, the head midwife of an urban district in Ouagadougou, has previously been working at a health facility for nine years and therefore she still sees patients from this district. Her office is a space for both office work and pre- and post-natal consultations. Most of the day patients line up outside the office and when she can squeeze it into her program she invites them to enter the office for a consultation. Today Djénéba, who is visibly pregnant, is asking for a late pregnancy check-up. Madame Ouédraogo asks Djénéba to step up on the scale in the office. At first the scale won't turn on but after a few firm kicks by Madame Ouédraogo it does. It shows a weight above 100 kg. Madame Ouédraogo firmly instructs Djénéba to try to eat more healthily as the elevated weight might pose a risk for the remainder of the pregnancy and the birth. As Djénéba is not very tall, she is aware that she is overweight but still, she is surprised that the weight is so high. To continue the consultation a physical examination is needed, and for that purpose the two ladies leave the office and walk to the clinic, located in a building next door. Next to the clinic entrance Djénéba spots another scale and insists that she should try this one too. It shows 90 kg – a difference of more than 10 kg from the other scale. Madame Ouédraogo acknowledges the difference but it does not prompt her to adjust her advice. She is used to equipment that is imprecise, so she has trusted her judgment and advised more on Djénéba's physical appearance than the number on the scale.

The vignette describes a consultation, an antenatal visit, as an example of the basis for entries made in the health facility register at the health facilities. The focus is on the function of the measure supporting the making of the reference, rather than the entry itself. During the consultation, the measure also functions to guide clinical decision-making. The weight of a pregnant woman helps the health worker to determine whether there is a risk to the pregnancy. A weight too low can reduce the growth of the fetus and a weight too high might lead to preeclampsia, gestational diabetes or other risky conditions. The weight is determined by using a tool – a scale, which would be assumed to give a precise measure. In this case, the weight is not very precise as the scale is malfunctioning, but to the midwife the weight appears to be good enough to proceed with determining a diagnosis. The number produced by a scale can be seen as having some degree of interpretive flexibility. To the pregnant woman it is grossly wrong as it describes her as very overweight. To the midwife it is good enough to confirm that there is a risk to the pregnancy that needs to be handled. And to the statistician at the family health directorate it will represent a flaw in data quality that undermines the precision of the maternal health statistics. The improvisation done by the midwife in deciding to use the weight, even though it was probably wrong, provides an example of functional diagnosing (Feierman 2011). While it works in the clinical context, where the aim is to guide pregnant women towards lowering pregnancy-related risks, it does not provide for exact numbers of high-risk pregnancies in the population. Such inconsistency between the relative tolerance to imprecise information when it comes to supporting clinical decision-making in the clinical setting in contrast to the need for sharp numbers for statistical purposes has also been observed by others (Moser and Law 2006).

I have included this vignette to show that in the context of the health sector in Burkina Faso even basic medical equipment such as a simple scale cannot be trusted to create sharp numbers. Secondly, the vignette articulates the type of improvisations which take place to handle the uncertainty that occurs on a daily basis in the health sector. While the number does not create certainty, it does create an indication that is functional and allows the midwife to proceed with her work.

(15. May 2015)

The health statistics directorate has gathered in one of the ministry of health's meeting rooms to work jointly on the annual statistics for 2014. Everyone sits with his or her own computer, immersed in work. A projector is running on a table in the middle of the room. It is connected to the lead statistician's computer and it is projecting the interface of the application he is running, which is the national database for routine health information, ENDOS. Although ENDOS is a cloud-based database, the lead statistician, Mr. Kaboré, is not using the built-in features to analyze the data. He has made a series of bookmarks pointing to the many tables of countrywide data that he needs. It takes a minute or two from the time that he clicks on one of these bookmarks until the table opens. Once the table has loaded he presses "Ctrl + a," "Ctrl + c," shifts to an Excel spreadsheet, opens a new sheet, and presses "Ctrl + v" to paste the data he just copied from the web-based application.

This vignette describes a rather small step in the work that takes place when analyzing information in the HIS. In this example, data is circulated from the health facilities to the national directorate for health statistics. The individual patients have gained comparability as they have been reduced to standardized parameters of gender, age, diagnosis, and geographical location restricted to the health facility they visited. As such, it should now be possible to work with this data. However, the data is now in the web-based national HIS, and access to the internet is required to work with it. Internet connections are very limited across Burkina Faso, even in the major cities, making it impractical to do the data analytics directly in the web-based system. It is too time-consuming and makes the risk of losing unsaved work too high. Consequently, workarounds such as the one described in the vignette are applied. Copying the data to Excel separates it from the original data source, which would normally be considered a risk to data quality. However, for Mr. Kaboré it has the advantage that once the data is saved on his computer, he can work with it without being dependent on a highly unreliable internet connection.

The vignette illustrates a well-known premise for health information construction and use in resource-constrained settings. It highlights how choices of tools or technologies to manipulate the data are dependent on contextual contingences, such as reliable connectivity. However, the vignette also highlights that people working under these conditions creatively employ functional practices in their work to accomplish their tasks. I have included the vignette because this is important to keep in mind, but also because it brings up a challenge specifically related to data use. As data entry is less time-consuming than analysis, it is less sensitive to unreliable internet connections. This means that in the case of Burkina Faso the web-based HIS functions relatively well when it comes to data entry, but when it comes to data extraction and use, it is not being used much aside from the production of the annual health statistics.

In summary, the three vignettes represent parts of the epistemic machinery representing typical conditions for gathering health data in Burkina Faso. While the first vignette considered the health facility register as the cornerstone of HIS, the second described an unreliable scale as the starting point for making a reference. The third discussed a workaround as an example of a contextualized practice that supports the creation of national health statistics.

In conclusion, the vignettes suggest that the epistemic practices in an HIS are not simply confined to the best way to collect and treat data; they also comprise contextually adapted components that make the practices functional under given conditions. In the next section, I will discuss these conditions further by introducing the notion of uncertainty.

4.2 Conditions of uncertainty in disease surveillance and response

(24. May 2016)

The car makes its way through the busy streets of Ouagadougou, the capital of Burkina Faso. I am accompanying Mr. Sawadogo, the vaccination program officer of an urban health district, on one of his tasks this week. Mr. Sawadogo tells me he has worked in the health sector in Ouagadougou since 1983. This is even before there was something called health districts, he recounts, and concludes the brief account of his career by thanking God that he had always had the health to keep on working all his life. "Without health, we are nothing," he says. "If you lose your health and ability to work, you are nothing. No one except the family will help you." Mr. Sawadogo is on his way to supervise a newly initiated HPV (human papillomavirus) vaccination campaign at one of the central vaccination sites, a public school. As with all the other times I have met him, Mr. Sawadogo is immaculately dressed in a suit and a tie. He has brought the paper forms for the registration of the supervision visit in a slim leather briefcase. Before we left the health district, he explained that running such campaigns involves a lot of registration. The week before the campaign, he and his colleagues from the health district conducted a count of the target population: girls of the age of nine years. As there are no registers containing this information, they collected it by visiting each house in the health district to ask and record the number of nine-year-old girls in the household. Now that the campaign is running, the number of vaccines given will be registered. When the campaign is done by next week, they will compare this number with the target population to calculate how big a percentage of the nine-year-old girls in the district have been vaccinated.

The vignette above introduces the notion of uncertainty and two different aspects of it. The vaccination officer's personal story expresses an existential uncertainty having to do with the unforeseeability of life. The construction of the target population reflects an institutional uncertainty having to do with the limitations to knowing that are inherent in the system.

Uncertainty in an existential sense can be very strong in low-resource settings where living conditions are sometimes harsh, including limited possibilities for having a decent income or only having a few options to rely on in encounters with unfortunate circumstances such as diseases. In the vaccination officer's words, in such conditions you can count only on religion or your network such as family to support you. It is an aspect of uncertainty that Whyte explores in her study of the Nyole in eastern Uganda, where uncertainty is linked to adversity (Whyte 1998). Although the vaccination officer is speaking of this issue as a private person, his statement indirectly reflects the conditions the health workers deal with every day, as they have limited tools and resources to help patients get well and be able to move on with their lives. An epidemic, or the threat of one, creates a similar type of uncertainty when it emerges, as it has the potential to take, or profoundly change, lives and living conditions.

Uncertainty in the institutional sense might be seen when structural capacities and resources to produce knowledge are limited. It is an institutional aspect of uncertainty that has to do with not-knowing and not knowing precisely, which is an aspect Street also discusses in relation to diagnostics in Papa New Guinea (Street 2011). This vignette invites a discussion of how we know in public health, as it points to the institutional foundations for construction of health information. The number reflecting the target group for the vaccine needs to be created manually as the national population register does not provide this specific information where certain age groups of the population are linked to locations. In the following section, I discuss such conditions of uncertainty further through the empirical example of an outbreak of dengue.

4.2.1 Navigating uncertainty

(5. May 2017)

The health district manager, Dr. Traoré, and his deputy manager, Dr. Bambara are discussing the monthly activity plan for the health district in Ouagadougou that they are in charge of. They are trying to fit in both the activities for which funding is confirmed and some activities that were not done during the past months. The plan has too many activities and too few days. They discuss whether to use weekends for work or to leave less time between the activities. I ask what they will do in case of an 'activité hors plan'[2], and Dr. Bambara says that of course these unexpected, unplanned activities will come, but he does not know when. Dr. Traoré elaborates that these activities will only be announced a few days in advance and when that happens, they will have to reschedule their program. When I probably look a bit puzzled, he just smiles and says that when activities are initiated from above, you just do them. He continues and offers me an example: last night he received an email from the DRS (directeur regional da la santé) saying he should send three nurses to participate in a seven-day training course starting the following day (today) at 8.30 a.m. When this happens, it is not appropriate to ask questions or try to explain why it is inconvenient. Instead, Dr. Traoré explains, he had made calls to the health facilities in the district to identify who should go. He adds that he prefers training courses that do not exceed four days as any longer disturbs the health district plan too much.

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[2] 'Activité hors plan' is a concept used to account for activities that are not included in the annual plan.

This vignette describes some of the practices employed to deal with uncertainty. While the previous vignette reflected on what uncertainty is and which conditions shape it, this one discusses how uncertainty is handled in situations where it cannot be avoided. In this discussion, I draw on the work of Appadurai and Whyte, who both argue that uncertainty can be a force. While Whyte (1998) argues that uncertainty has pragmatics, Appadurai (2013) talks about handling uncertainty through strategies of hope and aspiration rather than through strategies of fear and risk. Below I discuss these strategies in relation to both existential and institutional uncertainty.

The vignette illustrates a slightly different, yet pragmatic way of dealing with uncertainty in the day-to-day activities at health district level. While health district managers make plans, these plans are often overruled by decisions from higher levels, or by sudden provision of funding, which results in uncertainty regarding what activities to carry out next. In the case of epidemics especially – but also to a certain extent in planning – these are issues that are beyond the control of health workers and managers. The health district manager has become so used to having his program reorganized due to circumstances beyond his control that he keeps it extremely open in order for it to be flexible enough to absorb these uncertainties. These techniques are elaborated further in one of the research papers concerning the use of health information for planning. It is shown that a concept like ‘off-plan activities’ is actively used to anticipate and account for the uncertainties and the changes they introduce. While this can appear to be disorganized, it is shown to be a very rational way of organizing the work under these circumstances.

Chapter 6 Findings and analysis

In this chapter, I present an analysis of the empirical material, including how the findings support understanding the role of uncertainty in the social construction and use of health information.

The chapter begins with brief summaries of the four research papers that form the basis of the thesis. From there I move to a more in-depth discussion of the HIS as epistemic machinery and how this machinery can support disease surveillance and response. In the analysis of the material, I draw on my theoretical perspective and the concepts of interpretive flexibility, circulating reference, multiplicity and uncertainty.

4.3 Short summaries of research papers

The four research papers that constitute this thesis all seek to go beyond the information deterministic paradigm underpinning much IS and HIS development and implementation. I employ a social shaping, practice-based approach to the analysis of the processes of collecting and using data in the context of disease surveillance and response. The papers correspond to the sub-themes engaged with during the fieldwork.

Paper 1) Practices of disease surveillance and response

"Practices of disease surveillance and response in Burkina Faso." Rasmussen (2017). In Proceedings of the 14th IFIP WG 9.4 International Conference on Social Implications of Computers in Developing Countries, Yogyakarta, Indonesia, May 22-24, 2017 (pp. 333–344). Springer, Cham.

The paper analyses the IDSR system in Burkina Faso from a practice-based perspective to study how knowing is enabled in disease surveillance and response. The following research questions are employed: What are the characteristics of practices of disease surveillance and response? How is knowing-in-practice established in disease surveillance and response?

By comparing the IDSR guidelines and actual practices in the disease surveillance system in Burkina Faso, the paper highlights that while most health workers and managers have experience with routine surveillance, very few have experience with response. This is positive in the sense that it indicates that there are not many epidemics, but it also underscores that when it comes to response, knowing is quite different from surveillance.

The paper shows that while surveillance and response hang together, they also involve two distinct practices that need to be dealt with differently when it comes to supporting them through an HIS. Surveillance is well grounded in practice and similar to routine data collection. Response, on the other hand, is sometimes unexplored in practice and therefore more challenging to integrate into existing HIS and to explore empirically.

Paper 2) Information and substance as defining elements of meningitis surveillance and response

"Information and substance as defining elements of the epistemic cultures for meningitis surveillance and response in Burkina Faso." Rasmussen, S. L. and Sahay, S. Under review by The Information Society (Invited to revise and resubmit).

The paper focuses on the IDSR surveillance system through the case of the meningitis disease, which is very well integrated in the national IDSR framework. The paper studies the details of the passive surveillance system and articulates through a social constructivist lens how information about meningitis is constructed, circulated and acted upon in the multidisciplinary network that constitutes meningitis surveillance.

The paper combines Latour's notion of 'circulating reference' with Knorr Cetina's idea of 'epistemic culture' to form a theoretical lens that can help understand how collaboration is achieved in multidisciplinary settings such as a medical one. The lens is also a first step towards an articulation of the sociological aspects of health information construction and use.

The paper explores the following research questions: How is important knowledge to support disease surveillance and response to meningitis produced? Who needs to know what in the context of the management of meningitis? What are the flows of materials and information from the patient to the health system and back that both require and enable knowing?

The theoretical lens helps to understand the gap between the multiplicities of the world and the representations used to describe them. By analyzing the practices of meningitis surveillance in Burkina Faso, the paper traces chains of reference, and finds that not only is knowledge shaped by different rationalities, it also relies on more than one epistemic practice, and is significantly defined by its origins of either medical records or substance. Viewed in this perspective, integration of disease surveillance systems into routine HIS becomes a challenge of integrating not only the multiple rationalities of disease specific systems. It is also a challenge of integrating different epistemic practices and for allowing multiplicity to co-exist.

Paper 3) Disease surveillance and response in conditions of uncertainty

"Disease surveillance and response in conditions of uncertainty: the case of 'palu dengue' in Burkina Faso." Rasmussen, S. L. and Sahay, S. Under review by Information and Organization (Invited to revise and resubmit).

The paper analyses the IDSR system with a particular focus on response through the case of an outbreak of dengue in Ouagadougou that took place before dengue was integrated in the national IDSR framework. The paper discusses the 'information for action' paradigm from the perspective of a neglected tropical disease.

Theoretically, the paper frames the question of information for action as grounded in an ideal about seeking certainty and being rational. Some limitations of this view are that it does not take into account the conditions of uncertainty and the absence of facts, both of which are inherent in everyday practice. The concept of uncertainty is discussed as a supplement to the idea of information for action.

The paper looks at the following research questions: What conditions contribute to uncertainty? How do health functionaries act in such conditions? What is the role of HIS in identifying (or not) conditions of uncertainty and dealing with it?

In answering these questions, the paper shows how cases of neglected tropical diseases and emerging outbreaks are characterized by uncertainty, which is shaped by a variety of conditions including the lack of prior experience, inadequate resources, ill-designed protocols and other institutional constraints. Health staff do not stop acting under these conditions even though they may have only partial information. Instead, they tend to rely on improvisations such as diagnosing by exclusion, exchanging information informally through social relationships, and structuring practices locally. While from a rational perspective these can be seen as bad or wrong practices, they can also be seen as ways to make things work under conditions of uncertainty. Therefore I argue, in line with Appadurai (2013), that uncertainty should not be seen so much as a condition to be eliminated as a resource in aspiring for a more positive future.

The findings are used to articulate uncertainty as an inevitable dimension of health information construction and use. Practically the findings highlight that while HIS do play a role in conveying information, under conditions of uncertainty there are limits to what they can do when it comes to supporting the creation of certainty. Action must be taken although uncertainty persists or certainty is only partial. Consequently, other mechanisms for creating and sharing information, including about the unknown, need to be incorporated into HIS. This is not a trivial design challenge.

Paper 4) Plans and 'off-plan activities'

"Plans and 'off-plan activities': exploring the roles of data and situated action in health planning in Burkina Faso." Rasmussen, SL (2018). Electronic Journal of Information Systems in Developing Countries. 2018;e12049. https://doi.org/10.1002/isd2.12049RASMUSSEN 9of9

The paper takes health planning as its starting point, and tackles health information construction and use from a perspective broader than the IDSR framework. This allows for an exploration of the concept of uncertainty in a planning and evaluation framework within a larger health systems setting.

The research questions addressed are: Why do health managers make plans when we know they do not necessarily follow them? What exactly do they use them for, and how do they organize activities according to both the plan and the contextual circumstances of the action itself?

The paper focuses on how health managers and workers organize health activities in an uncertain context where local plans often are overruled with directives at short notice from higher levels, unexpected developments in diseases, sudden possibilities of funding or the withdrawal of existing budgets. In this context, deviation from the fixed and agreed upon plan is not seen as problematic. Instead, the paper focuses on how health managers and workers engage in establishing some sort of order under these adverse circumstances by adopting a mental and physical flexibility towards plans. For example, they use the concept of 'off-plan activities,' which makes it possible to both mentally handle and account for the unforeseen events that affect daily practice. Furthermore, plans are not written down physically, which allows them to stay flexible. Instead, mobile phones are used extensively to make and remake plans.

The paper concludes that the findings invite us to consider a less data-centric approach to the role of HIS data in disciplining practices around health service delivery, such as one in which data is seen as one of many elements that guide individuals in their daily work.

In the following sections, I present more details from the cases and analyses presented in the papers. The presentation adds to the findings in the papers. By contrasting the meningitis and dengue surveillance system, I develop a contextualized view on uncertainty.

4.4 The epistemic machinery underlying meningitis disease surveillance and response

In this section, I account in more detail for the network that supports meningitis surveillance and response. In doing so, I use the notions of interpretive flexibility, circulating reference, and multiplicity to account for some of the different connections enabled by the network.

Two overarching features shape the network of people, technology and materials comprising the meningitis surveillance system in Burkina Faso. First, the system as a whole is standardized and based on the international IDSR guidelines. Second, diseases are different so the system varies slightly from disease to disease. In the case of meningitis, the system in Burkina Faso is especially robust due to strong support from international donors.

The IDSR guidelines describe different types of surveillance and different types of actions. These both have generic and disease-specific components. To start with, the generic aspects include a ‘national passive surveillance’ system for routine reporting on certain selected diseases. The reporting consists of suspected cases, confirmed cases, and deaths for each disease, usually done on a weekly basis. Active national surveillance is accelerated disease control where suspected cases are actively investigated through, for example, expanded laboratory testing or interviews with affected communities. Finally, there is sentinel surveillance, which provides for thorough testing for a disease in a certain geographical area suspected of having a high number of disease instances, typically not covering the whole country. There are different thresholds or triggers for when to move from passive to active surveillance for each disease, depending on how contagious it is.

Meningitis surveillance is especially strong in Burkina Faso as the disease has had a longstanding status as a serious health threat in the country. The North Africa region where Burkina Faso is located has the dry and dusty climate of the Sahara and Sahel, which significantly contributes to the transmission of meningococcal meningitis caused by bacteria.

Countries in this region have been characterized by frequent epidemics of meningococcal meningitis, which cause a large number of deaths. A newly developed vaccine, MenAfriVac, has directly targeted this type of meningitis. Since its introduction, the frequency of epidemics and rates of infected people have dropped significantly in Burkina Faso and other countries that have introduced the vaccine (PATH 2017; WHO 2017b). While the introduction of MenAfriVac marks a global public health success, it has also affected disease surveillance procedures. The interventions done to test the vaccine also involved building technical capacity in managing the new vaccine, doing surveillance and case confirmation, and cold-chain management (Djingarey et al. 2012). This process has contributed to the establishment of a very fine-grained meningitis surveillance system based on analyses of spinal fluid samples from all health facilities across the country. This data is necessary for the continuous monitoring of the security of the vaccine (Djingarey et al. 2012). Furthermore, as epidemics become less frequent, the meningitis surveillance now focuses more on maintaining the high standards of laboratory testing, as well as monitoring closely for outbreaks caused by other strains of meningitis (LaForce et al. 2017). Consequently, the MenAfriVac program has changed the epistemic foundation for meningitis surveillance and response in Burkina Faso. Further, it underscores that data is not only used locally to identify and respond to epidemics but also globally to monitor the long-term prevention, which takes place through the vaccine program.

In the graphic below, I trace the process of circulating reference for the meningitis disease. It depicts how information on meningitis flows through the health system from a health facility to the national level. This includes two streams: one that is based on the record (paper-based or electronic) and another that is based on substance (the lab specimens). The display also shows the different tools and technologies that are used to treat and make sense of the information at each step of the circulation process. These tools differ according to whether the material basis of the information is record or substance.

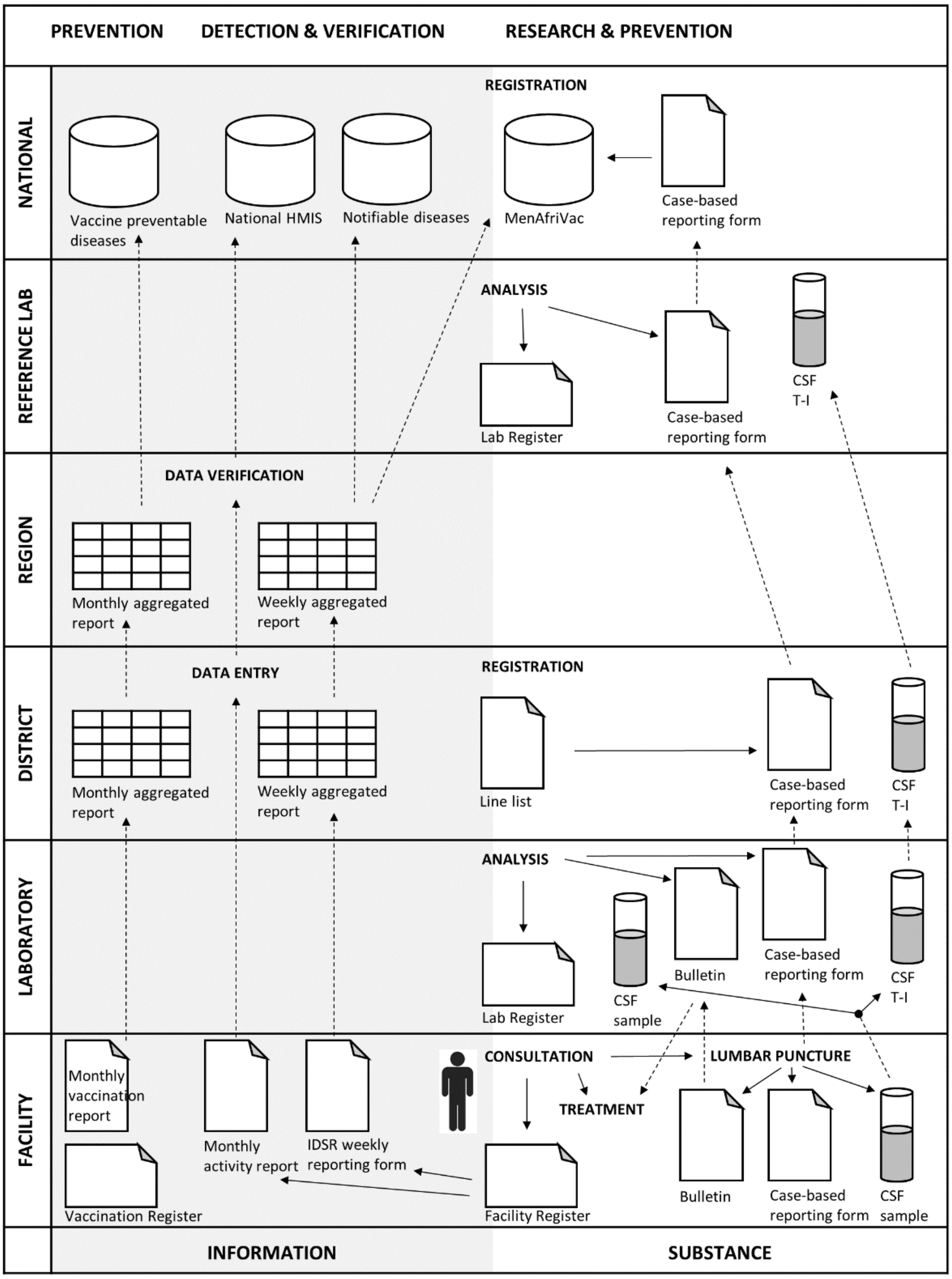

Figure 4: Chains of translations in the meningitis surveillance system

As discussed in the previous section, the construction of health information starts as soon as a patient consults a care provider in a health facility. This first clinical encounter includes collection of information based on the patient’s own statements about his or her experienced symptoms and through a physical examination. The nurse or physician uses this information to make a tentative diagnosis, also referred to as a ‘suspected case’ of meningitis. The criteria for such a diagnosis are described in the IDSR guidelines, which consequently function as an inscriptive device to help the health workers to systematically make sense of the symptoms. Regular training of health workers and lab technicians ensures that health workers throughout the health system are well aware of meningitis and its symptoms. This knowledge limits the degree of interpretive flexibility regarding the meaning of the symptoms. High fever, severe headache and pain in the joints are very clear indicators of meningitis, meaning that the tentative diagnosis is usually clear enough to be used as a basis for treatment even without laboratory confirmation. Immediate treatment or care is started and the suspected case of meningitis is recorded in the health facility register. A reference has been made and the disease has begun its translation from a physical and observable manifestation in the patient's body to a case of meningitis.

To confirm if the suspected case is indeed meningitis it is necessary to conduct microbiological analysis of the cerebrospinal fluid (CSF) in a laboratory. The nurse collects it through a lumbar puncture procedure where some of this liquid is drawn from the patient's spine into a cryotube. This process results in another reduction of the patient as a person to liquid in a small glass tube. At the same time, this also constitutes a gain as the body fluid can be manipulated and studied under a microscope for further determination of the diagnosis.

Both these references are subsequently circulated through the health system for further analysis, creating with them chains of translations (Latour 1999), which in turn create possibilities to establish a link between reality and the words we use to describe it. Through inscriptive devices such as the IDSR guidelines, the kit for the lumbar puncture and the laboratory equipment, the disease – manifesting as high fever, headache and neck pain – can now be defined as meningitis. There are two chains of translations based on the patient examination in the clinic. One is based on the record – the suspected case of meningitis which is transmitted through the passive surveillance system. The other is based on the CSF sample from the patient – the cryotube transmitted through the laboratories. This simultaneous reduction and amplification makes it possible to compare cases of meningitis across space and over a certain limited period of time. The record-based data is aggregated to pin various suspected cases to their location, which helps the epidemiologists and managers at the district, regional and national levels to determine if there is an outbreak under way and where. The microbiological analysis of the patient's CSF determines if the fever is actually due to meningitis and if so, which type of meningitis. This information helps the physician to determine which treatment to give the patient as well as allowing epidemiologists at the national level in collaboration with international partners to continuously monitor if the MenAfriVac is indeed effective against meningitis strain A. In this way, the different chains serve to build coherence between reality and our representations of it.

The graphical display shows the division in the flows as being determined by their origin, which is either record or substance. In the HIS literature this division is typically attributed to tensions between programs, such as the vaccine-preventable disease program versus the disease surveillance and response program. On the other hand, this example highlights that the material foundation constitutes another important dimension of this division, which is the physical basis of the information. Different epistemic systems or cultures have been put in place to handle these different types of data.

This is an interesting perspective to consider when thinking about which factors shape health information construction and use. There is usually a tendency to view this as a tension grounded in different rationalities between different professional groups or communities of practice. However, this material dimension invites an analysis that sees it as a prerequisite for collaboration in a multidisciplinary system such as disease surveillance and response. This distinction between the clinical and the pathological branches of the health sector is similar to the one Mol (2002) makes in her analysis of the atherosclerosis disease representing multiple objects. Multiplicity exists: meningitis implies fever and pain to the patient, while for the health facility nurse it is the patients' inability to bend their neck and the texture of the spinal fluid. To the lab-worker, it is the small dots they see in the spinal fluid sample under the microscope, and to the epidemiologist it is the number of suspected and confirmed cases noted in the weekly report. As room is made for these differences to coexist, it becomes possible for these groups to work together across sites and professions on the detection and description of meningitis.

In this section, I have analyzed the network of people, technology and materials that enables knowing in disease surveillance and response. The network is multidisciplinary, comprising health workers, nurses, facility managers, district data managers, epidemiologists, and scientists. Similarly, the technology used for health information construction and use in the context of disease surveillance and response is diverse, and the electronic HIS constitutes only a small part of these tools. Other tools include paper and advanced diagnostic tests and procedures based on the lumbar puncture. While the availability of this type of equipment is structural as it is largely shaped by the international need for reliable data on meningitis, it can also be seen as a material divide between two distinct epistemic cultures in the medical domain: the clinical and the pathological. For the electronic HIS to function better in this network there might be a need to further consider supporting the pathological flow of information.

4.5 Uncertainty during an outbreak of dengue

Contrary to meningitis, dengue is considered a neglected tropical disease, despite a worldwide increase in cases (Herricks et al. 2017; Stanaway et al. 2016). Although the biggest rise has been seen throughout Southeast Asia, dengue more recently has also started to develop into larger epidemics in West Africa. In Burkina Faso, very few cases had been detected since 1925, but since 2010 there have been cases reported, including a minor outbreak in 2013 (Ridde et al. 2016). In spite of these observations, dengue had not been included in the national passive surveillance system, when an outbreak with around 2000 registered cases and approximately 18 deaths hit the country in 2016. It was the largest to have ever hit Burkina Faso, although it was mostly confined to the Central Region and especially the capital of Ouagadougou (BBC Afrique 2016; WHO 2017a). The outbreak began to develop sometime between August and September, but it was not officially declared before November 2016. Thus there was a gap of about two months between the detection of the first cases and the official reporting of cases.

The graphical display below depicts this development through a timeline, which I have constructed based on interviews with health workers and managers from health clinics to the national level as the outbreak was ending. The timeline is divided between the information that was available and the action that was taken. It has been marked with small asterisks highlighting the three-month gap between the moment some facilities started seeing a rise in cases in August and the moment the outbreak was officially declared in November. The display also shows that the three-month lag did not stop the health workers from taking action. Thus, the issue I explored in this case is the relationships between uncertainty, knowing, and taking action during an outbreak situation. This is discussed in the research paper *Disease surveillance and response in conditions of uncertainty: The case of 'palu dengue' in Burkina*

Faso. Here, I contrast the case with the meningitis surveillance system to articulate different conditions of uncertainty, and to further discuss uncertainty as a resource.

			INFORMATION				
	* Some private facilities see rise in cases						
	Rumors from private sector are circulated						
	Reports of ‘palu dengue’ on radio and TV						
		Public facilities see patients with unusual symptoms					
		Dengue suspected at public health districts					
			Dengue appears in MoH weekly bulletin by the end of the month				
				Dengue reported regularly			No new cases
2016 **Before Aug**	**Aug**	**Sep**	**Oct**	**Nov**	**Dec**	**Jan**	**2017** **After Jan**
							Evaluation with partners
							MoH continues analysis of outbreak
					Spraying of central sites in Ouagadougou		
					Number of TDR testing increases		
					National database established		
				* Outbreak officially declared			
				Assessments by district investigative teams			
				TDR being made available at some sites			
			Initial assessment by MoH and WHO				
			National committee to handle epidemics CNGE to meet regularly				
			MoH begins communication via the media				
			Dengue integrated in routine surveillance				
			New guidelines circulated				
			Training in regions and districts				
		Districts start to prepare and prevent informally					
Routine surveillance done via TLOH (dengue only part of monthly reporting)							
Research at selected sites							
			ACTION				

Figure 5: Timeline of the 2016 outbreak of dengue in Ouagadougou

Conditions such as lack of prior experience, absence of protocols and routines, lack of resources for testing, and price and function of tests were identified in the analysis as important conditions of uncertainty during the outbreak.

As the first cases were detected in a number exceeding just a few odd instances of unexplainable high fever, most health workers were unable to distinguish this disease from malaria. The symptoms are very alike, so it can be a hard distinction to make. But the issue here was that apart from some government officials, not many health workers had heard of dengue. Dengue was not included in the passive surveillance system at that time, which meant that there were no protocols in place to help the health workers recognize the disease due to the lack of prior experience. Consequently, even though many health workers did begin to hear, or sometimes even experience in their own health facility, that an unknown disease was starting to spread, they could not report it as they did not have a language or a system to report on the unknown. Thus, rumors transmitted in the media or from neighboring clinics and laboratories were one of the major sources of information about the outbreak. But in the meantime, the disease was invisible in the formal disease surveillance system.

Another factor that increased the invisibility was a lack of resources for carrying out the tests that identify the disease. The diagnostic system is very similar to that of meningitis, apart from the fact that a dengue test is based on a blood sample instead of a CSF sample. Diagnosis takes place first through syndromic assessment (in other words based on symptoms and clinical analysis) followed by rapid diagnostic tests (RDTs) or laboratory tests, with lab confirmation being the most accurate. RDTs, laboratory testing equipment and reagents for dengue were unavailable in public facilities as the disease was not anticipated to constitute a risk prior to the outbreak. Consequently, most public health facilities could not perform the diagnostic tests for dengue as the outbreak started to emerge. Furthermore, the RDTs are relatively expensive, so even as they did become available later, many patients opted not to pay for them. There is no specific therapeutic treatment for dengue other than dehydration therapy, which can be given even without a diagnosis. This reduced the value of the test significantly from the patients' perspective. To most patients the value of knowing they were dengue-positive was not worth the price of the RDT. This dynamic, however, undermined the public authorities' attempts to map the prevalence of dengue in the affected region as such mapping could not be based on the results of the RDTs as it usually is. This can be understood as interpretive flexibility of the RDTs. To the health authorities RDTs are a source of information, to the patients they are an economic burden, and to health care workers they are a device that could limit uncertainty about the cause of the patients' disease without changing the scheme of treatment.

During the outbreak there was uncertainty about the disease, and consequently about practices concerning what to do and how to do it. The lack of protocols and routines further contributed to generate uncertainty. In contrast, the meningitis surveillance system had been well established with knowledge on how to conduct testing and with tests and treatment provided for free. This difference in support and attention a disease gets from donors also constitutes a condition of uncertainty.

Conditions of uncertainty in disease surveillance and response are thus constituted through inadequate tools to produce knowledge and lack of capacity to produce it, which in this case was further challenged by a lack of support for and internal interest in the results of the test. However, the unforeseeability of a phenomenon is also a condition of uncertainty inherent to disease surveillance and response, which is seen when diseases travel to new regions where awareness of them is low. In such cases, lack of previous experience with a phenomenon becomes an added condition of uncertainty.

These conditions appear to be both institutional and existential, as they are the consequences of, on the one hand, limitations in the epistemic machinery's ability to provide sharp information and, on the other hand, of an inability to foresee the next epidemic developments. Even though conditions for generating better data can be improved, this cannot be done fast enough to help the individual health worker who is facing a case of dengue in Ouagadougou. At the same time, even if the system is improved there are still predictions that cannot be made. Consequently, the question of handling uncertainty is thus not only a question of generating more data but also a question of how to react when data is not available. I will turn to a discussion of this in the following section.

As the dengue outbreak in Ouagadougou emerged, uncertainty remained high for quite some time due to the absence of official advice on how to handle it. Local strategies for dealing with it began with attempts to get more information. An example of a functional local strategy to get more information was seen in the informal information sharing made possible through personal relationships between health facility and laboratory workers.

> *As we are just next door to the laboratory, often they informed us, they raised our awareness and directed our attention to certain possibilities. […] It is next door, so we just go there when they call us. And they come to tell me, as there is another priest who works there, we sleep in the same house, we eat together, we pray together, we do everything together. So, already at the table we tend to those things. And me too, I start to discuss with the other colleagues if there is something we can do to raise the awareness.*
>
> *Head nurse of CSPS*

While this type of information sharing most likely takes place regularly, it became essential during the outbreak. In fact for the health worker it constituted a critical source of information, if not the only one. Apart from creating awareness of the situation, the nurse also explained how the information helped him to prepare for how to handle the patients coming to his health facility with suspected dengue. This sort of preliminary preparation was also seen in other sites. For example, one district manager began to make and implement his own local guidelines for how to handle the dengue outbreak in his district until the official guidelines were in place.

Another strategy was seen in the development of improvised practices for how to understand the disease when neither the knowledge about dengue nor diagnostic tests was available.

> *Voila, before September there were often cases where we received a patient and treated correctly for malaria. Afterwards we send the patient to do a malaria control. The malaria was negative but the fever persisted. We tried to investigate to understand what was wrong, we did a review. But we didn't get the idea to search for dengue. [...] We thought about other things than dengue, it was new to us.*
>
> *District head nurse*

The health workers would see that there was a disease that looked like malaria, but they could also see that it was not malaria. They engaged actively in coming to this conclusion by monitoring how the patients responded to the malaria treatment. While this is not usually considered good clinical practice, in such situations it becomes a pragmatic way of seeking information.

Even as the RDTs and laboratory tests began to be available, a lack of laboratory capacity still resulted in a delay of at least a week for a diagnosis to be confirmed. While this was not considered very serious to the epidemiologists working on mapping the disease at the national level, to the health worker or manager who needed to treat a patient without a firm diagnosis, it meant that uncertainty could not be eliminated. In that situation something had to be done. One district health manager described it this way:

> *As we don't always have the means, the tactic that we use is the case definitions, which allow us to act. Because in our country, if we have to wait until everything is confirmed, that will be after the death of many patients.*
>
> *District health manager*

The statement points to a pragmatic attitude towards uncertainty, meaning that it is better to engage actively in acting on the information at hand, even though it may be flawed or incomplete, than to wait for the more precise information to be available. In the dengue outbreak this was seen in the need to make decisions quickly on which treatment to choose, or how to approach a rising number of patients with similar but undefined symptoms. In such cases, the only choice was to rely on suspected cases, or in other words information that was only partially certain. In the meningitis surveillance system, however, a similar but more institutionalized logic is in use. Suspected cases are also the foundation of the passive surveillance system, which functions through a rapid, weekly circulation of these cases. Each week, all the suspected cases from the 1.600 health facilities across the country are compiled into a report on the national status of epidemic-prone diseases, and this is published and circulated back through the health system. For the purpose of this reporting it is more important to have an overview every week than very precise data. As there is not time to wait for the lab results, the suspected cases, even though they are uncertain, are viewed seriously enough to provide an idea of the prevalence of the 13 diseases monitored. The circulation of the report on the 13 diseases is done by paper or email and could potentially be done through the web-based HIS. However, the unreliable internet connection makes this impossible at the moment as it is important that the information is circulated quickly. Instead, mobile phones are used to pass information that needs to be passed quickly.

> *Yes, at the moment it is not used. The template is there but presently we are not using the TLOH in the HMIS. With regard to the difficulties with the internet connection, since it is something fast, you have to do it quickly. It is not like the monthly reports where you have to wait for the things. With the telephone it is possible to call.*
>
> *Regional data manager*

Such practices of using the phone are employed when it comes to sharing the weekly passive surveillance data, notification of suspected cases in other districts, and the coordination of daily activities. The choice of which medium to use to transfer information is thus not given beforehand but decided in practice based on constraining factors such as whether the task has time constraints, or if access to other tools is limited.

In summary, there are several strategies for handling uncertainty, which all involve taking action to improve an adverse situation where complete information cannot be obtained. Some of these strategies are informal while others are more institutionalized. The informal strategies include knowledge sharing through personal relationships, exchange of information among health workers working at the same organizational level, functional diagnosing through exclusions based on preliminary treatment, and development of local preliminary guidelines. The main technological options that support such initiatives are mobile phones and Excel spreadsheets. These are characterized by being flexible enough to do so. The more formal strategies for handling uncertainty included the use of suspected cases as partially certain information, which could lead to further tests and initial treatment, as well as being accumulated to give an indication of the prevalence and development of the disease.

In this chapter, I have accounted for and analyzed the empirical details of the findings. I will use this as a basis for the next chapter, where I link the findings to the research questions and reflect on their theoretical implications.

Chapter 7 Contributions and discussion

In this chapter, I relate the findings discussed in the previous chapter to the literature. I contrast my two main cases of the system in place to support a highly contagious disease that has recently been a focus of attention from the global health community versus the system in place to support an outbreak of a neglected tropical disease. Based on this framing, I elaborate on two main ideas constituting my contribution. The first is that epistemic practices are shaped not only by multiple rationalities but also by the multiplicity of the disease as an object. The second concerns the role of uncertainty as a resource in the production of knowledge and as essential to aspiring for a better future. These ideas correspond to the two empirical research questions: '*What are the networks of people, technology, and materials that enable knowing in disease surveillance and response?'* and *'Which conditions of uncertainty affect production and use of information in disease surveillance and response?'*

Answering the first question regarding the network, the findings provide a design-oriented description of the social shaping processes that constitute health information construction and use in the domain of disease surveillance and response. Theoretically, this description involves viewing this network, and implicitly the HIS, as epistemic machinery. Here the different elements are connected through the idea of multiplicity, implying that although the network produces knowledge about the same phenomena, this does not necessarily happen in the same way.

Answering the second question concerning the conditions of uncertainty, the findings show that aspects of uncertainty exist in disease surveillance and response, and that action is taken in spite of these conditions. The conditions can be both institutional and existential, but they are accounted for and handled differently in the routine surveillance taking place on an everyday basis and the active surveillance that is done during an outbreak. Theoretically, the articulation of uncertainty as inherent in decision-making and knowledge construction invites reflection on how it can possibly be considered in more detail in IS research.

The answers to the first two research questions help to answer my overall research question, '*How can the concept of uncertainty inform the understanding of the challenges to health information construction and use in the context of low- and middle-income countries (LMICs)?'* Articulating uncertainty as inherent to construction and use of health information provides an alternative way to think about information for action. It goes beyond the mere production of more data as it focuses on utilizing the data that is already there as it is. Analytically, this becomes a question of accounting for how the unknown shapes motivations and possibilities for taking action, and how this action might be different from situations where information is available. It also invites reflections on epistemic practice as coexisting procedures through which useful information is created continuously as the procedure unfolds. This perspective is a supplement to knowledge production as a means to create certainty through the fixation of information in a specific representation.

I elaborate further on the implications of these findings in this chapter, which is organized as follows. First, I discuss how the framework of the sociological aspects of health information construction and use helps to address the information action assumptions underlying much HIS research. Then, I elaborate on how these insights can be extended to the IS domain more generally. I conclude with a discussion of how the findings and their theoretical implications are relevant when it comes to theorizing from a LMIC context.

4.6 Sociological aspects of health information construction and use

Development of and research in HIS in LMICs have gone hand in hand with a global demand for more and better health-related data. Although the underlying rationalistic assumptions concerning data and action have been challenged (Kelly and Noonan 2017; Kelly, Noonan, and Sahay 2013; Lewis and Sahay 2009), there is still a need for more research in this area, especially when it comes to understanding how health information use can be promoted (Sahay, Sundararaman, and Braa 2017). One underlying theme of this research has been to engage in this discussion by assessing the role of health information in social settings where not only information determines how action is taken. To support this, I developed a lens that accounts for the different transitions information undertakes in practice to enable knowing. The lens builds on a social constructivist position. It combines different sociological aspects of health information construction and use and articulates health information construction and use in an HIS as a social process (see figure below).

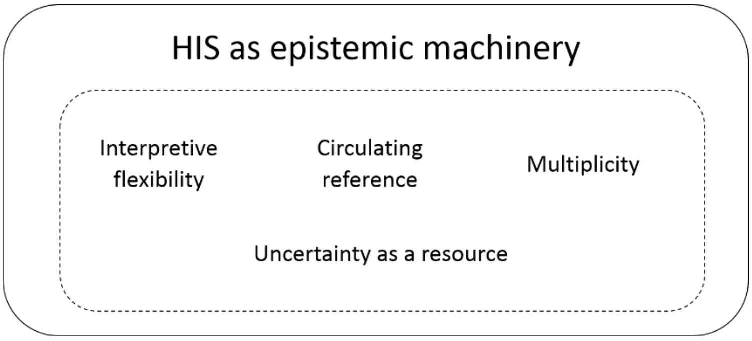

Figure 6: Analytical framework

Regarding the social construction of health information, the analysis underscored that public health and particularly disease surveillance and response is a collective effort that concerns different diseases across different sites. It consists of a multidisciplinary, multisited network where health workers and managers across professional and physical divides engage on a daily basis in practices aimed at controlling infectious diseases. Some of these practices concern the creation of knowledge about diseases based on how the disease manifests itself in the individual patient as well as in the population as a whole. These practices correspond to some extent with Latour's description of losses and gains in the production of scientific knowledge about the Amazon rainforest (Latour 1999). What is slightly different in this case is the coexistence of several epistemic cultures in the health sector. There is especially a division between two of these cultures – the clinical and the pathological. They serve two different purposes and within each of them knowledge is produced through very distinct methodologies: that of aggregation and that of microbiology. Viewing an HIS as epistemic machinery helps to see some challenges to how current HIS support the creation of knowledge for disease surveillance. While the web-based HIS employed in Burkina Faso and a range of other LMICs has been designed to specifically support the clinical epistemic culture, future efforts should focus on including the pathological epistemic culture if the HIS should cover the whole epistemic system for disease surveillance and response.

Another division is seen in mechanisms such as interpretive flexibility and the representation of reality through chains of translations. While the first refers to how different social groups see an object or information, the latter refers to how reality is directly reflected in the words used to describe it. In the analysis, both construction mechanisms were seen to affect data collection. Interpretive flexibility existed in the RDTs for dengue, which were subject to different interpretations by different groups concerning their quality as a device to produce certainty. The concept of circulating references, on the other hand, was the key to detailing each transformative step that health information takes through the health system, as well as how the technology applied affects the translation. Understanding these details enables a conceptualization of the different epistemic practices that a disease surveillance and response system should support. It also helps to see these practices as grounded in more than professional boundaries, as it shows that they are grounded in the materiality of the object that knowledge is created from, as well as the methods and technologies applied to generate this knowledge. The co-existence of these different conceptualizations of knowledge creation underscores that disease surveillance and response is diverse and cannot be defined only by the meanings given by the people in the machinery, nor by the tools they use. Production of knowledge in the health care domain is most likely a combination of the two.

Another aspect of health information construction and use has to do more specifically with the materiality of objects and the idea that they can be multiple. Instead of focusing only on the 'how' – the epistemic practices – it focuses on the 'what': on diseases as objects, and the specific nature of these objects (Mol 2002). The analysis of the meningitis surveillance system shows that although meningitis by and large[3] is one disease, it is enacted differently across the health sector, whether by the patient, the nurse, the laboratory worker, the statistician, or the manager. To all these groups meningitis manifests differently. In this sense multiplicity is an important principle as it facilitates a deeper understanding of how these professional groups collaborate on disease control even though they do not share the same language for talking about the disease. The implications of this view can be a bit more challenging because it comes with a question rather than a solution. The question it raises, when it comes to HIS design and implementation, concerns how to represent different enactments of an object in the HIS without fragmenting them into several objects. This question supplements discussions around what health data can be used for (Chilundo and Aanestad 2005). It invites discussions around what data is necessary for which decisions, and it shows that collaboration can be achieved even when needs for data are diverging. It also invites a discussion of what counts

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[3] I am aware that there are different strains of meningitis that are indeed diverse. However, in order to keep this analysis manageable meningitis is referred to as one disease.

as good data, or rather good enough data – which, in the context of LMICs, is highly relevant as high quality data is not always available.

It may seem like a paradox that a sociology of health information construction and use should include an insistence that we cannot not know. It is indeed vulnerable to the argument that if there is no information, then there is nothing to be used, and then it no longer makes sense to talk about information use. While acknowledging this risk, I will, however, argue that exactly this aspect of our limited knowing, whether it is severely disenabled or just slightly distorted, is overlooked when we talk about knowing in relation to IS and HIS. Further, I argue that there is no final state of knowing. Knowing is continuously obtained and action is taken *while* more knowledge is obtained, and not only *after* knowledge is obtained. A simple example would be that initial knowledge about a problem, such as for example cases of a contagious disease, will inform what steps to take to get more knowledge about this problem. As has been demonstrated empirically, uncertainty also informs knowing about something and especially the systems we use to know. The time that is available to make a decision determines how much effort can be put into making information more accurate. For these reasons, uncertainty, as in not-knowing, should be regarded as part of the conceptualization of information construction and use.

In summary, the framework, as an analytical tool, emphasizes the interplay between the social aspects of use of health information. It treats the link between data and action less as a linear sequence of practices than as a bundle of situated practices. This perspective has the advantage of showing that there is an order to practices, even though they appear random and untidy at first sight. It helps to explain that they can actually be quite well appropriated to enable action in conditions of uncertainty where knowing cannot be taken for granted. The findings underscore that taking action for health is as much about finding ways to deal with various forms of uncertainty and incomplete certainty as it is about producing better and more data. This is in line with other HIS literature discussing information for action more broadly, for example through practice-based perspectives. This literature has emphasized social aspects such as the role of conversations around data (Kelly, Noonan, and Sahay 2013) or the enactment of data into broader organizational practices (Kelly and Noonan 2017), but it has been done with actual data or information as the central component. While the findings in this thesis correspond with the contextual position, they add that considerations of conversations around data should include how these can be meaningful when data is imprecise or lacking.

In the next section, I turn to a discussion of how this contribution concerning uncertainty is relevant to IS research more generally.

4.7 Understanding uncertainty in relation to IS

Social shaping approaches have been an important theoretical tool for thinking about both the technological artifact and the content and processes of IS. In this thesis, I am using a social constructivist framework for knowledge creation in health care to discuss the creation of knowledge as a situated practice. While the framework indeed draws heavily on sociology of knowledge and sociology of science, it also introduces the notion of uncertainty as conceptualized in the anthropological domain. I have supplemented social constructivist approaches with this concept in order to discuss the boundaries and drivers of knowledge creation.

Uncertainty is not as such an unfamiliar concept to IS research. For example, it has been discussed in work on clinical decision-making, where it has been shown that it is part of a physician's progress notes as it is used for making sense of patients' medical histories (Mønsted, Reddy, and Bansler 2011). However, it is more typical that uncertainty is discussed indirectly as a contextual factor that shapes the adoption of technology and therefore needs to be accounted for and dealt with in organizational work (Orlikowski 1996, 2002). Medical sociology has specifically discussed uncertainty in quite a similar fashion concerning knowing and doing. Here it has been seen as a critical dimension of learning to be a doctor, where the gap between theory and practice has been conceptualized as uncertainty (Fox 1980; Timmermans and Angell 2001; Wendland 2010).

Nevertheless, it is more typical that social constructivist IS research adopts a focus on the construction of either things or categories of information – artifacts or facts. This diminishes uncertainty to a contextual factor that is best avoided or, at least, limited. Therefore, the view that uncertainty can also constitute a potential resource rather than simply be a contingency is different to how it has typically been applied in social constructivist IS research. Integrating uncertainty into a social constructivist approach helps to consider more specifically in what ways it affects how we know in context. This can be as a resource that helps us to ask questions in order to get explanations and diagnoses (Whyte 1998), or to aspire for a better future (Appadurai 2013).

The findings of the thesis stress that production and use of health information are situated activities, especially at the point of care, where there is a need to account for contextual factors when using information as a basis for decisions. In this sense, in the use of health information, uncertainty is always inherent. Avoiding these uncertainties with data and more information is often impossible due to time constraints or lack of technical capacity. Therefore, a more proactive and situated approach to uncertainty has to be adopted. As highlighted in the analysis, uncertainty can be a fundamental aspect of life, as it involves never being able to fully determine what will happen next, but it can also be related to not-knowing or just knowing partially.

Uncertainty is thus an intrinsic component of both everyday practices and critical situations. Uncertainty is very present when an outbreak is emerging but it is also part of more routine practices such as treating meningitis, which is often done based only on suspected cases that have not been confirmed in a laboratory. Reflecting further on uncertainty as a dimension in decision-making helps to construct a language for discussing information construction and use that is most often overlooked.

This use of uncertainty in this thesis is more in line with Suchman's ([1987] 2007) articulation of situated action concerning how we act in a rational way in seemingly irrational situations. While situated action refers to how humans act in unfamiliar settings or situations, the concept of uncertainty helps to describe these settings or situations in more detail. When conditions are uncertain we cannot just rely on data and certainty. Instead, uncertainty also becomes a resource as it makes us ask questions, improvise, and rely more heavily on day-to-day practices of structuring. For example, we adapt the plans according to the situation at hand. While situated action is a well established concept that accounts for the contextual factors shaping human action, the idea proposed here is that uncertainty is also part of the content and processes of IS, which means that it cannot only be seen as external to an IS but also as being an internal part of the IS.

Although the empirical findings are somewhat specific to the HIS domain, their theoretical implications are also relevant to the IS field, where data-deterministic agendas are reemerging following new developments in big data (Alexander and Lyytinen 2017; Sahay 2016). Big data inherently promises to provide new ways of knowing about the world and social phenomena. While this is definitely true, it should be supplemented with the notion that action is socially embedded and driven by more than information. The idea of focusing on uncertainty as a source of human aspiration rather than something that should be limited through risk reduction strategies should be an interesting path to develop further in order to develop such alternatives.

4.8 Theorizing from LMIC phenomena

Drawing the discussion of uncertainty into the broader IS domain touches on a discussion that has been brought up in ICT4D research concerning theorizing from phenomena observed in an LMIC context as an alternative to simply bringing theoretical perspectives from the West to make sense of these phenomena (Walsham 2017; Sahay, Sein, and Urquhart 2017). I believe this research contributes to that discussion in the sense that both my theoretical framework and the empirical findings are drawn specifically from an LMIC context. Theoretically, I have discussed the concept of uncertainty by drawing chiefly on the definitions of Whyte (1998) and Appadurai (2013) but also others (Street 2011; Wendland 2010; Haram and Yamba 2009), who developed their definitions through studies in LMICs. Empirically, I have seen it develop as a theme in my research material and during my experience from working in the context of the health sector in Burkina Faso. The interplay between the empirical material and the theoretical conceptualization was made possible by the interpretive research approach, which allowed me to switch back and forth between my observations and the development of my theoretical perspective.

Exploring uncertainty as one of the key elements in knowledge construction and decision-making has provided a different perspective on it. What we can learn in general relates to seeing uncertainty as a resource. In the context of LMICs, it is a necessity as life, both privately and professionally, is uncertain. Some of these conditions are fundamentally different from the West, for example when it comes to access to health care and the quality and availability of diagnostic equipment and expertise. On the other hand, some of these conditions are quite similar: clinical decision-making is underpinned by uncertainty, as having state-of-the-art diagnostic equipment at hand is no guarantee of a clear diagnosis, nor is there always time to wait for a result to arrive before taking action. In this sense, uncertain situations are also found in the medical domain in the West. Taking these insights back to IS development in the West, they might help us to think about how uncertainty can drive action by being clearly articulated and categorized in the same way as the suspected cases in the passive surveillance system. However, the bigger contribution might lie in the addition to the theoretical frameworks we use to describe the relationship between information and action – or knowing and doing. Developing an approach to data use that builds on aspirations rather than risk might take us in other directions if we are willing to make such a turn.

Finally, for practitioners working to improve information for disease surveillance and response the relevance of the findings lies in the detailed descriptions of the networks of information and their needs and flows in disease surveillance response. These can inform HIS design to better support these processes, as well as contribute to reflections on how to take into account the multiplicity of diseases. Furthermore, the findings identify specific practices undertaken locally to complement data as a driver of action. These practices include improvising and keeping a flexible attitude, and one of the ways these are manifested is in not writing things down. Contrary to how it may first seem, these practices are neither random nor disorganised, and consequently they can be treated as clues for where an HIS should be made more flexible or supplemented with other technologies. The implications of this perspective are not a rejection of what has already been done in HIS development and implementation. Instead, I propose it as a supplement, and as an invitation to reflect on how to develop new strategies for better handling of uncertainty in HIS, for example by allowing reporting of odd instances, or finding ways to sustain more dialogue, which could be done through focusing back-up communication procedures via flexible technologies such as cellphones.

Chapter 8 Concluding remarks

In this thesis, I have discussed how IS and HIS can support the creation of knowledge to enable decision-making in complex, multidisciplinary settings. I have been inspired by the call made by Appadurai (Appadurai 2013) and others (Haram and Yamba 2009; Whyte 1998) challenging anthropology to focus more on the future than the past, and to develop an agenda for change. While these suggestions are developed in the context of anthropology, I have found that the idea that we rely heavily on numbers and calculation of risk to describe the future is one that resonates with current challenges to IS design and HIS implementation in LMICs. In both areas, there has been a longstanding challenge to overcome technology and information deterministic approaches to IS design and implementation. It is an underlying assumption that information is a silver bullet that enables organizational and social change. As a result, improvement is often sought through the collection of more and more precise data and its speedy distribution; for example through making big data available, or in the case of LMICs the epidemiological data. In praxis, such approaches entail a strong focus on what can be made known through the analysis of data or studying the past. In this research I have attempted to propose an alternative way of thinking about the relationship between information and action, formulated as a framework considering the sociological aspects of health information construction and use. The framework acknowledges the role of numbers in enabling knowing, but at the same time, it considers their limitations. I have proposed that the conceptualization of IS should be slightly shifted; that instead of knowledge repositories we view them as knowledge constructing systems, where uncertainty is viewed both as part of the context and as a valuable cog in the machine.

More practically the findings show that it is not only in countries like Burkina Faso, where resources to sustain the health sector are low, that life is full of uncertainties on an existential level; there are plenty of uncertainties in organizational and professional life in the developed world too. These contributions are directly relevant to the HIS literature, where they support other efforts that seek to provide an alternative to the managerial attitude to HIS and their role in improving health service delivery. On this basis, it can be argued that an HIS should be seen not only as a system for analyzing the past but also as a system that should provide better support for handling diseases as they emerge. If HIS more generally do not find ways to deal with such uncertainties they will remain limited in their ability to support action – both in routine surveillance and especially in the case of emerging epidemics, where information is needed quickly.

The findings presented in this research project have the limitation that they have been derived from a study that has been conducted in a single country, focusing on data use within one area of health service delivery. On the one hand, this has contributed to the development of the in-depth understanding of the subject, but on the other hand it has been at the expense of a broader assessment of the topic that traverses other disease programs and countries. In this type of research, there is always a risk that the findings are not applicable to other settings. An avenue for future research could thus be to explore other health services or programs using the same framework of sociological aspects of health information construction and use. As argued earlier, this could be pursued both in LMICs and the West. Such work could also benefit from a more in-depth focus on the exact ways that uncertainty can, and cannot, function as a driver of change and inspiration to action. Another area of future research could be to link the findings more specifically to IS or HIS development in order to assess how the uncertain and unforeseeable can be accounted for more specifically in such systems. This research project has assessed information and use practices before their integration into an HIS. In order to truly understand how they could best be supported by an HIS, this would need to be attempted and tested. Supporting uncertainty with IS and HIS is thus a design challenge that remains to be solved and it would be very interesting to pursue further design-oriented work in this area.

Furthermore, one of the efforts undertaken in this project has been to create a multidisciplinary research framework which draws on IS research, public health, and social anthropology. A disadvantage in this regard has been that while it covers a lot of ground it might miss some detail of each of the fields. However, as global health challenges do not limit themselves to one specific domain but span most technical and social barriers, such multidisciplinary work might be necessary to respond comprehensively to these challenges. This effort resonates with calls made in public health (Farmer et al. 2013), as well as in the area of IS and HIS, where the idea of public health informatics has been established (Sahay, Sundararaman, and Braa 2017).

In conclusion, I emphasize that considering the sociological aspects of health information construction and use should be seen as a supplement to the ideas of data-driven decision-making rather than a rejection of it. By articulating these aspects in more detail, I hope this work can inspire HIS and IS researchers and practitioners alike to extend discussions on improving information to also include the creation of aspirations towards better health and better lives.

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Appendices

Appendix 1: Paper 1

Appendix 2: Paper 2

Appendix 3: Paper 3

Appendix 4: Paper 4

Appendix 5: Autorisation de Stage

Appendix 6: Autorisation d’Enquete

Appendix 7: Invitation DLM

Appendix 1: Paper 1

Practices of Disease Surveillance and Response in Burkina Faso

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Abstract. Efforts to fight communicable diseases in Africa have been harmonized through the Integrated Disease Surveillance and Response (IDSR) framework. Following recent large outbreaks of SARS and Ebola further calls to strengthen disease surveillance and response, for example through information technology, are being made. To avoid parallel systems, data for IDSR is sought to be integrated into countries' existing electronic health information systems (HIS). As experiences in this area are still limited, studying existing practices of disease surveillance and response could serve as a prerequisite for providing such electronic support for IDSR. The paper engages in this question by applying a knowing-in-practice perspective to a case of disease surveillance and response in Burkina Faso. The findings suggest that disease surveillance and response can be conceptualized as two interrelated yet distinct practices; that of surveillance and that of response. Surveillance is being both sustained and developed through everyday practices. It is also similar to routine HIS data collection, and thus seems fairly straightforward to integrate in existing HIS. Response, on the other hand, is both more complex and less sustained in everyday practice due to low frequency and unpredictability of outbreaks. Providing electronic support for IDSR should focus on maintaining a link between surveillance and response, but it would require an IS design flexible enough to also accommodate for situations that are yet unknown.

Keywords: Disease surveillance and response · IDSR · HIS · Practice theory

1 Introduction

Healthy populations are one of the prerequisites for development. If a population is not healthy, it does not have the capability to engage in work, politics, social issues and other activities that all together generate development in a society, in an economic sense as well as in a human sense [1]. Through delivery of health services by health systems countries ensure healthy populations. Disease surveillance and response is a corner stone of any health system. It is concerned with acquiring and sharing of up to date information about potential cases of communicable diseases to be able to take the necessary actions to fight these diseases. In an African context WHO-AFRO have developed the Integrated Disease Surveillance and Response (IDSR) framework, which unites these two purposes of monitoring and public health action [2].

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Recent large scale outbreaks have highlighted the importance of information gathering and sharing both on the events leading to the outbreak as well as evaluation of the response [3]. However, experiences so far with electronic support for disease surveillance and response are sparse [4] and have been mixed [5, 6]. In many countries data that supports monitoring and improvement of health systems is collected on a routinely basis often through electronic health information systems (HIS). As the main storage for health information, a well-functioning HIS could potentially play a critical role in disease surveillance and response.

Providing electronic support for strengthening of disease surveillance could lead to increased sharing of, and use of information for action. However, sharing of health information is likely to involve more than the technology, for example communication, knowledge management, learning and taking action [7]. It can be argued that in order for this to happen the HIS will have to correspond with the social structures surrounding it. Research in information systems (IS) has shown that this is a general issue when it comes to IS. To better understand the interplay between an IS and the social world it is a part of scholars have applied and further developed various practice theories. Practice theory is an umbrella term for several theories used to explain social change through the manifestation of knowledge into action facilitated by practice [8, 9]. An advantage is that it is an approach that is not individually oriented; instead it conceptualizes action as an endeavor dependent on its location, the actors, tools and practices that are part of it. When it comes to understanding disease surveillance and response, which is a collective and distributed task involving multiple stakeholders at a variety of organizational levels, it is likely that there is something to gain from using such a perspective. The paper seeks to contribute to the design for integration of IDSR into HIS by using a practice lens to better understand the distributed practice of disease surveillance and response in a country.

Through a case of the national health system in Burkina Faso the paper presents an analysis of the practices of disease surveillance and response. The paper is organized in the following way; first disease surveillance and response is outlined, second a theoretical lens based on structuration theory is discussed, and third the theoretical lens is applied to the empirical case. The paper concludes with a discussion on the complexities involved in providing electronic support for disease surveillance and response as well as the benefits and limitations of using a practice theory to understand this type of work and inform future design.

2 Disease Surveillance and Response

Disease surveillance and response is the work that goes into monitoring communicable diseases in order to identify new cases and to control the transmission of these diseases before they spread and develop into epidemics. Surveillance can be done in different ways but it is important that the resulting information is used for public health action [10].

Following severe outbreaks of largely preventable diseases in Africa in the 1990's, the member states of WHO AFRO in 1998 adopted the resolution on integrated disease surveillance and response (IDSR) as an approach to strengthen disease surveillance in [2, 10]. IDSR has many objectives [10], which are all essential, but those that are of most interest when it comes to HIS are the objectives to integrate multiple surveillance systems, improve the use of information, and improve the flow of surveillance information. More than 45 diseases are included in IDSR, but as the burden of diseases vary from country to country, each country defines its own specific list of priority diseases.

Although the IDSR guidelines have been adopted in many African countries [4], recent epidemics in West Africa have shown that there's still a need to improve disease surveillance and response in the region. When it comes to information sharing and communication in outbreaks it has been difficult to diagnose fast enough, to provide up to date and accurate information to the highest levels, to coordinate among the many actors involved in the response, and to inform populations about the protective measurements to take [11–13]. Also data on the effectiveness of the response could be strengthened [3].

3 Practice Theories and Structuration Theory

The IDSR framework focus on the streamlining of practices of surveillance and response and the integration of those practices across organizational and sectorial levels. Providing technological support for IDSR for example through an electronic HIS needs to take into account the various dimensions of these practices.

Designing IS to support increased knowledge sharing has often been challenging as having knowledge at hand might not being the same as being able to act [14]. Much early IS research built on the rather positivistic assumption that an IS would lead to the change they were designed to bring along. This assumption was challenged by empirical research which argued that technology is not independent of the social world it is part of; instead it is used in a variety of unforeseen ways, which leads to unpredicted changes, sometimes completely different from the desired or expected changes [15, 16]. In ICTD this has also been the case, and it has been described as a design-reality gap [17]. A challenge to both IS and ICTD research has thus been to understand the relationship between technology and the social world it is being used in. In IS studies researchers have been engaged in developing theoretical frameworks that can span both the technical and social aspects of technology as well as the change technology brings about [18, 19]. Since the 1980's different practice theories have been explored as a lens to bridge this gap [20, 21]. Practice theories have also been used in ICTD [22], but much research has been more oriented towards design and less unifying in their use of theory [23].

3.1 Agency, Structure and Practice

Practice theories are characterized by their focus on uniting thought and action rather than separating them [8, 24]. Structure and agency and their relationship of mutual constitution are central aspects of Giddens' structuration theory, which is one of the most adopted in the IS field [20, 21]. According to Giddens too much emphasis is often put on the structures in society and their potential to shape human action. Instead he argues that structures and agency are mutually interrelated because they influence and are influenced by each other through time and space [25]. To illustrate this interdependent relationship Giddens introduces the concept of duality, which describes a mutually constituting relationship between structure and agency, or knowing and doing.

Structures are the rules and resources that human agents draw on in social actions. To Giddens it is the institutions in society or a social context. The rules – but also more than that; They are not to be understood strictly as rules in for example a game, instead they are defined quite broadly as both social norms or habits, and can therefore be more or less subtle or outspoken [25]. Agency, or human action, is the capability of a person, or an agent, to act in social situations. This capability is both dependent on the knowledge, experience and motivation of the agent as well as the situation where the action occurs [25]. According to Giddens human agents are always knowledgeable but their actions very often have unintended consequences, which can result in an unconscious reproduction of the social system or structural properties of it.

Practice and organizational change is closely linked to knowledge as one key idea of practice theory is that knowledge or theory is inherent in action and that it is manifested in action [24, 26]. An often used example is that of riding a bike; it is hard to explain how to do it in theory but easy to do once you have learned it. This idea is also sometimes referred to as "knowing in practice" [8, 9]. Orlikowski [9] further defines it as knowing rather than knowledge and stresses how knowledgeability that is built through every day practices is a central aspect of distributed work. She further argues that:

> "*… paying attention to organizational knowing might complement our understanding of organizational effectiveness by highlighting the essential role of situated action in constituting knowing in practice. In particular, we might learn some useful insights about capabilities if we also focus on what people do, and how they do it, rather than focusing primarily on infrastructure, objects, skills, or dispositions*" [9, p. 271]

Disease surveillance and response is carried out by many people over time and space, and is an example of a distributed practice. It is a practice that relies on knowledge of what to do and how to do it. In this paper a knowing-in-practice perspective will be applied to understand the distributed practice of disease surveillance and response.

4 Method

The empirical material for the paper is drawn from a larger on-going qualitative study of health information use from the national HIS in Burkina Faso. As the aim of the research is to better understand the social structures around the IS, the research approach has been interpretive [27]. The study was conducted over a one-year involvement with the Ministry of Health in Burkina Faso, where the researcher was affiliated with the IT-department in the Ministry of Health. Data for this paper was mainly collected through 22 structured and semi-structured interviews, which focused on health information use and practices of disease surveillance and response (Table 1). Additional material was gathered through observations, participant observation, as well as documents, such as the IDSR guidelines, reporting templates and surveillance reports.

Table 1. Overview of fieldwork

Level	Organizational unit	Observations	No. of interviews
National	Office for the fight against diseases		Data manager
	Office for statistics		Director Statistician
	Office for health informatics	Participant observation	Director Data base administrator
Regional	Region A: Urban		Director of health programs Data manager (2 times)
	Region B: Rural/semi urban		Director Data manager
District	District A.1: Urban	Observations of daily work	Director Data manager
	District A.2: Urban	Observations of data entry	Data manager (2 times) Data manager assistant
	District B.1: Rural/semi urban		Data manager
Facility	Clinic B.1.1: Semi urban	Observations of data entry	Managing nurse 2 nurses Mid-wife
Other	Academic		Epidemiologist Previous district director
			Total: 22

A weakness of the study, which will be returned to in the discussion, is that while data collection was going on, there were no epidemics taking place. Thus there are no observations from an epidemical situation to support the statements given by the participants. To compensate for this weakness, participants were asked to describe their work during response with reference to a recent epidemic.

All interviews were recorded and transcribed for closer analytical examination. Themes regarding disease surveillance and response, practices and knowledge where extracted from the transcripts and the notes. In addition, data collection and data dissemination flows were mapped out based on the empirical material, which showed a difference between surveillance and response. This difference was further explored in a matrix-mapping where different aspects of practices were related to the different phases of disease surveillance and response.

5 The Case

Burkina Faso shares borders with six other West African countries but was not directly affected by the 2014–2015 Ebola epidemic. However, during the epidemic the alert level was high in the country and procedures for identifying and handling an eventual case of Ebola were integrated into the country-wide system for disease surveillance. Apart from the apparent threats from the Ebola epidemic, Burkina Faso is prone to suffering from outbreaks of meningitis, measles and malaria. In total 14 diseases or conditions are monitored on a weekly basis and the information is collected and transmitted from facilities (CSPS from "Centre de santé et de promotion sociale") to the district, regional and national level. There are 13 regions, 63 districts and approximately 1,650 CSPS [28].

In Burkina Faso the IDSR guidelines have been adopted into its own country-specific technical guidelines [29]. These guidelines contain detailed information for each disease on how to handle disease surveillance and response at each level throughout the health system. The public health sector, which is responsible for the delivery of the majority of health services, is also responsible for the administration of the national IDSR-guidelines.

6 Analysis of IDSR Practices

Many of the interviewees distinguished between before, during, and after and epidemic. The work practices and information needs in each of these phases are somewhat different. For the purpose of this analysis focus will only be on the work that takes place before and during epidemics, including the transition between these two phases.

6.1 Surveillance

During the pre-epidemic phase surveillance takes place. All interviewees described a clear, consistent, and well-organized process for the weekly routine surveillance. The managing nurses from the 1,650 CSPS across the country report weekly data to the district health data manager. Once all CSPS have reported in, the data is compiled and aggregated and sent, via e mail or phone, to the regional level. Here, the regional level data manager repeats the process of compilation but also checks data quality, before forwarding to the national level. These initial steps must take place by 10 am every Tuesday. The national office for the fight against diseases produces a national bulletin that is used at the weekly ministerial meeting and also circulated back to the regional and district offices and other relevant partners. Observations confirmed the workload that this process generated on Monday, Tuesdays and Wednesday each week. Data managers were often unavailable for appointments on these days, and where observation was done, there were a stream of visitors coming in with reports or phone calls to report in with data. All of this information had to be taken down by the data manager. For surveillance, the IDSR guidelines seem to have provided a structure, which is both known and embedded in the work practices concerned with gathering and sharing information on surveillance.

There is one standardized template that is used for the collection of data at all levels. For each disease, aggregate numbers of suspected cases, confirmed cases and deaths are collected. Such standardized tool helps to reinforce the structure of the guidelines. However, small variations of daily practice also help to maintain the structure and keep it functioning. For example, facilities far away from their district can transmit data via phone instead of the form. Similarly, a phone call could be made from districts to regions in case the internet was down. In this way the structure is shaped by adaptations based on the environment within which the daily practice of surveillance is taking place.

The information flow described above is very similar to the information flow for collection of routine health information. The main difference is that the IDSR data are collected on a weekly basis where the routine data are collected on a monthly basis. But in both cases it is the data managers under the supervision of the facility, district or regional directors who are the key persons managing and transmitting the information. During interviews and observations with these two groups of people, they all explained how they worked with surveillance based on recent experiences. This similarity to routine data collection provides an additional structure that further strengthens the practice of surveillance.

6.2 Response

Surveillance is done to inform response. Turning to the possible outcomes of surveillance they can roughly be grouped into the following three; no alerts resulting in surveillance going on as usual, an alert resulting in further investigation and control of the situation, or an alert turning into an outbreak.

According to interviewees a level of alert is reached if the notified suspected cases reach a certain threshold. These thresholds are specified in detail in the national IDSR guidelines, but generally speaking it could be a single suspected case of one of the very contagious diseases or a certain amount of cases for other diseases. When this happens, contact is made immediately by phone to the higher level in order to ensure prompt notification of the potential risk. If a suspected case is reported two actions are taken; case confirmation and site investigation. A specimen sample is send to the closest laboratory for confirmation and further analysis. The documentation of this work is done with a line list, which there is a standardized template for. Furthermore, an investigative team can be formed at district level if necessary. The role of such a team is to go to the site of the case to analyze the nature of the case, how many have potentially been effected, and what protective measures should be taken? The documentation of this work does not follow a strict standard.

The main differences from the collection of routine health information collection is that much more information is being collected, there are differences in information needs between the diseases, and it is not done on a routinely basis but rather every other month. Many of the interviewees had experience with this type of work for diseases, such as meningitis or measles, which would most often be the ones with cases that needed investigation. Again the structure of the national IDSR guidelines would shape the work on case investigation.

During the epidemic phase surveillance must still be done to monitor the development of the outbreak, however the response takes priority. The type of response is very dependent on the disease, but it could for instance be vaccination campaigns targeting vulnerable populations, awareness campaigns in communities carried out in collaboration with community resource persons, or deployment of specialized treatment centers. A certain challenge here is that contextual factors also influence which actions can be taken. When it comes to known diseases, the national guidelines are very clear on how to respond on each specific disease at each organizational level. But the decision on which type of response to do is based both on the guidelines, the spread of the disease, and the analysis of the situation at the specific site. Some action is taken based on routine while other action is taken based on the actual characteristics of the epidemic. Agency, as in the capacity to take action, is thus not only dependent on the structure provided by the guidelines, but also on unknown structures specific to the nature of the disease. The guidelines recognize this by being specific about how to do the site investigations, but there are no daily routines to reinforce this structure into daily practice or vice versa.

In both the two regions where the study took place actual large scale outbreaks appeared to be quite rare. When asked to describe how response was carried out by taking a recent outbreak as an example, all participants would answer that it had been a long time since there actually were an outbreak.

> "*Well, luckily we've not had epidemics. For a good period of time, we've not had an epidemic. Since I've been in this office, there has not been any.*"

(Regional health manager)

Also during the time spent on site there were no investigative team missions done, nor were there epidemics taking place in the two regions. Response thus appears to be a task that is not routinely performed. This means that although the country specific IDSR guidelines are well known and well adopted there are not many possibilities to exercise them when it comes to response. Although everyone throughout the health system seems to be well aware of what to do and how to it, routine and experience has not been built or tested.

6.3 Knowing-in-Practice

Disease surveillance and response go hand-in-hand, which is logical as surveillance is supposed to trigger response. However, from the case it appears to be important to also recognize that it indeed covers two different practices. The national IDSR guidelines can be seen as a structure for how to do both surveillance and response. Health care workers can rely on this structure to seek knowledge on how to perform this type of work. However, following Orlikowski's argument that knowledge is not the same as knowing, this might have consequences for the capacity to act based on the guidelines. The table below summarizes how the practices of surveillance and response differ (Table 2).

Table 2. Summary of practices

	Surveillance	Alert	Response
Knowledge of tasks and procedures	Well-defined and adopted for all priority diseases	Well-defined and adopted for outbreak prone diseases	Well-defined and adopted for outbreak prone diseases
Frequency	High Done on a routine basis before, and during an outbreak	Low Done when an alert level is reached	Very low Done during an outbreak
Knowing-in-practice	Easily obtained due to weekly procedures	Obtained to some extent due to bi-monthly alerts	Difficult to obtain due to low frequency of outbreaks

The knowledge created through surveillance, response and evaluation it is not the same type of knowledge. The objective of surveillance is to spot a potential threat in order to be able to roll out the recommended treatment for this threat if it is detected. This is a routine task that becomes integrated in the daily work and where knowing in practice of how to do it is built through everyday activities. In a response phase the objective is to understand the development of a beginning or ongoing outbreak of one disease, the factors that nourish it as well as the effect of the action taken to counter it. When it comes to well-known diseases, where small-scale outbreaks occur more often, the response is to some extent done on a routine basis. But in large-scale outbreaks or outbreaks in a region previously unaffected, there are more unknowns and a higher chance that things may develop in unexpected ways. This can lead to ad-hoc decisions and new non-standardized procedures. Knowing-in-practice only becomes enacted as the outbreak unfolds.

From a practice-based perspective which recognizes a duality between knowing and doing, disease surveillance and response inherits a challenging paradox; that you need to be prepared (know what to do) for something that does not occur on a routinely basis or – as in cases such as Ebola in West Africa – have never occurred before. This is a phenomenon that applies to many aspects of medical practice, such as for instance treatment of life-threatening conditions. In many cases applied medical knowledge is obtained through practical hands-on experience. But there are critical situations, such as heart attacks where it would be unethical to ask a new doctor to practice on the patient [30]. In such cases techniques such as clinical simulation or emergency drills might be used in order for health workers to obtain the skills and experience need to act in an urgent situation. In Burkina Faso one simulation had been done as preparation for an eventual Ebola outbreak, but for other types of outbreaks it is not prioritized due to lack of resources. This might potentially also affect HIS design as it might be difficult to design a system for a practice that is mainly described in guidelines and where experience from real-life situations has yet to be gained.

7 Discussion

The case discusses how national IDSR guidelines provides a standard for how disease surveillance and response is done in Burkina Faso. It is argued that the guidelines can be seen as the structure that defines and dominate agency through both standardization and contextualization of practice. However, the mutual reinforcing relationship between structure, as knowledge, and agency, as action, is stronger for surveillance than response. This seems to be due to the low frequency of outbreaks and the effects this has on the opportunities to practice response and thereby obtain knowing-in-practice.

This difference also has a methodological implication. For the same reasons that it is difficult to exercise response, it also becomes more complicated to study it and to get solid information on how it is done. Consequently, a recommendation for future research is to consider paying more attention to this challenge both in the framing of the study and in the research design.

The analysis further highlights that the practice of surveillance is very similar to routine data collection in a HIS, while the practice of response is not. As a consequence, response might be overlooked when strengthening disease surveillance and response through existing electronic HIS. Attention should thus be given to keeping the connection between surveillance and response in such work.

The main focus of the paper has been to make an empirical contribution to the understanding of IDSR as a domain of international interest, and to use concepts from practice theory to unfold this understanding. The practice-based perspective, has served as a useful lens to analyze the interplay between the guidelines and the actions health workers need to take action based on both the guidelines and the situation on the ground. It has worked better for assessing the structures in this interplay than the agency itself. This might be due to agency being more a difficult concept to address empirically. As it is within the action the potential for change lies, it could be interesting to explore this part of practice further in future studies. This could also potentially support the calls made within ICTD for strengthening the link with theories of development in order to better assess the consequences of the technology [22]. Structuration theory, has been criticized for not focusing sufficiently on technology itself [21]. In this case the analysis did not provide many leads as to how to improve a technical solution for IDSR strengthening. It is likely that this is due to the practice-lens being less technology focused and thus less strong as a prescriptive tool.

In spite of the practices of surveillance and response being different they should not be separated. With action being an inherent part of IDSR, future research and design strategies should rather focus on reinforcing the link between collecting data and using data for public health action in order to provide electronic support for the whole IDSR concept. This would, however, require a stronger focus on the response part of IDSR. In addition, it would require strategies for doing IS design flexibly enough to accommodate for situations that are yet unknown – which is especially critical when it comes to countering epidemics in environments where a disease, or a new strain of a disease, occur for the first time. If this is not done, design-reality gaps might persist, and future IS to support IDSR might not hold the ability to support a change towards improving health for all.

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Appendix 2: Paper 2

Information and substance as defining elements of the epistemic cultures for meningitis surveillance and response in Burkina Faso

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Abstract

Health information systems often promote the vision that availability of data improves decision making. This view tends to take for granted that information systems support a truth. The notion of epistemic culture, as a knowledge producing machinery, helps to understand the gap between the world, the multiplicities involved, and the words used to describe them. By analyzing the practices of meningitis surveillance in Burkina Faso, we trace this machinery, and find that not only is knowledge shaped by different rationalities, it also relies on more than one epistemic culture, significantly defined by its origins of either information and substance.

Keywords: Circulating reference, Epistemic cultures, Health Information Systems, Meningitis, Burkina Faso

1 Introduction

Monday morning in Ouagadougou, the capital of Burkina Faso. The streets are bustling with people making their way around the city by car, motorcycle, bicycle, donkey chart or foot. On the dusty grounds of one of the city's five health districts, the sun has already made temperatures rise to 40 degrees Celsius. Inside the district data manager's office, activity is also high. The noisy, but functional, air conditioner is keeping inside temperature at a more pleasant level. The district data manager and her two assistants are occupied with one of the week's routine tasks, the compilation of the epidemiological status of the district. Based on data from its 90 health facilities. Most of the space in the office is occupied by three large desks covered by piles of paper and among them a computer used for data entry and retrieval. As usual, a number of people are shuffling in and out of the office. Everyone takes their time to chat a little, perhaps about the heat or the expectations to the newly elected government. Many of the visitors also hand over a sheet of paper to one of the assistants who acknowledges the receipt of *the document with a little tick on a list pinned to the board on the wall before filing the document in a colored sheet of paper resting on top of one of the piles. The document is called the TLOH, pronounced T.L.O., and short for "Telegramme Lettre Officiel Hebdomaire". It is the backbone of the disease surveillance system in Burkina Faso. Each week, information on 15 communicable diseases travels, via the TLOH, from the 1.650 health facilities around the country to the national directorate for the fight against diseases. It is important that it is collected and circulated quickly, which is the reason for the concentrated atmosphere in the data manager's office. Information like this that can make the difference to whether, or not, single occurrences of contagious diseases will grow into outbreaks and eventually epidemics. The minister of health holds the mandate to announce epidemics or alert situations and to provide directions for subsequent public health action. Such decisions are dependent on the knowledge created with the machinery that partly consists of the circulation of the TLOH.*

The vignette above outlines a small part of the machinery that produces knowledge about meningitis. The machinery consists of several other parts like this, and all together, they constitute the epistemic culture that enables the production of knowledge to support disease surveillance and response. As a constant struggle in public health management concerns the challenge of "how do we know", and who needs to know what, and exploring such epistemic cultures become a key to answering this question.

The question of how do we know is linked to the question of the what do we need to know, and the answer to this varies with who asks the question, for what purpose, and to whom this question is asked. A clinical doctor providing care in a hospital will like to know the diagnosis of the patient and the best form of treatment going forward. The answer to such questions may come through an understanding of the patient symptoms, a clinical assessment, and in some cases through a laboratory confirmation of tests conducted on the patient. A health program administrator at the regional or national level will like to know what has been the effectiveness of a program intervention, and how does the performance of the health system in the current year compare with previous years. This information is typically provided through aggregate statistics reported from each district in a country on a periodic basis. A district manager, located between the health facility and the national level, may need to know both details of patients confirmed to be suffering from a particular disease, as well as the aggregate performance of his/her district. There may be also some additional operational level information required, such as the supply of vaccines, human resource capacity and financial flows. The World Health Organization (WHO) may wish to know how the country is performing with respect to its SDGs (Sustainable Development Goals) or progress towards overall targets such as Universal Health Coverage (UHC). Scientists conducting biomedical research might need to know the effects of health interventions or novel biomedical solutions, such as for example a vaccine. It has been argued that medical research in Africa has shifted its focus towards large scale interventions that are cost effective and can document high impact on health (Prince and Marsland 2013). In the context of public health systems management, there are thus a multiplicity of questions and purposes involved in knowing.

Health information systems are a key tool to try to provide answers to the different aspects of knowing required by different stakeholders, catering to different forms of truth. The diversity of knowing involved has led to the proliferation of multiple HIS, as well as informal mechanisms of sharing information, catering to specific needs, which often tends to create immense fragmentation and duplications of data, which may run contrary to the objective of informing knowing. As a response to this condition of fragmentation, many international and national initiatives are taking place in various developing countries to integrate information systems and processes (Sahay, Sundararaman, and Braa 2017). This vision of integration has been difficult to materialize in practice, primarily resulting from institutional rather than technical reasons, such as the reluctance of different health programs to share data with each other, the lack of well-designed standards, such as the nomenclature of data elements being collected and shared, as well as the multiplicity of informal practices which exist that become problematic to be made explicit and be subjected to a computer-based logic. Furthermore, the idea of integration has been conceptually challenged by the notion that fragmentation of health data is not only due to poor capacity or arbitrary needs, instead it is occurring due to the multiple, and viable, rationalities that exist among the various stakeholders in the health sector (Chilundo and Aanestad 2005). Chilundo and Aanestad (2005) draw on the insights of Avgerou (2003) that a managerial rationality has been dominating global information systems design in the expense of other contextual rationalities. They show that rationalities in health systems are both contextualized and disease dependent, which in turn challenge integration of health information systems both vertically, due to different rationalities arising from the nature of specific diseases, as well as horizontally, due to different rationalities between the different governance and management processes at the “top” and the “bottom” of the health system. This perspective on integration emphasizes the question of who needs to know in health, but it is less strong for discussing how knowledge is created. As a vehicle to answer this question in more detail we use the concept of epistemic culture(s) (Cetina 2007), which implies a shift from the knowledge itself and the needs of different stakeholders, toward the machinery that produces knowledge.

We take the domain of disease surveillance and response as our analytical focus to explore this bridge between the world and the depictions of it made in the health system. In the wake of recent large scale outbreaks in the African region, calls have been made to strengthen information systems to support disease surveillance and response (Gostin and Friedman 2015). More specifically programs such as the integrated disease surveillance and response framework (CDC 2015) has been adopted in most African countries, and efforts are now undertaken in many countries, including Burkina Faso, to integrate functions for disease surveillance and control with existing relatively well-functioning HIS. Disease surveillance and control is concerned with the ability of the health system to monitor the prevalence of epidemic prone diseases (such as malaria, dengue, Japanese Encephalitis and others). It seeks to detect situations of outbreak or epidemics, and develop efficient response mechanisms, such as conducting inspections at the site of an outbreak, alerting the population at risk, carrying out curative treatments including testing, medication and in some cases hospitalization may need to be advised. These different activities then involve many other aspects of knowing, as well as mechanisms of building this knowing. For example, firstly a patient has to be clinically examined to understand the probability of a disease existing, this suspected case then needs a laboratory test for a confirmation, and from these individual cases we also need to know about population profiles of morbidity and mortality. Arguably, questions of knowing will vary with the types of diseases and the mechanisms in place (such as testing facilities and supporting HIS) to enable such knowing. These are important considerations in strengthening the effectiveness of the health system to manage disease outbreaks.

With this background, this paper focuses on the overarching question of how the essential knowledge to support disease surveillance and response is produced. Our focus is particularly on meningitis disease, which we explore with the following two sub-questions:

1) Who needs to know what in the context of the management of meningitis disease?
2) What are the flows of materials and information from the patient to the health system and back, that requires and enables knowing?

Answering these questions will provide important contributions to the domains of HIS in developing countries and broader ICT4D processes. Our analysis confirms the view that knowledge production for health is shaped by multiple rationalities among various stakeholders. However, our analysis also adds two other factors that contribute to how knowledge for health is created. First, it is a matter of the physical origin of the information. The practices for handling and producing data vary greatly depending on whether the data is based on substance or on information. Second, time or temporality also contributes to how precise the available knowledge can be in its depiction of the world. This implies that the idea that an integrated formal health information system can provide most of the answers to the management of a disease remains challenged. More importantly, it also implies that it is not only needs of information that determines what we know but also the means of production. While there is a dominant trend towards establishing integration of HIS, our analysis suggests it is important to examine the “why” of integration, and maybe in some cases, it is more practical to leave parallel systems as co-existing.

The paper is organized as follows. In the first part, drawing from the academic field of sociology of science, specifically Bruno Latour’s ideas of circulating reference. To develop a conceptual approach towards knowing in a context of multiple rationalities, we discuss concepts relating to circulation, translation and processes around knowing the “truth” about the world. We then turn to the case of meningitis surveillance in Burkina Faso, which we present through the description of information flows. The paper concludes with a discussion of how the notion of circulating reference shapes the ability to know and how that affects different parts of the surveillance system.

2 Theoretical framing

The research aim is to understand how health staff know and act in the context of management of disease surveillance and response, particularly related to meningitis care and prevention in Burkina Faso. We see this as a question of also understanding the machinery that produces this knowledge, something that the sociologists of science define at the “epistemic culture” (Cetina 2007). Cetina (2007) argues that while we accept scientific knowledge as the truth, we know little about how it is generated. She sees “knowledge making” as practices, arrangements and mechanisms that are often internalized, yet are designed to capture the truth about the world. Thereby she suggest a subtle, yet important, shift from focusing on knowledge as constructed to the construction of the machineries of knowledge generation (Cetina 2007). We find this shift useful for studying HIS, which can then be conceptualized as a part of a knowledge generating machinery, instead of an end product of “truth”. Our own epistemology is based on a practice-based approach where we seek to understand what people do in practice on the assumption that knowing is reflected and constituted in practice. To theoretically inform this analysis, we draw upon a strand of work within the sociology of sciences more generally. In particular, we focus on Bruno Latour’s insights on circulating reference to analyze the dichotomy of loss and gains in the production of depictions of the world. It enables us to discuss the process of producing knowledge wherein the information flows that the HIS could integrate are conceptualized as multiple chains of translations.

2.1 Circulating reference

Latour (1999) develops the concept of circulating reference by following a group of botanists, pedologists, and geographers during a trip to the Amazon rain forest, and empirically traces the successive steps through which empirical evidence (soil samples) gathered in the forest is gradually transformed into text. With each step, 'matter', a thing, is turned into 'form', a sign, which then becomes matter for the next step. There is thus a series of matter-form-matter-form transformations, which allows movement in both “directions” (from world to text, from text to world; back and forth along the matter and forms). Through this process, the material world undergoes a series of transformations and translations where each successive stage takes the place of the original situation. Each step includes different activities such as field walking, drawing sections, taking photographs, sampling, measuring, narrating, etc. With each step, the matter loses its "locality, particularity, materiality, multiplicity, and continuity," and gains in terms of "compatibility, standardization, text, calculation, circulation, and relative universality". This process of amplification and reduction is dialectical in nature, where each is inherent in the other. Taking an example from HIS, as a system scales up and becomes more universal, it inherently loses its particularity and materiality (Sahay, Sæbø, and Braa 2013). In the case of the research team in the Amazon, earth is the matter they master to perfection. In medicine, however, blood and other specimen samples are the matters of transaction. They are reduced through similar processes of reduction and amplification for clinical research, and in individual diagnostics. According to Whyte (Whyte 2011) blood is the “*mediating substance par excellence*” in medical research, but she also goes on to argue that paper holds some the same qualities by being the media where observed phenomena is recorded in notes, analyzed, and objectified in scientific papers. While Whyte is focusing on writing in medical research, this can also hold for writing in the paper-based medical record or register. In this perspective, HIS can be seen as mediating devices that potentially bridges the gap between the world and its representations.

Latour thus seeks to understand how science puts the world into words, and makes a reference, and moves between "the referent" (the thing in the world) and the reference. He writes: "*is what I point to with my finger outside of discourse or...what I bring back inside [that is, in the form of] discourse*" (Latour, 1999: p. 32). An important concept to understand the process of referencing is inscription. Robson (Robson 1992: pp. 691-692) describes an inscription as “*a material translation of any setting* *that is to be acted upon. Inscriptions have to travel between the context of action and the actor remote from that context*". Latour describes the graphs and numbers inside scientific papers as inscriptions used to point towards and to represent the phenomenon, the worldly thing that we are studying. Inscriptions also take the form of documents, data tables, maps, and images representing forms in which the world of matter is converted into. Important also in this regard, by which this inscription becomes a "black-box" and taken for granted representation of the phenomenon. In this way, Latour analyzes how we pack the world into words, by empirically creating a physical place that did not exist before, making it recognizable, and legitimating it with a landmark. As such, Latour (1999a: p. 30) argues that "*the sciences do not speak of the world but, rather construct representations of it that seem to push it away, but also bring it closer*". Science does not then seek "correspondence" (between our words about the world and the world itself) and settle instead for coherence, on how the world comes to hang together. Latour argues that is impossible to have a 100% accurate description of how something occurs in nature using a laboratory setting, given the countless number of variables occurring in nature. Scientists can only construct representations.

The step-by-step process by which the transformation takes place between matter and form is enabled through translations. The concept of translation has its roots in Actor-Network Theory where it is seen as a process that allows a network to be represented by a single entity, which can in itself be an individual or another network. Through translations, actors seem to create a forum, a central network in which all the actors agree that the network is worth defending. Translations take place as the project is taken and adapted by actors, as interests and solutions are developed and evolved. Through translations we can trace the webwork of persons/text/things in intimate relationship and how they move between matter-to-form-to-matter-to, which taken together represents the "circulating reference." This process is imperative in knowing the "truth", by looking into the past as well as the present. Circulating references facilitates retracing the process of transformation by following the chain of translations back to the material world.

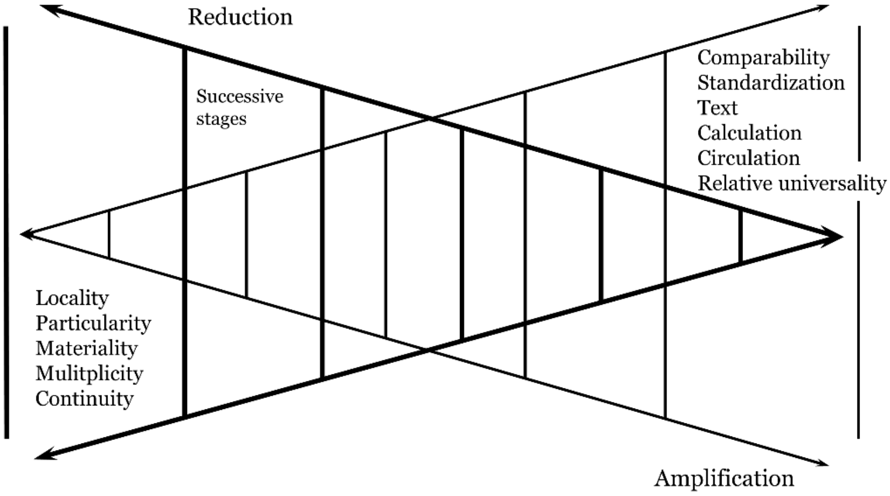


Figure 1: Latour's (Latour 1999a: p. 71) depiction of trade-offs between gains and losses in an information producing process.

The sociology of translation has found extensive application in the domain of information systems and information infrastructure. In the translation process, the designer who creates the artifacts intends for them to be used in a certain manner, this is then inscribed into the tool. Once created, the technology becomes an actor and imposes its inscription on its users, and in use one necessarily shifts back and forth "between the designer's projected user and the real user" reflecting a dynamic negotiation process of design (Akrich 1992: p. 209). Translation reflects the interpretations given by the fact or technology builders of their own interests and those of the actants they seek to enroll in order to transform their claim to a matter of fact (Latour 1987: p. 108). "*Translations help to create a black box, a sort of hegemony*" (Latour 1987: p. 121), which need to be maintained over time due to threat of new actors/elements.

The notion of translations has been explored in science and technology studies where it has been used for example to understand the transfer of technology from one context to another. Akrich shows how the natural, economic, and institutional realities of Nicaragua leads to a series of modifications to a Swedish wood-pulping machine, that enables the machine to be passed to its new environment (Akrich 1993 as recounted by Law 1997). Using a similar approach, Nhampossa (2006) describes the translation of a HIS developed in South Africa to the context of Mozambique. A process that involved interactions between culture, work practice and the technology itself. Sahay et al. (2013) also study a HIS and the processes of scaling up in three different contexts, which they call 'circulating translations' as it involves moving from the particular to the general.

These examples are concerned with the transport or translation of technology from Western or more developed countries to low-resource settings. The depictions strongly underline that the technologies are not transported and adopted just as they are. They undergo a series of transformations, which – in successful cases – enable them to gain a place and functionality relevant to their new setting. Nhampossa (2006) and Sahay et al. (2013) both analyzed translations of an open source software platform to different contexts. The content or the information stored in such systems, on the other hand, do not flow from the West to Africa, instead it flows from Africa to the West, as health data from African villages flows to the central administration of the country, and in form of reports to organizations like the WHO that monitor progress of countries globally. This information is more interpretively flexible (Orlikowski 1992) by nature and it is much less solid than a piece of equipment or even a piece of software. However, as HIS, unlike water pumps and forestry machines are designed to send something back through the system, they also present a somewhat different challenge to the study of translations. The processes of translation facilitated by a HIS and the registration practices around it are closer in form and nature to Latour's Botanists in Amazonas and the translation of the soil sample across the world to Europe. In our case, it is information about meningitis drawn from the population of Burkina Faso that has to be transported first to the national level and then to other global actors monitoring disease surveillance in Africa. Arguably, without knowing about the process of transportation of information facilitated by the HIS, it becomes difficult to know what knowledge is generated, for whom, and for what purposes.

In comparison to technology, information is more abstract, less material and more interpretively flexible, at least once it is recorded. This implies that a study of translations where the focus shifts from technology to information helps to better understand this immateriality. We find practice theory, with its view of knowing and doing as being mutually constitutive (Feldman and Orlikowski 2011), useful for this purpose. The advantage is that it that it focuses on knowing and avoids seeing knowledge as a commodity that can be moved around in a system. Finally, we believe the practice approach is also more useful for unfolding a discussion on what the information in a HIS should support. In line with how others have formulated it, we see it as a way to understand the circumstances within which technology, and in our case a HIS, has to be introduced (Feldman and Orlikowski 2011; Schmidt 2014).

As discussed in this section, action for better health requires production of sound knowledge. This production relies on both people and technologies, and HIS are becoming an essential part of such socio-technical system. We therefore propose that HIS are viewed in the context of knowledge producing machineries. To better understand what this entails we need to study the practices of knowledge production, and to do so we use the concepts of epistemic culture and circulating reference to focus our study the production of knowledge. The brings all the mechanisms together where the notion of circulating reference be the vehicle for describing the micro processes of knowledge creation and the meaning being transported through the system.

3 Method

The study builds on fieldwork done in Burkina Faso during a period spanning two years (2015-2017). One of the authors lived in Burkina Faso during this period and was formally affiliated with the HIS department of the Ministry of Health throughout this period. Data was collected in three stages. The study started out being open ended with the goal to understand data collection and use around the national electronic HIS in general. We saw that the primary purpose of the national HIS was for the production of the annual statistics, and mainly by and for the national level. Further, we understood such statistics were largely inadequate for understanding how disease surveillance and response took place, which required more local and spontaneous action. Consequently, the empirical focus of the study shifted towards understanding the practices of the staff at the peripheral levels of the health sector and how they generated data and how this moved up the different levels of the health administration hierarchy. As disease surveillance and response was a priority area of the Ministry of Health, and many of its international partners, we chose that as a primary empirical focus and the study of its ensuing practices. In addition, it was an area where the Ministry of Health and its partners were looking into strengthening with electronic health information systems. As all diseases are different, we focused on one single disease where the surveillance system was already well established.

Informed by our theoretical notions of circulating reference and to some extent also translations and practices, we drew upon the classic maxim of actor network theory to empirically “follow the actors” and their “world-building capacities” (Latour 1999b). The actors in our case where the different health staff engaged in meningitis surveillance and response, the patients coming for the care, the different artefacts in use (testing equipment, paper, computers etc.). Together they enabled the production and circulation of data. Empirically, we focused on the translations involved with two sets of flows and their inter-connections. The first related to the “flow of the spinal fluid sample” starting from the sample being taken from the patient, its flow to the testing laboratories, and the communication of results. The second was the “flow of information” originating from observations of the patient, its flow through the treatment and its role in other flows of information that the health system was interested in and for which data collection was taking place. Corresponding to these two flows, we focus on understanding two sets of knowing; one, related to the biomedical domain of where treatment of patients and the development of biomedical solutions are in focus, and two, around administrative needs of the administration in knowing disease burdens, profiling areas of incidence, and supply of drugs and logistics.

3.1 Data collection

To be able to study what health workers and managers do and the role of information in their day-to-day work, qualitative methods informed by a practice-based approach were adopted to the study. Data was collected through detailed observations, specific interviews, and the study of disease reports and other relevant policy documents. The other author of this paper did not visit the site but worked together with the first author to understand the data, help build interpretations of it and relate them to theoretical concepts.

Data collection involved 25 full days of observation involving two regions, three districts, two clinics and two laboratories. Participant observation was done with the HIS department of the Ministry of Health. Interviews were done with the health staff and managers from different levels of the health administrative hierarchy, details of which are summarized in the table below.

	Health workers	**Managers**	**Data managers**	**Directors**	**Other**	**Total**
Facility	3	5				8
District	5	3	7			15
Regional	1	2	4			7
National			5	10		15
Academic					4	4
International		1			4	5
Total	9	11	16	10	8	54

Table 1: Number of interviews done and corresponding level

Data collection was organized so that information from all levels could be gathered. Participants were asked to describe how they work with data, where they would get it from, what tools they used to process it, and how they would pass it on and to whom. Early in the process, the questions were more general in nature in order to explore data related work more broadly and to understand the context of data production and use in the health sector in Burkina Faso. As the research evolved, questions asked focused on more specific data flows of disease surveillance and response, and finally to meningitis. Along this process of going from the general to the specific, questions became more concerned with details about which data collection forms were used for what purposes, or how the biochemical analysis from a sample of spinal cerebral fluid was done. The questions were also differentiated according to organization level in order to elicit information concerning the specifics of patient care, observations and documentation at the clinics. Other questions concerning data flows and interoperability of the different national databases were mostly asked at the national level.

3.2 Data analysis

In line with the interpretive approach that suggests a continuous shift between data collection and analysis (Walsham 1995), data was analyzed throughout the research period. In this process, different analytical tools were combined to enable an understanding of both the micro and the macro functions and their inter-linkages of the disease surveillance system in Burkina Faso.

To describe the macro functions of the disease surveillance, maps of data flows were drawn from the beginning of the research. As the research progressed these maps were adjusted or enriched according to what had been observed or discussed during interviews or observations. When the maps were descriptive enough, they where also discussed with participants during interviews. The maps contained details of people, tools, activities as well as relationships and in this way they also served as representations of the phenomenon of disease surveillance and response. It was in the process of developing and fine-tuning the maps that the idea of two flows of information, substance and information became more solid. The flows were first mapped with reference to the type of mechanisms for their documentation; such as paper or electronic, then with reference to the functions they should support; detection, prevention or verification, and finally by their origin; substance or observation. This process shared some similarities to the data processing we observed in the field; through the abstraction of the data a macro level understanding of the overall system was gained, while an understanding of the particularities and the variations in practices at the micro level was lost.

To contrast and enrich these abstract descriptions of micro level work practices, which holds the risk of its decontextualization, we also developed rich and thick descriptions of the inter-connections between the work practices across the different levels of the health sector. These descriptions were mainly developed from the field notes done through observations, complemented by photographs of the various tools used as well as interview responses. In the beginning, the health workers' vocabulary and descriptions were used, what John van Maanen refers to as first-order concepts (as according to Walsham 1995), but as the understanding of the processes deepened, second-order concepts, such as actants, translations or references were developed. In this way, we used theory, ANT, to guide the analytical development of the empirical material. A challenge in this regard is not to impose these concepts on the material (Walsham 1995), which we tried to address by applying the concepts later in the process after the initial less abstract descriptions had been developed. In this way, our analytical development took place through an ongoing and iterative "conversation" between our empirical observation and the concepts in our heads.

4 Case context and description

Burkina Faso is a West African country. Compared to many other countries in the region, it has been quite peaceful and stable over the past decades. Yet it is considered one of the poorest countries in the world, ranked number 185 on the UNDP human development index (UNDP 2016). Consequently, the health sector, which has to do much with little funds and few health workers, is heavily dependent on donor support (Bodart et al. 2001). There are relatively many health facilities throughout the country, which means that health services are within reach of the population. However, it is not possible to staff these facilities with doctors and the services they offer are limited, leading patients to also rely on alternative options for care with for example traditional healers (Samuelsen 2004). Furthermore, user fees on many health services restrict equal access to care (Ridde 2003). During epidemics treatment and testing is usually made free of charge.

In health systems where institutional capacity of the state to deliver public health services for all are limited, dependence on donor funding and interventions remains high (Farmer et al. 2013). While donor driven efforts are easy to roll out even when the health infrastructure is limited, the other side is that these efforts fade away when donor support dries up. Other types of donor initiatives are explicitly trying to build in sustainability mechanisms in their projects, such as in the IDSR (Integrated Disease Surveillance and Response) program, which includes meningitis related care. We discuss IDSR next, to provide a richer context of our case analysis.

4.1 The Integrated Disease Surveillance and Response system in Burkina Faso

The integrated disease surveillance and response framework developed by CDC (Centers for Disease Control, USA) and the African branch of the World Health Organization (WHO Afro) has become the standard framework for disease surveillance and response throughout Africa. The approach has tried to address the lack of integration of surveillance activities traditionally existing between health programs through the development of standardized and comprehensive guidelines (CDC 2015). The IDSR framework has a number of objectives, which in summary state that data collection and dissemination should be streamlined through standardized common tools, such as software, forms and templates, and that information should be used for action (Kasolo, Roungou, and Perry 2010).

Burkina Faso has adopted the international IDSR-guidelines and developed a national version (Ministère de la Santé Burkina Faso and Organisation Mondiale de la Santé 2012). The Ministry of Health is responsible for the national disease surveillance and response, and its main offices are involved in meningitis surveillance and response include the Directorate for the fight against diseases, and the Directorate for vaccine preventable diseases. The Directorate for sectorial statistics is responsible for the management of the national HIS and the production of the annual statistics. Several international partners support the Ministry of Health, technically and financially, for meningitis control including their testing and treatment during epidemics. This support has enabled the provision of all vaccines given through the public vaccination programs to be free of charge. A key initiative in this area is the MenAfriNet project, which we will discuss in the following section.

4.2 The MenAfriVac in Burkina Faso

Burkina Faso is located in the Sahel, the region just below the Sahara desert. The climate of the Sahel is dry and dusty and the dry season lasts seven months from October through April. Respiratory diseases are rampant, and lower respiratory infections are the major cause of death among adults (WHO 2015). The dry climate also contributes strongly to the transmission of meningococcal meningitis, a bacterial form of meningitis, as the dust easily transmits this type of infection. This is not only a problem in Burkina Faso, but in all the countries of Northern Africa from Senegal in the West to Eritrea in the East. In the context of meningitis, this area is also referred to as the ‘meningitis belt’, as it has been suffering from frequent large-scale epidemics due to meningococcal meningitis resulting in large numbers of infections and deaths.

Recently this challenge was effectively addressed through the development of the low-cost meningococcal A conjugate vaccine (MenAfriVac), which was developed through a global partnership between WHO (the World Health Organization), the non-governmental organization PATH, and the Serum Institute of India (PATH 2017; WHO 2017). The vaccine directly targets the meningococcal meningitis serogroup A, which has been one of the leading cause of epidemics due to meningococcal meningitis in sub-Saharan Africa. Since 2010, more than 250 million people in several countries across the meningitis belt, including Burkina Faso, have been vaccinated. Early studies of the MenAfriVac rollout in Burkina Faso showed a very high impact of the vaccine both on risk of infection and fatality (Novak et al. 2012), and it is confirmed that the vaccine has contributed to the dramatic drop in the prevalence of meningococcal meningitis caused by the serogroup A. Since 2017, the MenAfriVac has been included in the national child immunization program of Burkina Faso. The introduction of the MenAfriVac vaccine also involved building technical capacity in managing the new vaccine, doing surveillance and case confirmation, and cold-chain management, as in building capacity through partnerships (Djingarey et al. 2012). This process facilitated the establishment of the current surveillance system, which allows for a three-step consecutive, detailed analysis of spinal fluid samples, necessary for monitoring the effects of the vaccine (Djingarey et al. 2012). In this framework, extensive data collection is still going on to monitor continuously the quality of the vaccine. Following the success of the MenAfriVac campaign, challenges to the meningitis surveillance and response are now focused on maintaining the standards obtained, and to monitor closely for outbreaks caused by other strains of meningitis (LaForce et al. 2017).

5 Case narrative

“*We must communicate; In all things we must communicate, voila! […] It's like a chain. In a chain, there is not an element that is not good. Anyway if you take the motorcycle chain, it is small but it is important. If it fails, straightaway there is no more chain. It must be soldered. So that means that in the system we are like that; there is not an element which is not good. Everybody is good. So we must work together with everyone in order for this to work. That's what makes the system.*”

Regional health data manager

Disease surveillance and response can be seen as a chain where each link of the chain plays a certain role in the processing of information. Information is transmitted from each level to another on a routine basis, or with higher frequency in case of an alert situation. The information is analyzed and feedback is given back throughout the chain. Feedback can be decisive (declaration of an epidemiological status), instructive (on how to act), or controlling (supervision on data quality).

In this paper, we focus mainly on the chain of information from the health facility to the national level and the translations it undergoes at each step where it is handled. We are aware that the chain arguably begins before the health facility level, in the communities where people live and are exposed to contagious diseases. Equally, the chain can also be extended beyond the national borders, to include a range of international stakeholders who receive and make use of meningitis information. We have chosen to keep our case within the boundaries of the national health system of Burkina Faso, as it allows us to focus on detail and the bigger picture in one case. The image below gives a schematic overview of this process, which we depict as two sets of flows based on information and physical substance.

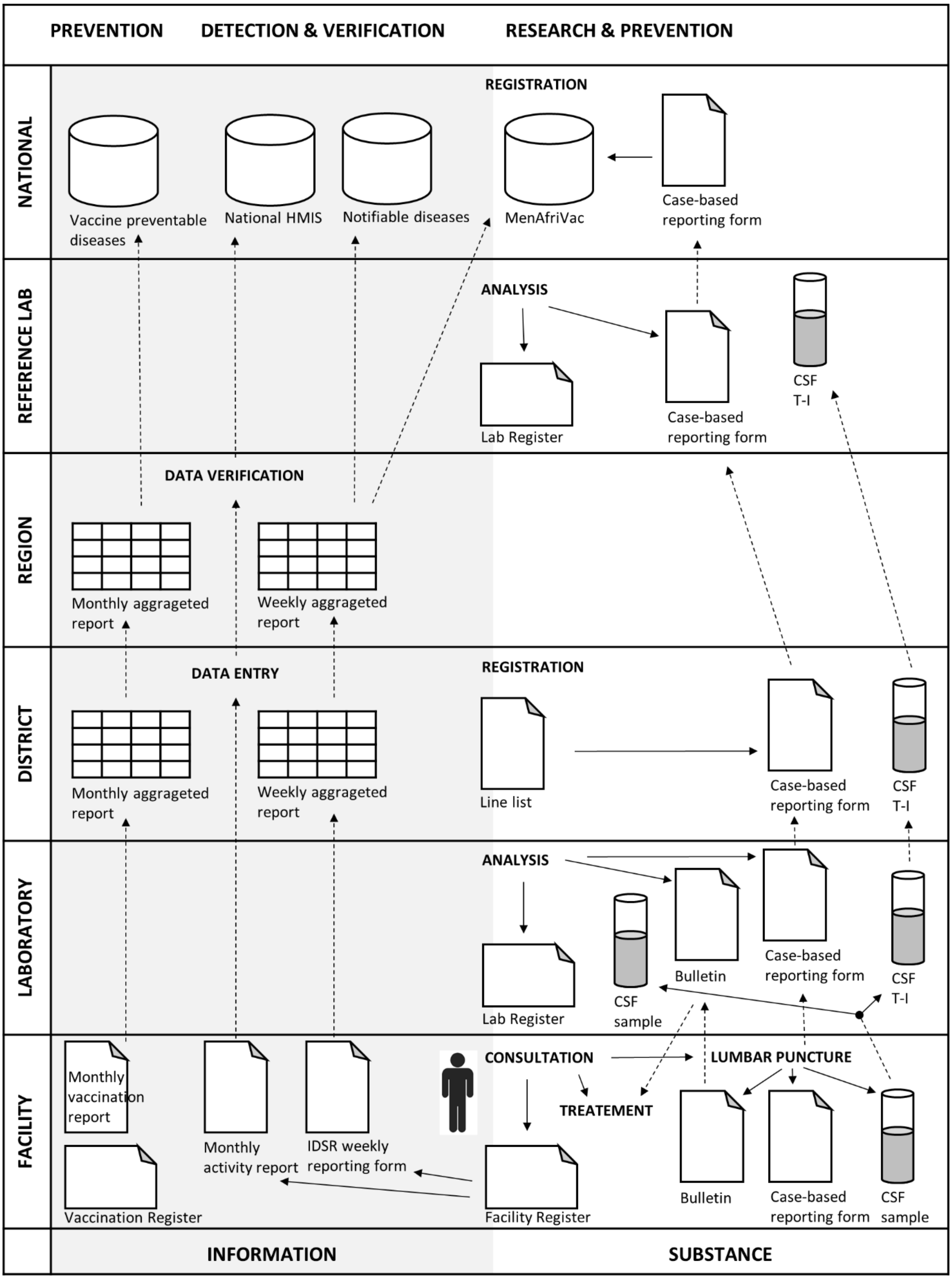

PREVENTION
DETECTION & VERIFICATION
RESEARCH & PREVENTION
NATIONAL
REFERENCE LAB
REGION
DISTRICT
LABORATORY
FACILITY
REGISTRATION
Vaccine preventable diseases
National HMIS
Notifiable diseases
MenAfriVac
Case-based reporting form
ANALYSIS
Lab Register
Case-based reporting form
CSF T-I
DATA VERIFICATION
Monthly aggregated report
Weekly aggregated report
DATA ENTRY
REGISTRATION
Monthly aggregated report
Weekly aggregated report
Line list
Case-based reporting form
CSF T-I
ANALYSIS
Lab Register
CSF sample
Bulletin
Case-based reporting form
CSF T-I
Monthly vaccination report
Vaccination Register
Monthly activity report
IDSR weekly reporting form
CONSULTATION
TREATEMENT
LUMBAR PUNCTURE
Facility Register
Bulletin
Case-based reporting form
CSF sample
INFORMATION
SUBSTANCE

Figure 2: Overview of meningitis-related data flows in the health system of Burkina Faso from health facility to national level

The flows describe the socio-technical system that altogether supports a number of meningitis related domains of knowledge; diagnosis for treatment, surveillance and response for the detection of epidemics, distribution of vaccines for prevention, as well as research and development of new vaccines for prevention.

However different they might be, the flows still share the same starting point; the patient's pathology. A patient who seeks medical care at a health facility will do so based on an experience of not feeling well or by an observation of physical changes, for example pains, itches or rashes. These symptoms constitute the pathology, and the health worker will try to make sense of them by observing and talking to the patient. In the case of meningitis, the pathology is high fever, headaches and a stiff neck. The nurse can make sense of this pathology talking to and examining the patient. The observations the nurse makes, lead to two distinctive flows; one based on information and another based on substance. In the following, we will detail these two flows separately in order to trace the translations, and the gains and losses of each one. Finally, we will show how these two flows are reconnected to tell the story of meningitis in Burkina Faso.

5.1 Information flows

"You can use a gun to kill an ant. [...]. So sometimes the actions taken will maybe request a lot of resources. And maybe with the use of proper data, you won't need a lot of resources to do it. So it will affect the effectiveness of the actions. Now what to do, some people can die from meningitis [when] they type the data and analyze the data but the epidemic has already killed many people. So what I am saying is that sometimes the action is not taken at the right time, and sometimes it does not target the right people"

Researcher/Former district manager

The flow based on information is supported by a number of paper-based forms and databases, which act as the mediating devices for this flow. Below is a diagram of the passing of meningitis-related information from the patient encounter through the health system.

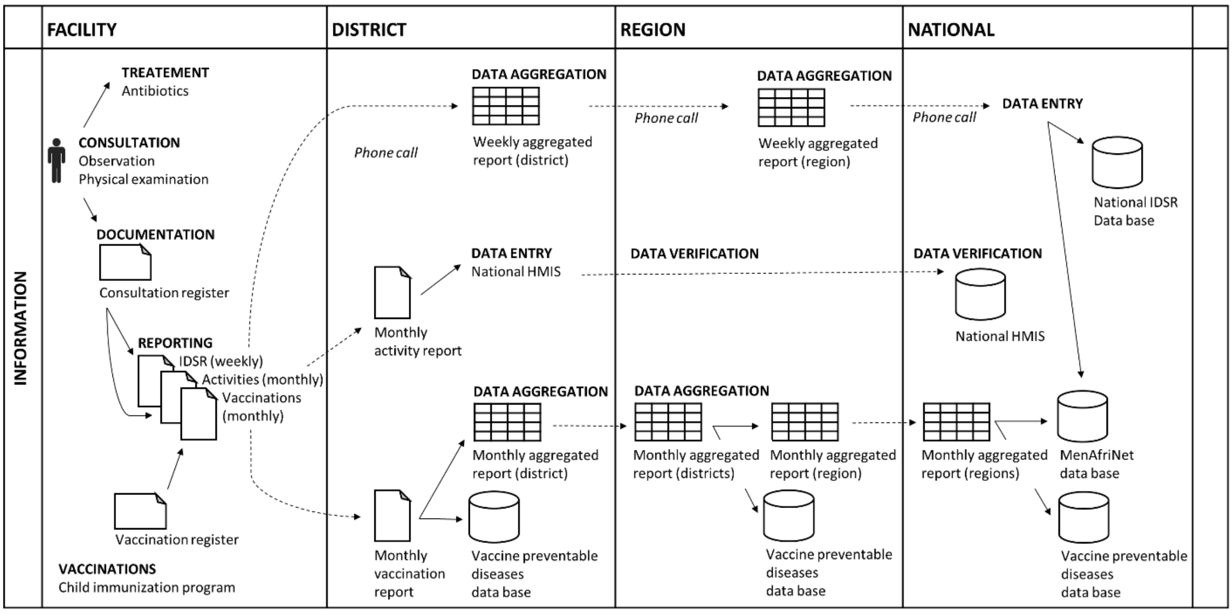
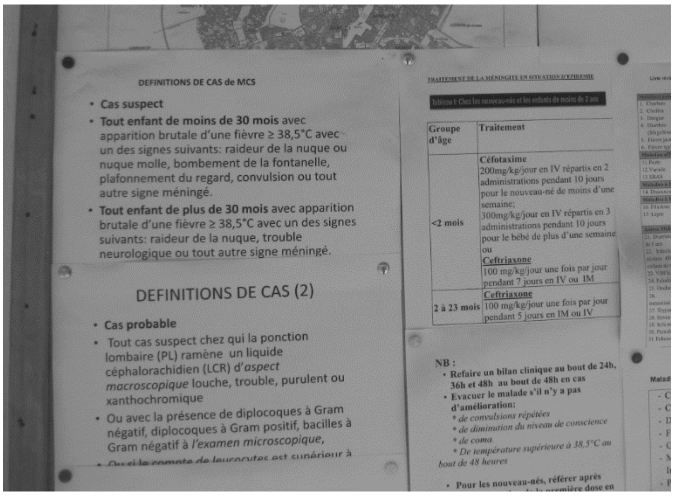


Figure 3: Schematic overview of flow based on information

Health facility level

The symptoms that point to meningitis are similar to symptoms of other diseases such as malaria or dengue. At the health facility, the nurse will talk to the patient and perform a physical examination to determine if there are other things, such as infected wounds, that could be causing fever in the patient. The nurse will especially pay attention to see if the patient is suffering from severe pain at the neck or lower back. Such symptoms are strong indicators of a meningitis infection. However, as malaria is very common in Burkina Faso, the nurse might also decide to do a Rapid Diagnostic Test (RDT) for malaria, just to rule it out. To support this examination, the resulting analysis, and its conclusion, the nurse will draw both on his/her experience, as well as standard case definitions. These definitions are standardized by the Directorate for the Fight Against Diseases at the national level. They are made known to the nurses by training, and they are available in the national IDSR guidelines. Usually they are also displayed on the walls, in all in-patient clinics. The image below is an example of such a case definition at a health facility.



DEFINITIONS DE CAS de MCS

- **Cas suspect**
- **Tout enfant de moins de 30 mois** avec apparition brutale d'une fièvre ≥ 38,5°C avec un des signes suivants: raideur de la nuque ou nuque molle, bombement de la fontanelle, plafonnement du regard, convulsion ou tout autre signe méningé.
- **Tout enfant de plus de 30 mois** avec apparition brutale d'une fièvre ≥ 38,5°C avec un des signes suivants: raideur de la nuque, trouble neurologique ou tout autre signe méningé.

DEFINITIONS DE CAS (2)

- **Cas probable**
- Tout cas suspect chez qui la ponction lombaire (PL) ramène un liquide céphalorachidien (LCR) d'*aspect macroscopique* louche, trouble, purulent ou xanthochromique
- Ou avec la présence de diplocoques à Gram négatif, diplocoques à Gram positif, bacilles à Gram négatif à *l'examen microscopique*,
- Ou si le compte de leucocytes est supérieur à

TRAITEMENT DE LA MÉNINGITE EN SITUATION D'EPIDEMIE

Tableau I: Chez les nouveau-nés et les enfants de moins de 2 ans

Groupe d'âge	**Traitement**
<2 mois	**Céfotaxime** 200mg/kg/jour en IV répartis en 2 administrations pendant 10 jours pour le nouveau-né de moins d'une semaine; 300mg/kg/jour en IV répartis en 3 administrations pendant 10 jours pour le bébé de plus d'une semaine ou **Ceftriaxone** 100 mg/kg/jour une fois par jour pendant 7 jours en IV ou IM
2 à 23 mois	**Ceftriaxone** 100 mg/kg/jour une fois par jour pendant 5 jours en IM ou IV

NB :

- **Refaire un bilan clinique au bout de 24h, 36h et 48h au bout de 48h en cas**
- **Evacuer le malade s'il n'y a pas d'amélioration:**
  - ** de convulsions répétées*
  - ** de diminution du niveau de conscience*
  - ** de coma.*
  - ** De température supérieure à 38,5°C au bout de 48 heures*
- **Pour les nouveau-nés, référer après**

Image 1: Standard case definitions for cerebrospinal meningitis (MCS) as displayed at a health facility

Based on the examination and the pathology's compliance with the diagnostic guidelines the health facility nurse can diagnose the patient with meningitis. This is the very first translation in the information-based flow. Here the patient's symptoms are translated from physical signs to a category, which is a standardized instance that can be shared with other health workers or across the health system. This translation is very useful as it supports at least three actions; treatment, request for further laboratory tests for confirmation (this aspect is treated in the section 5.2 on substance flows), and documentation for the purpose of health systems analysis.

Some types of meningitis can be fatal if not treated immediately, meaning that there is not time to wait for a laboratory test to be done to confirm the diagnosis before beginning treatment. Instead, the standard case definitions are the mechanism the nurse relies on to translate the patients' physical symptoms into a disease category, representing the diagnosis. Once this diagnosis is done, the facility nurse can proceed with treatment, and administer antibiotics.

Subsequently, the nurse documents the diagnosis and the treatment given in the health facility's consultation register. The case of 'suspected meningitis' is documented with the patient's details (such as name, sex, age, and contact information). Below is an image of a health facility consultation register. Each line contains information about one patient.

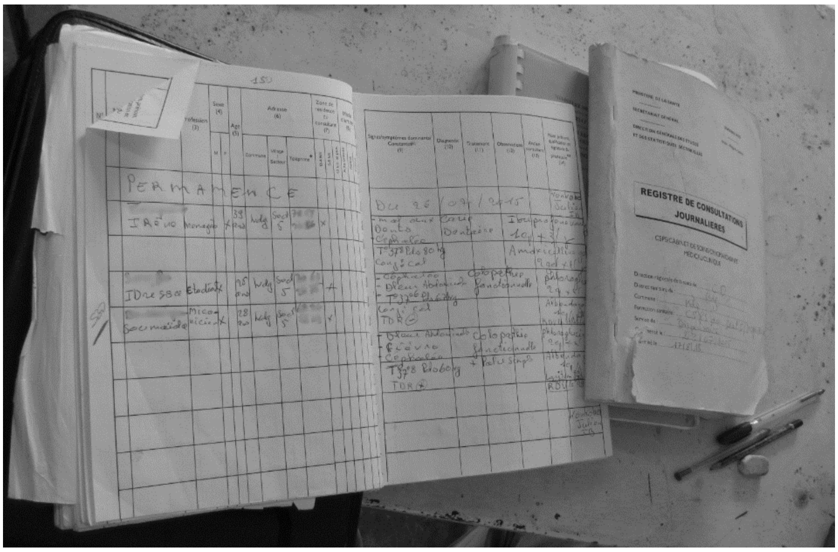


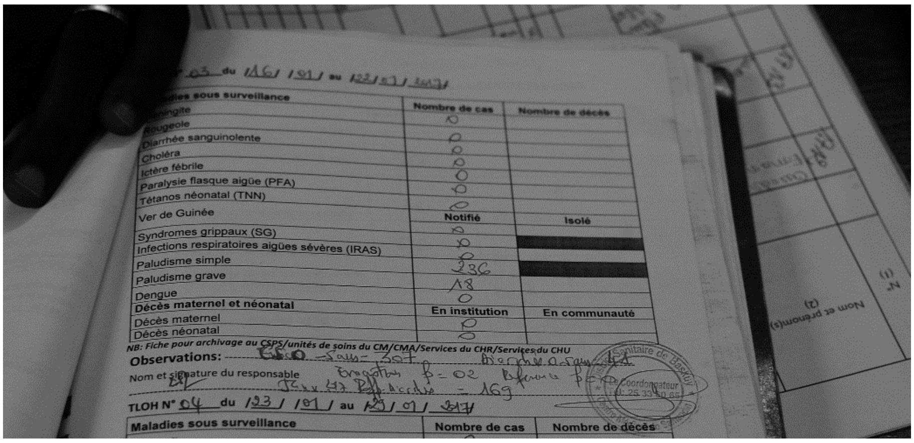
Image 2: Health facility consultation register

The patient's symptoms have already been translated to a category, suspected meningitis. In the health facility consultation register, the patient as a physical person is translated into a data entry composed of a series of standardized categories, such as name, age, sex, vaccination status, diagnosis etc. This serves the purpose of amplifying the descriptive characteristics needed for getting an overview of the person as a patient and for keeping track of the patients consulting the health facility. Obviously, the physical presence of the patient as a biological person of flesh and blood is lost.

There is still much more that can be achieved from the information about suspected cases. One case of cerebrospinal meningitis is a serious issue, especially to the patient herself as the disease can be fatal, however, as it is also very contagious, one case can quickly multiply and create a threat for a larger population. To know the nature of this threat, it is necessary to know the incidence of cases in the population. This requires that information about an individual patient is translated to become information about a population.

To achieve this information a series of steps are needed. The first step at the health facility level is to aggregate the individual cases into bundles of cases compiled on reports that can be transmitted to the next level. Each health facility generates about 20 weekly, monthly and quarterly reports. Three of these contain meningitis data; the weekly surveillance report (TLOH), the monthly health facility activity report, and the monthly vaccine preventable diseases report (PEV).

The weekly surveillance report is compiled each Monday. The facility head nurse brings out the health facility consultation register and counts the total of suspected cases of meningitis. The total is written in the TLOH register, a smaller notebook (see the image), where details of all other infectious diseases under surveillance are also noted.



03 du /16/ /01/ au /22/ /01/ 2017

dies sous surveillance	Nombre de cas	Nombre de décès
ningite	0	
Rougeole	0	
Diarrhée sanguinolente	0	
Choléra	0	
Ictère fébrile	0	
Paralysie flasque aigüe (PFA)	0	
Tétanos néonatal (TNN)	0	
Ver de Guinée	0	
	Notifié	**Isolé**
Syndromes grippaux (SG)	0	
Infections respiratoires aigües sévères (IRAS)	0	■
Paludisme simple	236	
Paludisme grave	18	■
Dengue	0	
Décès maternel et néonatal		
	En institution	**En communauté**
Décès maternel	0	
Décès néonatal	0	

NB: Fiche pour archivage au CSPS/unités de soins du CM/CMA/Services du CHR/Services du CHU

Observations: [illegible]

Nom et signature du responsable [illegible]

TLOH N° 04 du /23/ /01/ au /29/ /01/ 2017

Maladies sous surveillance	Nombre de cas	Nombre de décès

Image 3: Weekly aggregation of suspected cases and deaths of diseases under epidemiological surveillance.

In this process the individual patient data is translated to a number (total of suspected cases) that amplify the potential presence of meningitis in the health facility’s uptake area.

At the end of each month, the facility nurse uses the register to compile an activity report for the health facility. There are preprinted templates for the report to ensure national comparability. In the image below a facility nurse is entering the totals from the consultation register to the monthly activity report template.

Image 4: Compilation of a monthly health facility report

This is a process where the information about the patient as a person with specific characteristics is translated into a group of patients with only that in common that they have a meningitis diagnosis. This makes it possible to talk about the prevalence of meningitis in the health facility's uptake area. As the consultation register consists of many pages where the registrations are done with a pen, distortions are likely to occur. Some information might be missing or a number might not be readable. In such cases, the nurse makes a quick interpretation of what is the most likely registration and transfers that to the report. Other distortions are likely to occur in the actual counting process. The compilation of the monthly report takes a couple of days. As it is not possible to dedicate a person full time to do data entry during these days, the work is often interrupted. Furthermore, the nurse uses a little sheet to keep track of the aggregations, as it is easy to skip numbers when for example flipping a page.

The report on vaccinations and surveillance of vaccine preventable diseases is also compiled on a monthly basis, but it is done by the vaccination officer (PEV). This report includes an overview of all the vaccines administrated by the health facility. Vaccines are given either as part of targeted campaigns or through the routine vaccination program. This form also holds information about cases and deaths by meningitis, but only for children under five. Below is an example of a monthly facility vaccination report.

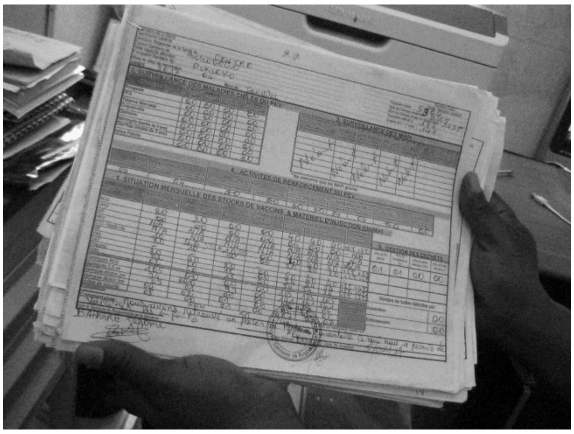


Image 5: Vaccine report compiled monthly by the health facilities.

In the process of putting together this report the information regarding the individual meningitis patient is translated to information regarding a specific group of meningitis patients – that of children under five.

In each of the three reports, the individual patient case data is translated to a single number representing the aggregate of all patients with suspected meningitis in the health facility during a specific month. As the patient is reduced to one in many, the specifics of the particular patient, such as name, date of birth, sex are lost, while simultaneously the specifics of the whole health facility's population is amplified to reflect total number of suspected meningitis cases for the week, the month, or a certain group of meningitis patients.

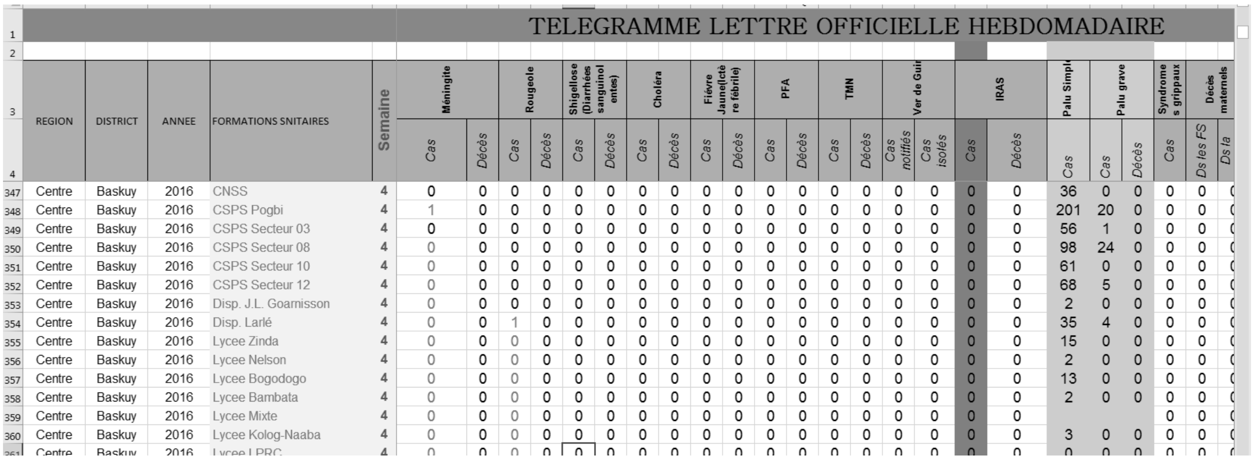
District level

After compilation, the three reports are transferred to the next level, the health district. The disease surveillance information in the TLOH is handed over by phone, where physical copies of the activity report and the vaccination report are physically brought to the district by someone from the health facility.

The form is there, but for the moment we don't use ENDOS (the national HIS) for the TLOH. With respect to the difficulties with the internet connection, since it is something quick that you have to do fast. It is not like the monthly reports where you can wait. With the phone, you can just make a call.

District data manager

The disease surveillance reports from the facilities are compiled by the district data manager. Currently there is no shared electronic storage for the TLOH information, given the poor Internet connection nationally, including even in the large cities. As timeliness is key, the incentive to switching to electronic reporting is weak. The communication by phone allows for transporting the number without its physical registration. The physical presence of the information as something that is visible on paper or on a computer screen is lost but through this loss, it gains transportability. This translation is possible because it is relatively few numbers that are handed over this way. When the district data managers receives the disease surveillance information, she makes an overview of the district by compiling them in an excel sheet. An example of such a sheet is displayed below.



TELEGRAMME LETTRE OFFICIELLE HEBDOMADAIRE

	REGION	DISTRICT	ANNEE	FORMATIONS SNITAIRES	Semaine	Méningite		Rougeole		Shigellose (Diarrhées sanguinolentes)		Choléra		Fièvre Jaune(Ictère fébrile)		PFA		TMN		Ver de Gui		IRAS		Palu Simpl	Palu grave		Syndromes grippaux	Décès maternels	
						Cas	Décès	Cas	Décès	Cas	Décès	Cas	Décès	Cas	Décès	Cas	Décès	Cas	Décès	Cas notifiés	Cas isolés	Cas	Décès	Cas	Cas	Décès	Cas	Ds les FS	Ds la
347	Centre	Baskuy	2016	CNSS	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	36	0	0	0	0	
348	Centre	Baskuy	2016	CSPS Pogbi	4	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	201	20	0	0	0	
349	Centre	Baskuy	2016	CSPS Secteur 03	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	56	1	0	0	0	
350	Centre	Baskuy	2016	CSPS Secteur 08	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	98	24	0	0	0	
351	Centre	Baskuy	2016	CSPS Secteur 10	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	61	0	0	0	0	
352	Centre	Baskuy	2016	CSPS Secteur 12	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	68	5	0	0	0	
353	Centre	Baskuy	2016	Disp. J.L. Goarnisson	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	
354	Centre	Baskuy	2016	Disp. Larlé	4	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	35	4	0	0	0	
355	Centre	Baskuy	2016	Lycee Zinda	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	15	0	0	0	0	
356	Centre	Baskuy	2016	Lycee Nelson	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	
357	Centre	Baskuy	2016	Lycee Bogodogo	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	13	0	0	0	0	
358	Centre	Baskuy	2016	Lycee Bambata	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	
359	Centre	Baskuy	2016	Lycee Mixte	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0				0	0	
360	Centre	Baskuy	2016	Lycee Kolog-Naaba	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	3	0	0	0	0	
361	Centre	Baskuy	2016	Lycee LPRC	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	

Image 6: TLOH with data from all health facilities in one district

In this process, the data representing a health facility is translated to represent a larger geographical area. The translation helps to amplify the distribution of suspected meningitis cases across the country, while simultaneously the geographical boundaries of the region, district, health facility and the individual's home is successively lost.

The activity reports from the facilities are also compiled by the district data manager. Once the reports start to pile up at the district data managers' office, they are entered into the national HMIS. The national HMIS is built on a cloud-based technology, which makes it possible to enter data at district level directly to the shared served. The HMIS database has been built around the monthly activity data, it contains information about the activities carried out at each level of the health sector. It has been expanded with information regarding disease specific programs for example malaria and tuberculosis. Below is an image of a pile of monthly reports from all facilities in a district and the data entry screen of the HMIS.

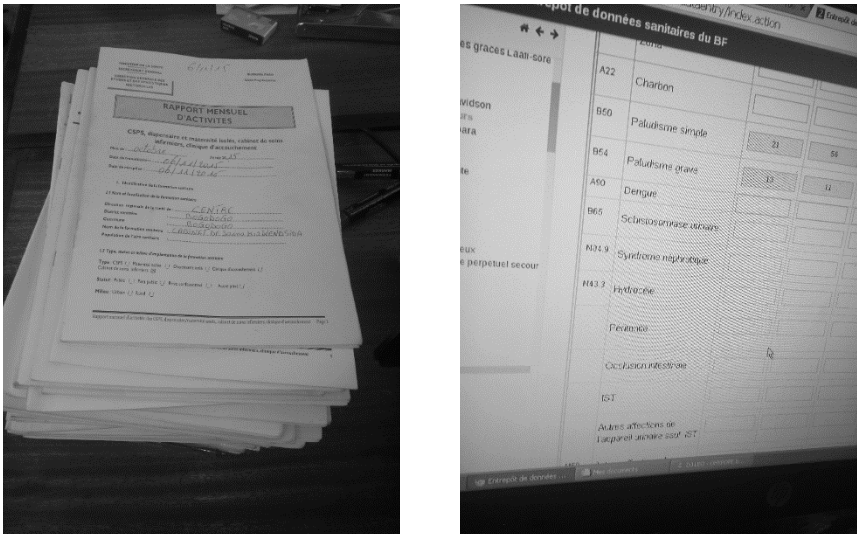


Image 7: Monthly reports from health facilities (left). Data entry screen of national HMIS (right)

When entered into the HMIS, the numbers from the monthly activity reports are translated from being representative of one smaller geographical area (the district) to represent a larger geographical area (the country). At the same time, they are converted from paper to electronic form, which gives them the advantage that the geographic relationship can be changed by the user of the system according to his or her preferences. There are several sources of distortions when this data is entered. One example is that the number of facilities in a district ranges between 20 up to 60. Entering data from so many locations makes the task rather time consuming, which increases the risk of making data entry mistakes.

Interpretations have to be made by the data entry clerk as how to handle forms that are filled out wrongly, missing data, and use of forms that are outdated. Furthermore, this task is challenged by the poor internet connection across the country.

The vaccination reports from the facilities are compiled by the district vaccination officer. They are compiled in a standardized Excel sheet. Furthermore, the data is stored in a district level stand-alone database concerning vaccine preventable diseases. In image eight below the paper-based vaccination report and the excel-file are shown.

Image 8: District vaccination officer with the health facility reports in his hands, while the compiled district overview is shown at the computer screen in the back

In this process these data is translated from being specific to the health facility to being specific to the district. They no longer represent individuals consulting the health facility but instead a district performing in a region.

For one of the three reports, the monthly activity report, the data is stored directly on a central HMIS server, which makes it available immediately throughout the system to everyone with access to view this data. The HMIS is managed by the directorate for statistics (DSS) at the national level. The statisticians in this directorate use the data to do the annual health statistics for all of Burkina Faso.

The two other reports compiled at district level, the weekly surveillance report, and the monthly vaccination report are transferred to the next level, the region, by email. As the surveillance report has to be sent quickly, the numbers might be transferred by phone.

Regional level

The disease surveillance reports from the districts are compiled by the regional data manager, who uses another Excel spreadsheet, which is not standardized. It is up to each regional data manager to make their own. It has the advantage that they can use the spreadsheet as a generator of the regional statistics they need to make on a regular basis. The translation is similar to the other translations as the health facility data gains the comparability with data from other facilities but it does not yet gain the comparability at a national scale. Instead, it becomes comparable with the previous data of the region thereby gaining the ability to display changes over time.

The vaccine reports from the districts are compiled by the regional vaccination officer in a standardized excel template. In this way the data gains comparability across the region. The data is also entered to a regional stand-alone database, which allows it to be used at regional level independent of internet connection but also disables it from being compared to data from other regions.

National level

Once the directorate for the fight against diseases (DLM) has received all information from the disease surveillance reports, one of the national data managers at the DLM enters the data into several databases. The key database to disease surveillance is a database called ‘SIMR’. It has the weekly notification data for all diseases under surveillance, as well as the data from the laboratories that comes in whenever it is ready (the flow for this data will be detailed further in the next section). When the data is entered into this database, it is translated from being tools for notification to a tool for describing the suspected prevalence of meningitis in the whole country in Burkina Faso. The combination with the laboratory data allows this information to not only show the suspected level of meningitis but also the confirmed level of meningitis. What is lost in this process is the particularity of the patient as a person and as a patient with certain characteristics, and the specificity to the health facility as a location.

The national data manager also enters the information from the disease surveillance report into a regional database containing data of West African countries. This database brings together the total number of cases and deaths as reported by the surveillance report. Once the data is entered, it gains comparability with the other countries in West Africa but it loses its connection to the other data describing Burkina Faso.

At the Directorate for the Vaccine Preventable Diseases (DPV), the national data manager enters the data from the regional vaccine reports into the national MenAfriNet database. In this database, the data will be connected with the laboratory data (the flow for this data will be detailed further in the next section).

All in all this information-based flow transforms a person into a population through the translation of the person's pathology to a suspected case of a classifiable disease, which is quantified from being a diagnosis to the total of patients with the same diagnosis. The gains and losses of this flow are summarized in the figure below.

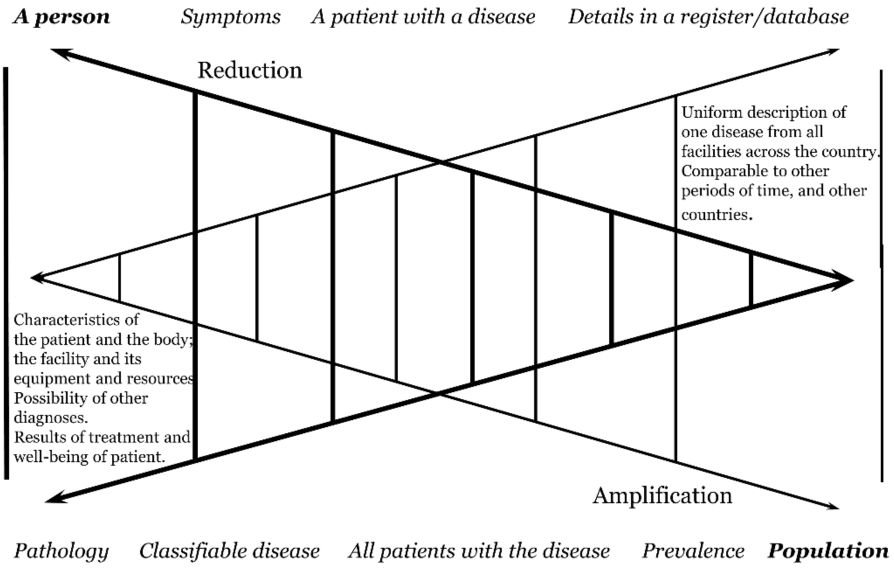


Figure 4: Summary of losses and gains in the information-based flow. Based on Latour's (Latour 1999a) dichotomy.

First, the specifics of the individual patient is lost for the gain of a disease classification that is recognizable through the system. Second, the relation of these suspected cases to specific geographical areas are continuously lost while the prevalence of the disease in the whole country is gained. The accuracy of this information depends on the health workers abilities to recognize and diagnose meningitis, the precision applied to the counting in the aggregation and the tools that compile the information, as well as time-constraints. For the disease surveillance, which is done on a weekly basis the accuracy of the information is distorted as it is based on suspected cases, which have not yet been confirmed. Nevertheless, the information is useful for the production of a weekly snapshot of the potential presence of contagious diseases in the population.

5.2 Substance flows

Parallel to the information-based flow is another flow, which is much more specific to meningitis. The primary mediating device in this flow is a substance; cerebrospinal fluid (CSF), which is taken from the patient's spine by a procedure called a lumbar puncture, and it allows the acquisition of further knowledge regarding this patient. Below is a diagram displaying how the passing of this substance is handled from the patient encounter through the health system.

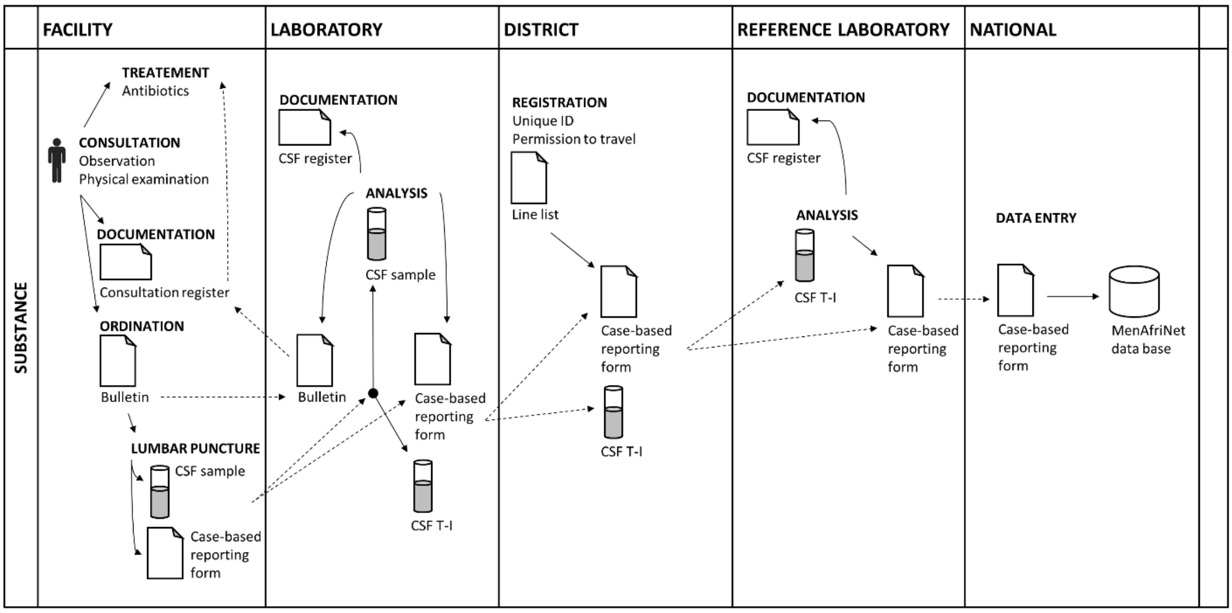
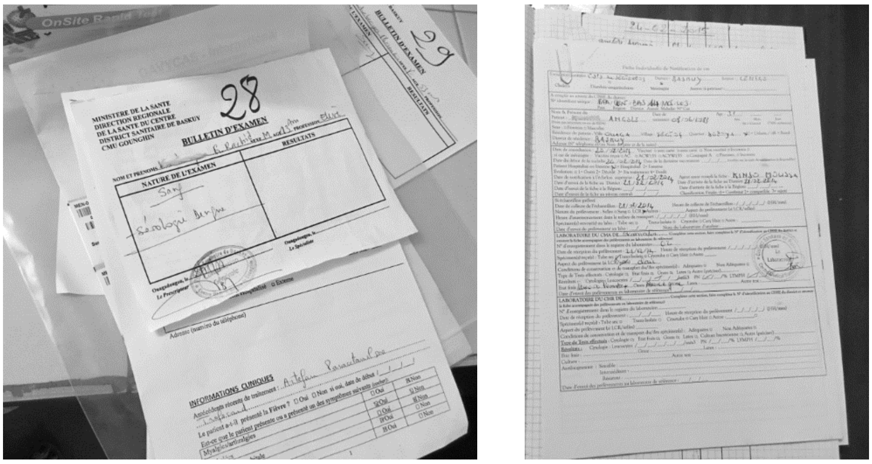


Figure 5: Schematic overview of flow based on substance

To describe this flow we need to go back to the consultation with the patient with the newly received diagnosis of suspected meningitis. It was the point of departure for the flow based on information and it is the point of departure for this flow based on substance.

Even though the patient can be treated already based on a suspicion of meningitis, this treatment can be adjusted according to which type of meningitis the patient is suffering from. Furthermore, this precise information is highly relevant to planners and medical scientists as it can support strategic planning as well as meningitis research. The key to this knowledge is a substance from the patients' bodies. However, before extracting this substance, the nurse needs to record that it should be done. This is done with a request slip (which will later be used to carry the result back to the health facility). The request slip is a piece of paper size A5 with the patient's personal details, such as name and age as well as the ordered test – in this case the lumbar puncture. Additionally, the nurse will start a notification sheet, which is a travelling document that follows the CSF sample and carry information about it through the system.



29

BULLETIN D'EXAMEN

28

MINISTERE DE LA SANTE
DIRECTION REGIONALE
DE LA SANTE DU CENTRE
DISTRICT SANITAIRE DE BASKUY
CMU GOUNGHIN

BULLETIN D'EXAMEN

NOM ET PRENOMS [redacted] B. Rachid SEXE M AGE 13 ans PROFESSION Elève

NATURE DE L'EXAMEN	RESULTATS
Sang Sérologie Dengue	

Ouagadougou, le
Le Prescripteur

Ouagadougou, le
Le Spécialiste

Adresse (numéro du téléphone)

INFORMATIONS CLINIQUES

Image 9: Examples of request slip (left) and notification sheet (right)

When the notification sheet is started, the nurse only completes the upper part. It contains information about the patient as well as what time the lumbar puncture was done.

Equipment to do the lumbar puncture is available at all health facilities. Below an example of such a kit is displayed. It consists of needles to do the punctures, gloves, sterile bottles, mouth protection mask and liquids that can be used for treating severely affected patients.

Image 10: Kit for doing a CSF sample

To be able to retrieve the sample, the nurse asks the patient to lie down on either side with the back curved. With an injection needle, the nurse withdraws a small amount of CSF (cerebrospinal fluid) from the patient's spine. The sample is stored in a sterile tube. This is the first translation taking place in this chain. Mediated by the testing kit, the CSF is translated from being part of the patient's body – a biological ecosystem – to a sample of a specific fluid that can be further analyzed. It is reduced to a small sample losing its ability to support the body of the patient but on the other hand gaining the ability to transmit further information about bacterial meningococcal disease. If the patient is suffering from meningococcal disease due to bacteria, the sample will contain these bacteria. This can be suspected already when the liquid is withdrawn from the patient. Cerebrospinal fluid from a patient who is not sick is clear, while it is cloudy when infected by bacteria. This information is recorded on the notification sheet.

In this process, a material and active component of the patient's body is translated to a liquid sample contained in a plastic bottle. This translation also comes with the risk of transporting the disease to the laboratory. The materiality of the body gets disconnected, and simultaneously another materiality of the spinal fluid for laboratory analysis through a microscope is gained. This translation and subsequent testing is made possible through the testing kit and the training that the health care workers have received. Possible distortions of the translation are contamination of the sample by other bacteria, which can happen if the tube used for the sample is not sterile. The bacteria also die over time, and therefore it is very important that the sample is transported to the health facility laboratory quickly.

Health facility laboratory

Usually it is the patient's or a relative's responsibility to bring the request slip, the CSF sample, and the notification sheet to the health facility laboratory – or if the health facility does not have a laboratory, to the one closest by. The technicians at the health facility laboratories can do a quick analysis within a couple of hours, which helps to determine whether it is meningitis, or not. This information will change the status of the registered case from suspected to probable or not meningitis, depending on the test results. The lab workers register the patient data in the laboratory's CSF-register, while the patient is asked to wait in the waiting area. The lab worker splits the CSF sample in two. One potion is stored in a glass bottle with a Trans-Isolate (T-I) medium, which is a biphasic medium that ensures that the CSF sample can last longer at room temperature. This sample will later go to the reference laboratory. The rest of the sample is prepared for analysis by microscopy and cytology. This is done by smearing part of the CSF sample to a glass slide that can be looked at under the microscope and by centrifuging another part of the CSF sample, a process that separates the bacterial matter, which can then be analyzed in the microscope.

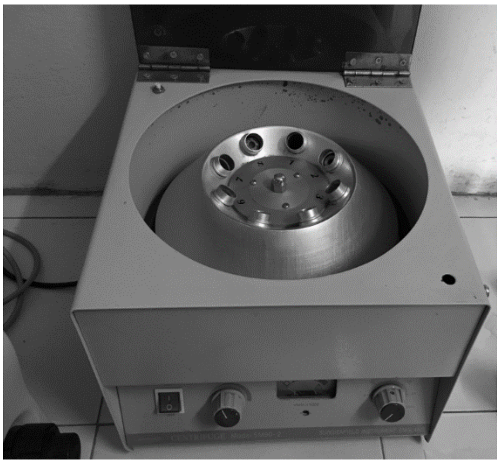


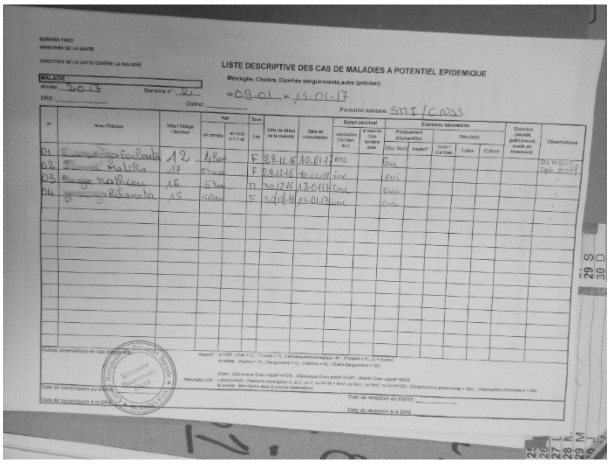
Image 11: A centrifuging machine

The results of these analyses are noted at the notification sheet and on the request slip. When the results are ready, the patient takes the request slip back to the clinical consultation room to show to the nurse who will decide how to proceed.

Generally speaking, what happens at the health facility laboratory is a translation of the body fluid to numbers that can point to a more specific diagnosis. The fluid is reduced to a number, thereby losing the physical properties that allows for a microscopic analysis. At the same time, this number helps to amplify the certainty of the patient's disease status – positive or not. The mechanism by which this becomes possible is the lab technology (latex agglutination or culture) and the practices of the lab technicians.

Health district

The sample in the T-I bottle and the notification sheet is transported to the reference lab by the lab worker. On the way to the reference laboratory, the laboratory technician will pass by the health district to get money for the gasoline and to get a unique ID number for the sample from the CISSE who adds the sample details to the district line list.



BURKINA FASO
MINISTERE DE LA SANTE
DIRECTION DE LA LUTTE CONTRE LA MALADIE

LISTE DESCRIPTIVE DES CAS DE MALADIES A POTENTIEL EPIDEMIQUE
Méningite, Choléra, Diarrhée sanguinolente,autre (préciser)

MALADIE :
Année 2017 Semaine n° 2
DRS
District
du 09-01 au 15-01-17
Formation sanitaire SMI/CNSS

N°	Nom / Prénom	Ville / Village / Secteur	Age en année	Age en mois si < 1 an	Sexe	Date de début de la maladie	Date de consultation	Statut vaccinal: Vaccination (Oui, Non, Inc.)	Statut vaccinal: Si vacciné, Date dernière dose	Prélèvement d'échantillon (Oui, Non)	Aspect*	Résultats: Gram / état frais	Résultats: Latex	Résultats: Culture	Evolution (décédé, guéri, évacué, en traitement)	Observations
01	[redacted] Foulmata	12	[illegible]		F	28-12-16	10-01-17	inc		Oui						DENGUE IgG [illegible]
02	[redacted] Malika	17	03ans		F	28-12-16	10-01-17	inc		oui						
03	[redacted] Mathieu	16	57ans		M	30-12-16	13-01-17	inc		oui						
04	[redacted] Rihanata	15	50ans		F	30-12-16	13-01-17	inc		oui						

Image 12: Transportation box (left). Generic district line list (right)

The line list is the district's record of the probable meningitis cases in the district. In this step the information about the sample is given a unique identifier which makes it possible to match the result with to the patient they came from. This can be quite useful in case certain information must be given to the patient after the test results have been obtained. It is a translation that enables a complete physical detachment of the patient from the sample, but by the mechanism of the unique identifier, the possibility to reconnect them is gained.

Reference laboratory

Once the CSF sample is received at the reference lab, which are five labs connected to the large university hospitals, it can be determined by which strain of meningitis disease the patient is infected. This information is used to decide which treatment the individual patient should have as well as the preventive treatment for the area where the case has been discovered. However, it might also later be used for analytical purposes to detect patterns in disease development, which informs more broadly surveillance processes, vaccine development, acquisition of vaccines, international and national strategies etc.

The results of the laboratory analyses by the reference laboratory workers are recorded on the notification sheet.

Ministry of health

A laboratory worker takes the notification sheet to the Directorate for the Fight Against the Diseases (DLM) at the ministry of health. The national data manager enters the detailed information about the particular case of meningitis to a national database for the monitoring of the MenAfriVac, which is named MenAfriNet after the network producing and monitoring the vaccine. The MenAfriNet only contains meningitis specific information, but in addition to the laboratory results, it is also updated weekly with the information from the weekly surveillance forms (TLOH), as well as from the vaccine programs (the monthly vaccination reports). This information is used to monitor the effectiveness of the MenAfriVac. With the meningitis strain A no longer reported, the vaccine is considered to be efficient. Once the numbers are in the database, they are ready to be analyzed for developing potential snapshots of the current meningitis situation in the country, including the type of meningitis present and in what numbers. This then informs whether a preventive vaccination campaign should be started. The diagnostic numbers from the lab have been translated into indicators. In this process, everything personal regarding the patient has been lost, and a regional snapshot has been gained of incidence by different types of meningitis in the country. In the process of entering the information based on substance into this database, the data is translated from being about an individual person and a specific infection with meningitis to be a part of all the cases of meningitis across the country. In the process, the person is lost but the specifics of the disease has been gained.

In this flow the body fluids of an individual patient is transformed into a test result pointing to a specific disease. By the quantification of the test results, the individual test results become a description of a disease. The process is summarized in the figure below.

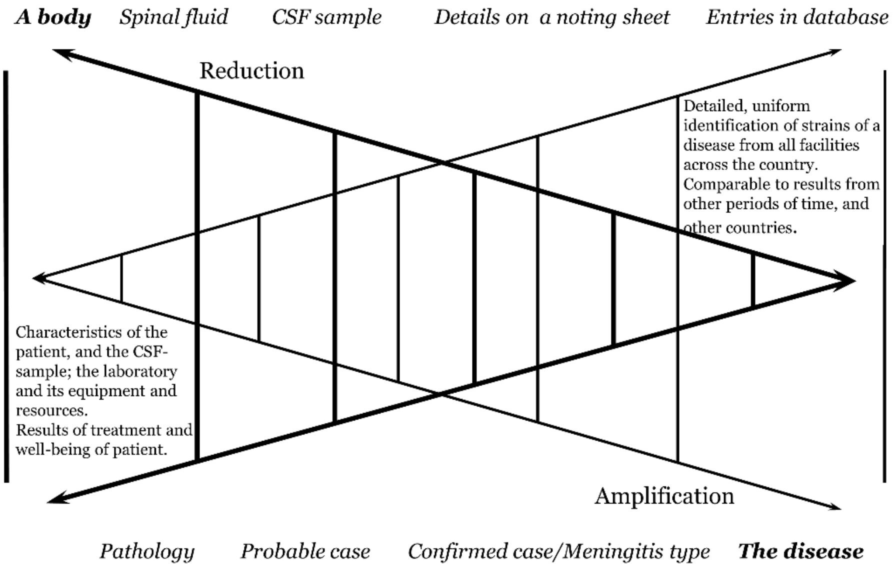


Figure 6: Summary of losses and gains in the substance-based flow. Based on Latour's (Latour 1999a) dichotomy.

Here the body of an individual patient is lost for the gain of an extract (a sample) of the spinal fluid. Second, the physical presence of the spinal fluid is lost as it is being analyzed while the details of the meningitis disease is gained. The accuracy of this information depends on the technical, laboratory capacity and the ability of health and laboratory workers to do the test and analyses as recommended. A two-step testing process has been enabled so the accuracy of the knowing is increased incrementally in the system. Thereby, relevant knowledge is produced for both the clinical level where the patient is treated and a quick less precise answer is needed, as well as for the analytical levels where the administration and development of vaccines are handled and more precise information is needed. This testing capacity has been strengthened with the introduction of the MenAfriVac vaccine, as the monitoring of the vaccine would rely heavily on the ability of this epistemic system to produce precise information.

6 Analysis

The case describes the socio-technical network that produces knowledge to tell the story of a disease (meningitis) in a country (Burkina Faso). The network consists of both people and technology: Of health workers, test kits, microscopes, paper and body fluids. The description is about how scientists, health workers, and health managers put the world into words. It describes the gap between the physical world of patients and their sufferings and the language of national health statistics, and global health monitoring. It enables us to understand in more detail to what extent we can know from a disease surveillance system. Paper and body fluids are the mediums that allow information about people all over Burkina Faso to travel through the health systems facilities, districts, and regions to the national level, where they are prepared for their new role as parts of international health statistics. These data and substance based flows are captured through different forms of representations – note sheets, test reports, monthly reports etc. – inscribing different rationalities and means of knowing.

In disease surveillance and response, it is important to know, as knowing supports response. However, response is characterized by possibly being both short-term and long-term. Short-term response consists of immediate actions such as detection and treatment, where long-term response consists of more time-consuming actions, such as the development of biomedical technology, vaccines, and standard operating procedures such as the IDSR guidelines or national guidelines. Other long-term response related activities include strengthening of human capacity in the health sector and strengthening of awareness of meningitis in the population. To support these different aspects of response, different kinds of knowledge is needed, and these different kinds of knowledge are produced through different epistemic systems.

By using the concept of circulating reference and the dichotomy of losses and gains, we see how the particularity and locality is lost in favor of the gains of comparability and relative universality. For example, the personal details of the patient lost in favor of computing totals of patients with the same disease. This aggregation is useful for the long-term response, which relies on statistical and scientific methods, but less useful for short-term response, which relies on provision of health services and day-to-day operational actions. To accommodate these various needs, the socio-technical network builds different chains of matter to form translations, where a physical matter is turned into form. Unlike the botanists in the Boa Vista rain forest who describe one chain of translations, the meningitis data in Burkina Faso is transformed through at least two very distinctive chains of matter to form translations. Due to the different purposes of knowing that they serve, information and substance, these chains are separated already at the patient encounter. As they require different expertise, laboratory and statistical, for their handling they remain separated until they are brought together again at the national level. Here they complement each other thereby making it possible to tell stories that are more coherent about the meningitis disease at the national level.

The system thus does not produce simply one representation of meningitis in Burkina Faso. Instead, it produces several. One is about the prevalence of confirmed cases of meningitis every year, another is about the prevalence of suspected cases of meningitis every month, and a third is about the effectiveness of the MenAfriVac vaccine. The differences in these representations have to do with tolerances for accuracy. While those activities dealing with long-term response, such as development and testing of vaccines do not tolerate inaccuracy, those dealing with disease detection do accept certain ranges of inaccuracy. For the statistical and research functions of the health system there is plenty of time to wait for the production of accurate data. For the surveillance and treatment related functions, however, there is no time to waste waiting for precise information. This means that a time dimension also separates the chains of matter to form translations. This goes both for the information based chain, which has a quick flow of surveillance data, and a slow flow of statistical data. Similarly, the substance-based chain has a quick flow for immediate testing used for treatment and a slow flow used for research. This entails that the level of certainty produced also has to do with the time available to do make the translations needed to do so.

Translations are facilitated by mechanisms such as the standardized IDSR guidelines, the CSF testing technology, and the standardized forms. These mechanisms carry very specific inscriptions to support the translations taking place in the network. Other mechanisms are the training of health staff, the definition of the organizational hierarchy and the distribution of health and testing facilities across the country. Normally inscriptions are seen as the means to direct use of tools and technologies. What is interesting to add from this case is that tools, such as mobile phones and excel spreadsheets, that do not hold hard inscriptions enables a flexibility to the translations that ensures the flow of the translations in cases where it would otherwise be blocked.

Altogether, this network composes the epistemic cultures of meningitis surveillance. Analyzing such epistemic cultures shows that providing information for action is also about how the information is produced by people, tools and technologies. It shows how representations of the world are not separate from the world they describe but instead are derived from the world that they also shape through a direct line of chains. The analysis underscores that information is not something waiting to be picked up and used, instead it needs to be made available. That is the role of an epistemic culture, and the working of this culture determines what information is available.

7 Conclusion

By tracing the production of meningitis related information in Burkina Faso through the concepts of epistemic culture and circulating reference, we have been able to unpack the “how to know” in disease surveillance and response. Our analysis shows that not only is the epistemic culture for knowledge for better health shaped by multiple rationalities among the stakeholders, it is also shaped by the material nature of the data at its origin and the tools and techniques required to handle this data. Thereby we become able to add two factors that contribute to our understanding of how knowledge for health is created. The first factor is that the practices for handling and producing data vary greatly depending on the physical origin of the data – whether the data is based on substance or on information. The second factor is that time, or temporality, also affects our ability to know as it affects the efficiency of the data production and thereby the degree to how precise the knowledge is in its depiction of the world. In summary what health workers and health managers are able to know is strongly dependent on the nature of the epistemic cultures that support knowledge production.

Our analysis highlights that separate data streams not only exist between different health programs, but also appear within single disease specific health programs, such as that of meningitis. This finding carry practical implications for the development of health information systems support to the disease surveillance system in Burkina Faso. For example while it appears that there should be something to gain from integrating some of the many national level databases and stand-alone databases that hold meningitis related data, this should not be done without considering the production of data, as well as the trade-offs between precision and timeliness. For Information Systems researchers the findings underscore that providing information for action is about making different information available to different stakeholders across the health sector, and that this is also a question of the making of this information. Viewed in this perspective, integration of health information systems becomes not only a challenge of integrating disease specific systems and the multiple rationalities they entail. It is also a challenge of integrating different epistemic systems.

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Appendix 3: Paper 3

Disease surveillance and response in conditions of uncertainty: The case of 'palu dengue' in Burkina Faso

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Abstract: Information systems tend to be designed under assumptions of rationality towards their design and use, typified by the statement "information for action". Rationality implies the quality or state of being reasonable, based on facts or reason. It conditions that we know what information to collect for what action. However, reality may be different. In the case of emerging diseases we might not know in advance what is the disease we are trying to tackle and what information is needed to deal with it? In other words, what do we do in such conditions of uncertainty or not-knowing? Given that this is not an uncommon situation in the context of disease surveillance in developing countries, we explore this situation through three key questions: what conditions contribute to uncertainty?; how do health functionaries act in such conditions?; and, what is the role of HIS in identifying (or not) conditions of uncertainty and dealing with it? The empirical analysis is based on a longitudinal study of the disease surveillance system in Burkina Faso, with a particular focus on a dengue outbreak in 2016, when the health system did not have the resources to identify and treat the dengue disease immediately. Our analysis identified reasons contributing to uncertainty including lack of prior experience, inadequate resources, ill-designed protocols and institutional constraints. To deal with these conditions, health staff relied on improvisations such as making exclusions, exchanges through social relationships, and structuring practices informally. In conclusion, while HIS do play a key role in conveying information, there are limits to what they can do. A key implication concerns making HIS to have more "open spaces" to flag unusual events or unknowns. We argue that uncertainty should not only be seen as a condition to be eliminated, but instead as a resource in aspiring for a more positive future.

Keywords: Disease surveillance, Developing Countries, Uncertainty, Dengue, Health Information Systems

1 Introduction

The assumption that better information will lead to better decisions for improvements in health services is often repeated when new Health Information Systems (HIS) are introduced. However, the quest of information for action reflects a rather simplistic assumption regarding the rationality of health staff on how they make decisions in their daily work. The lack of success of many of these technological introductions for better health tend to challenge the inherent assumptions of rationality (Sahay, Sundararaman, & Braa, 2017).

Many disciplines such as sociology, organizational studies and behavioral economics have dealt with the concept of rational behavior and shown in different ways that rationality is often bounded due to lack of or incomplete information, absence of previous experience, or poor understanding of factors to take into account, as well as potential outcomes. Drawing from discussions in organizational studies, Sahay et al. (2017) have identified various reasons as to why assumptions of rational decision making do not hold in everyday organizational work, such as due to bounded rationality, resource dependence, the politics of information, and various others. Despite such insights, HIS tend to be repeatedly introduced with the information for action paradigm as a driving motivation. Consequently, the introduction of various new ICTs such as the mobile phone comes with a promise of providing more information for action faster and more efficiently.

Often an initial response to challenges of incomplete information is to develop models that account for this uncertainty and seek to eliminate it, or simply omit it. Such modelling is also a strategy of many public health interventions, which HIS are eventually designed to support. However, insights from medical anthropology show that the provision of health care services in low-resource settings often is taking place under conditions of significant uncertainty, prevalent in daily life including in the provision of medical care.

Appadurai (2013) revisits the American sociologist Frank H. Knight's work to distinguish between risk and uncertainty. Risk is associated with situations with unknown outcomes but where there are recognizable factors that need to be taken into account. In contrast, in conditions of uncertainty knowledge of factors to be accounted for is largely absent. Appadurai argues that this definition of risk has been an underlying principle in modernity exemplified by modern capitalism incorporated in financial models, where uncertainty on the contrary has been absent. He welcomes a discussion in the sociology of finance on how to approach the understanding of uncertainty. We believe a similar discussion is relevant in HIS design where there a similar tendency to focus on the elimination of risk and the assumptions of certainty, rather than trying to manage under conditions of uncertainty. In this paper we take up this invitation, and address the question of uncertainty in relation to information systems for supporting disease surveillance and response. We study this in the context of a dengue outbreak in the West African country of Burkina Faso.

The fact that epidemics do not know borders has for a long time made disease control a question of global concern (Zacher, 1999). Recently, large-scale outbreaks have underscored the relevance of this question and led to increased global efforts towards strengthening of disease surveillance and control including building HIS to improve information for public health action locally as well as globally. A central idea in surveillance and response is that availability of epidemiological information on potential outbreaks will lead to public health action being taken in time to prevent outbreaks and mitigate their adverse consequences. This assumption resonates with a central idea behind HIS that health systems and health service delivery can be improved through decisions based on timely and accurate health information. Supporting the IDSR (Integrated Disease Surveillance and Response) information flow electronically through national HIS appears to be a promising way to support decision making by optimizing the speed and quality of data transmission and making the data available faster to those making the central decisions. Such efforts are currently being undertaken in Burkina Faso, but also in various other countries across Africa and Asia.

Many HISs face challenges when it comes to practically promoting data use to strengthen health services delivery (Sahay et al., 2017). However, while it is largely agreed that it is problematic if health information is collected and gathered but not used, it is more challenging to be specific about what the use of information actually entails. Sometimes information use is viewed as the processing of the information and the actual creation of information products such as reports. An example of such a conception is the TALI tool (Braa & Sahay, 2012), which seeks to make information use measurable, but does not fully capture whether the information is used for other purposes than simply demonstrating that it is being handled and work is being done (Mosse & Nielsen, 2004). It has been argued that information use is not only about focusing on the end products, but involves the entire process from collecting data, putting data into context as information to knowledge, to knowing and to action (Kelly, Noonan, & Sahay, 2013; Lewis & Sahay, 2009; Sahay et al., 2017). Such processes, however, are often depicted as linear (Gonzalez-Zapata & Heeks, 2015) or circular (Braa & Sahay, 2012). While these depictions capture the many steps involved in data processing and use, they remain rather general and do not attribute attention to details on what kind of action the data ultimately should support. Furthermore, they appear to build on assumptions of rationality reflecting a linear relationship between data, information and action.

The analysis presented in this paper draws both on longitudinal fieldwork on the disease surveillance and response-related information system more generally in Burkina Faso as well as a more in-depth exploration of an outbreak of dengue in 2016. According to the World Health Organization (WHO) (WHO, 2017a) the dengue outbreak slipped the attention of the health system due to insufficient dengue surveillance despite the existence of the IDSR information system. The paradox in this slip of attention lies not so much in the fact that it happened, delays are not unusual when it comes to detection of emerging epidemics (Hewlett & Hewlett, 2007; Mondor et al., 2012; Zacher, 1999). Rather it lies in the fact that although information about a new disease was present in the health system already in August, the outbreak was not officially announced until late October when the number of cases had risen to the highest level ever seen in Burkina Faso.

This gap between information and action indicates that, also in disease surveillance and response, it is not only the availability of information that determines action. Health workers engage in practices of handling the outbreak without knowing what it is. Such practices are in contrast to the assumptions made in the design of the system.

The paper is organized as follows. In the next section we develop our theoretical lens through a discussion of how rationality and uncertainty has been dealt with in other domains. These readings help us to introduce the concept of conditions uncertainty within the practices that HIS should support. Next the empirical approach and methods are outlined, followed by the case and analysis. We conclude with a discussion of what the notion of uncertainty can offer IS and HIS theory and practice.

2 Theoretical lens

This section consists of four main parts. In the first, we seek to understand uncertainty, drawing particularly from social sciences and behavioral economics. Our focus is on understanding what conditions contributes to uncertainty and how do people try to deal with it. In the second, we seek to understand the role of uncertainty in shaping public health practices, including relating to public HIS). In the third, we outline our perspective to empirically study HIS and uncertainty in the context of disease surveillance in developing countries, with a particular focus on Burkina Faso. Finally, we summarize the analytical framework adopted in this paper.

2.1 Understanding uncertainty

The notion of uncertainty has been discussed widely in domains such as social sciences, behavioral economics, organizational sociology and decision sciences. Notions of uncertainty are often tied up with those of risk, rationality, or the lack of it, on how people make choices. A recent example of this line of thinking comes from 2017 Nobel Prize winning economist Richard Thaler who has argued that "*Supposedly irrelevant factors, or SIFs, matter a lot, and if we economists recognize their importance, we can do our jobs better. Behavioral economics is, to a large extent, standard economics that has been modified to incorporate SIFs*" (New York Times, 2015). Thaler argues that the basic assumption of rational behavior is challenged because humans have cognitive limitations, particular social preferences, and a basic lack of social control. While risk is associated with dealing with conditions of "bounded rationality" (Simon, 1957), uncertainty points to something which is more generally unknown, rather than being known to a limited extent.

Appadurai (2013) argues that uncertainty is a concept that ought to be further explored in the social sciences, and treated an "anthropology into the future". He argues that social science, and in particular anthropology, has been characterized by a sense of pastness, which has been a consequence of the critiques of modernization and its ideas of change and progress. Consequently, social science has been challenged to build views on the future which, Appadurai argues, has left us only with rational choice theory which, despite its limitations, is concerned with the future. He challenges academics to reflect on how anthropology can become a science of the future instead of a science of the past.

"*Here I will simply state that this ethical commitment is grounded in the view that a genuinely democratic politics cannot be based on the avalanche of numbers – about population, poverty, profit, and predation – that threaten to kill all street-level optimism about life and the world. Rather is must build on the ethics of possibility, which can offer a more inclusive platform for improving the planetary quality of life and can accommodate a plurality of visions of the good life*." (Appadurai, 2013, pp. 299-300)

In this way, Appadurai talks about aspirations and hopes, as in what we desire, instead of fears and risk, as in what we are afraid of. The ethics of possibility instead of ethics of probability. In pursuing this agenda, Appadurai revisits Weber and his reading of Knight and the influence of his work on finance, where risk has been given a much more prominent role than uncertainty in accounting because it is, exactly, easier to account for (Appadurai, 2012) and also has become a key driver of capitalism. Uncertainty is both a common and highly context specific feature of life, stemming from its unforeseeability, which is determined both by events beyond our control as well as the (unintended) consequences of the choices we make (Appadurai, 2013; Giddens, 1984; Whyte, 1998).

Behavioral economics seeks to understand the nuances of why people act in certain ways, with limited rationality. Some powerful scholars such as Simon (1957), Tversky and Kahneman (Kahneman, 2003; Tversky & Kahneman, 1974) and Thaler and Sunsteing (2009) have emphatically established that humans being humans have unpredictable and "non-perfect" ways of making choices. These scholars have placed behavioral psychology within economics and challenged the idea of rational behavior by showing how different types of heuristics, biases, mental shortcuts, and framings of questions shape or disturbs our ability to judge risk or choose what would normally be regarded as the best option (Kahneman, 2003; Tversky & Kahneman, 1974).

Rationality is also challenged by the notion of unintended consequences of arguably well-considered actions. Different accounts have been provided for these unintended consequences. The German Sociologist Ulrich Beck in his "Risk Society" thesis (Beck, 1992) has argued that the agenda of modernity is inherent with unintended consequences, which will grow exponentially and at a faster rate than intended consequences. The hope that modernity would overcome the chaos of nature is bound to fail, and attempts to control nature will only lead to more chaos and uncertainty, which Beck exemplified through the phenomenon of pollution. Beck called this new modernity 'reflexive', in that the impact of actions determined largely by politics would rebound upon us, interfering with our original aspirations, and unknown risks will grow exponentially with time. In contrast to Beck who took this macro societal view, Giddens (1984) argued for unintended consequences from the perspective of individuals. He argued that human agents are by definition reflexive, knowledgeable and continuously monitoring their own actions and that of others. This reflexivity leads individuals to revise their practices, aimed at ensuring ontological security, contributing to consequences that are unintended when compared with the original aim of the action.

From these brief readings above, we can argue that uncertainty can be experienced by anyone, anywhere and at any time. However, some contexts experience more uncertainty, as is closely linked to living conditions and societal structures which determine the type of resources that can be drawn on to handle uncertainty (Farmer, Kleinman, Kim, & Basilico, 2013; Haram & Yamba, 2009). The availability of such resources, including knowledge and technology, varies greatly from place to place, and that is what makes uncertainty specific and situated. Everywhere people are working hard to reduce uncertainty in their private and professional lives, but since the means to do so varies, different strategies are developed in varying contexts. Some take a reductionist approach focusing on minimizing risk or creating transparency for choices. Others take a contingency approach, where uncertainty is not per se avoided, but instead articulated, taken into account and maybe even seen as a resource for engaging in change (Appadurai, 2013; Cooper & Pratten, 2014; Whyte, 1998; Whyte & Siu, 2015). It can be inferred from Giddens that humans establish routines in their everyday lives in an effort to deal with uncertainty: "*Routinized practices are the prime expression of the duality of structure in respect of the continuity of social life. In the enactment of routines agents sustain a sense of ontological security*" (Giddens, 1984, p. 282). At the level of organizations, there are varying power structures and resource dependencies and how these unfolds in everyday work shape conditions of uncertainty (Perrow, 1986).

2.2 Uncertainty, public health and public HIS in low resource settings

Public health systems in developing countries are pregnant with uncertainty, where living conditions and delivery of health services are influenced by poverty, risk of armed conflict, variability of infrastructure, and weak governments public sectors (Farmer et al., 2013). As a result, health workers have to deal with multiple contingencies, not just those directly related to care provision which often can compromise the health of populations. Patients can often not be sure that health clinics can deliver what they need, and "*caring for a sick child becomes a routine based on uncertainty*" (Østergaard, Bjertrup, & Samuelsen, 2016; Samuelsen, 2004). There tends to be inadequate provisions to protect health workers during work in epidemics as dangerous for the health personnel as the 2014-2016 Ebola outbreak was (Østergaard, 2015).

Uncertainty and its relationship with human practice has been widely dealt with in medical anthropology, however not often distinguished from risk (Haram & Yamba, 2009; Whyte & Siu, 2015). Various accounts have been provided of uncertainty from the health domain in Africa, with an interesting caveat being that it is not something to be identified and avoided, but can also serve as an important resource to enable change (Haram & Yamba, 2009). Uncertainty, coming from a complete lack of information and a state of not-knowing (Last, 1981; Street, 2011), is dominant in low resource settings where resources and diagnostic capacities are severely limited (Street, 2011). Based on empirical work in hospitals in Papua New Guinea, Street argues despite conditions of uncertainty, basic principles of Western medicine are followed. She goes on to argue that knowing and not-knowing do not exclude each other, but are interdependent and interchangeable, and both can be used as valuable resources in the provision of care.

Uncertainty also comes from the lack of experience with a phenomena, such as emerging diseases like cancer not expected in a specific context (Livingston, 2012). When resources, both diagnostic and medical, at the same time are limited, strategies to handle them build on improvisation (Livingston, 2012). In developing countries, there is often the lack of technologies required to produce the necessary knowledge to support clinical decisions (Street, 2011). In her work on Malawian medical students Wendland (2010) observes a mismatch between the technology the medical students learn about in their textbooks and what they find available and functional when engaging with clinical practice. She observes that while American medical students tend to be more scientific, mechanistic, and reductionist, the Malawian medical students draw upon different values of social engagement. They see themselves as working for the service of the people of Malawi, for a collective good rather than for an individual. They employ some kind of activism to cope with the circumstances they encounter which are very different from what they have learned in their textbooks. Adhering to scientific principles of medicine also compels doctors to hide uncertainty, as it is incompetent to display that you do not know. "*Students don a "cloak of competence" even when they do not feel competent, to mask uncertainty, consolidate status, and demonstrate authority. They routinely pretend to greater knowledge, experience, and certitude than they actually possess. This cloaking increases in the clinical years, as they negotiate between their own inexperience and their need to demonstrate the technical ability (and the eagerness to intervene) that will mark them as real medical professionals*." (Wendland, 2010, p. 20).

Whyte (2009) describes uncertainty, insecurity and contingency are part of the unforeseeability of life in rural Uganda. She defines uncertainty as a state of mind, insecurity as a social condition, and contingency as being interrelated or dependent on others (Whyte, 2009). Contingency, implies relations as well as time and process, with an underlying positive tone: "*To be contingent upon persons or happenings that cannot be fully foreseen is to lack control and be subject to uncertainty. But to try to create contingencies in the sense of making connections to possible forces for improving security is to attempt to move an uncertain situation towards greater confidence*" (Whyte & Siu, 2015, p. 19). Contingency reflects a more dynamic concept than uncertainty, and indicating more than just an absence of, through the exercise of agency of actors who are not mere spectators (Whyte, 1998).

Given that there are so many conditions contributing to uncertainty and so little resources at hand, it becomes not possible to rely only on strategies to reduce uncertainty. Wendland (2010) critiques how the identification of such conditions can lead to conclusions of living in the past, rather than the future which is uncertain. Instead, she argues, we should focus at the reimagining the underlying practices of how we do knowledge work in settings that constitute everyday reality. Uncertainty she argues should not be sought to be avoided, rather embraced as a driver of change. Wendland's argument is especially relevant in the case of epidemics of infectious diseases, where we tend to depend on grossly inadequate statistics and more hard data, over insights from social sciences (Farmer et al., 2013). Outbreak situations are characterized by high levels of dynamic complexity and uncertainty, requiring emphasis on sense making and collective minds (Weick & Roberts, 1993) as means to "organize doubt" and guide required action despite the unknowns (Kramer, 2007). With recent outbreaks like of Ebola in West Africa, the recognition of the contributions from social sciences have started to grow (Abramowitz et al., 2015; Feierman, Kleinman, Stewart, Farmer, & Das, 2010; Hewlett & Hewlett, 2007). However, whilst dealing with uncertainty, the dominant approach still remains the development of more sophisticated tools such as forecasting models, early warning systems, and formalized infrastructures (Heymann, Rodier, & WHO, 2001; Li et al., 2017; Liu, Poccia, Candan, Chowell, & Sapino, 2016).

Health information systems in the context of public health in developing countries can broadly be argued as being quite inadequate in supporting the management of uncertainty, and to be even quite poor in dealing with certainty. A mass of literature on HIS in developing countries over the last two decades have pointed out to the inadequacies of routine reporting systems, which by definition seek to provide conditions of relative certainty in terms of what data should be reported on, the periodicity of these reports, and from where they should come from. HIS development in low and middle-income countries (LMIC) have historically been linked to the domain of public health, which relies strongly on health statistics to provide measures to guide analyses of health sector and services (AbouZahr & Boerma, 2005; Lippeveld, Sauerborn, & Bodart, 2000) with a strong focus on the measurable (AbouZahr & Boerma, 2005). This connection has made HIS powerful tools to support management of the health sector in countries (Madon, Krishna, & Michael, 2010). With the introduction of global data driven agendas such as the Millenium Development Goals, HIS has also become an important resource on the international scene (Travis et al., 2004). The scale of these agendas have furthermore strengthened the focus on the measurable and the role of HIS.

Over the last decade, many countries have been able to tackle many challenges to HIS development and implementation. For example, as many LMICs now own and control their national HIS repositories, they are also in charge of their own data (Sahay et al., 2017). Country HIS have become a steady source of country-wide health information with routine data flowing on a regular basis from the peripheral to national levels. These advances have been driven by innovative and networked approaches to HIS development and sustainability (Braa, Monteiro, & Sahay, 2004), as well as responsiveness to new technological advances such as diffusion of mobile phones (Asangansi & Braa, 2010) and internet, as well as cloud computing (Denis L. Adaletey, Olav Poppe, & Jørn Braa, 2013).

While welcoming these improvements in HIS in developing countries, we argue that there is still a long road to cover when we talk of supporting situations, which are rife with uncertainties, such as related to disease surveillance and response. As infectious diseases, including neglected tropical diseases (NDTs), constantly develop and change in unexpected ways (Heymann et al., 2001; Michael & Madon, 2017), uncertainty is an unavoidable part of disease control. The challenge is to find ways to recognize it and to deal with it. A common approach seen within HIS design in such contexts of complexity is that uncertainty is dealt with as imperfection and poor numbers, which is seen to be accounted for by bringing in new data collection technologies, such as the mobile phone and social media, and thereby new methods, such as big data based scientific techniques. There are even questions being raised whether the use of these modern methods will imply the “death of epidemiology” with the epidemiologist being replaced by techniques of correlations and machine learning driven on big data (Sahay, 2016). Such trends signal the reverse of emphasizing of the social in favor of more reductionist approaches.

In this paper, we argue that HIS can indeed play an important role in supporting the management of disease surveillance, but the approach to its design and use needs to be radically reconsidered. We believe aiding this can be a social science based understanding of uncertainty, complementing its design and use. Drawing from medical anthropology, we argue rather than viewing uncertainty as a constraining factor, we should try to view it as an enabler of change (Appadurai, 2013; Whyte, 1998; Whyte & Siu, 2015). This will require an acknowledgement of what HIS can do and cannot do, and reflect these assumptions into design and development processes. These, we argue, are empirically grounded questions, and in our next section we outline our approach to the same.

2.3 Studying uncertainty: a practice based lens

Sociology, by its very nature, does not subscribe to generalizable facts. It is occupied with meaning and understanding societies and people. The main focus is on the setting people live and work in and the practices they adopt to go about their every day tasks. Social realities are seen as becoming constructed by people, their actions, and the settings they take place in. Such mutual constitutive processes are also referred to as the practice perspective (Nicolini, 2012).

How do individuals and collectives deal with uncertainty? This become an empirical question, since such strategies are not written down and explicit but manifested in social and professional practices.

Practice theory is concerned with bridging knowing and doing (Nicolini, 2012; Schmidt, 2014). Such bridging is seen in the concept of agency, which is the ability of human agents to act and make decisions. It is about the resources one poses to do so rather than the will (Giddens, 1984). Structuration theory regards all people being knowledgeable actors, who then are aware of the actions they take and the consequences of them. This is not the same as saying that people are solely responsible for the consequences of all their actions, as Giddens also stress that this knowledge is bounded by both what we not aware of as well as the unintended consequences of action. In this way structuration theory stress that people are knowledgeable, but it does not claim that they know everything. Rather, not-knowing is part of everyday life. What practice theory offer is not so much this insight, but a way to account for it by studying what people do, for example when they work. Practices are the manifestations of how people build bridges between what they know, or do not know, and what they do (Schmidt, 2014). In this doing, uncertainties become accounted for and handled, but not necessarily consciously and therefore practices become highly interesting fields for identifying and understanding uncertainty. We lend the definition of practice from Schmidt who states that: "*the point is that work, when conceived of as a practice, is not reduced to mere activity, more or less regular sequences of operation, but is taken to also encompass the ways in which workers competently handle contingencies and variations, ensure orderly alignment of their distributed activities, as well as sundry intellectual activities such as envisioning the outcome, devising methods and plans, identifying tasks, preparing and allocating tasks, etc*." (Schmidt, 2014, p. 429)

However, to be able to articulate work practices, specific examples are required. We are interested in knowing more about these unacknowledged conditions manifest themselves in the specific organizational context of the health system of Burkina Faso. Seeing and articulating such strategies requires that we as researchers immerge ourselves in the settings we wish to study. This follows a tradition in CSCW and STS were tools from the ethnographic toolkit are used to better understand work practices and the role of, or the place for, technology in these practices (Blomberg & Karasti, 2013; Mol, 2008). An advantage of the practice perspective is that it is a way to start with the human processes rather than the technology (Jones, Orlikowski, & Munir, 2004; Orlikowski, 2002; Schmidt, 2014; Walsham, 2001). Off course there is then a risk of losing sight of the technology but in a context such as the health system in Burkina Faso where there is not yet an HIS in place to support disease surveillance and response exploring existing practices and existing tools is valuable to inform design of the eventual introduction of the HIS.

2.4 Summing up: Keys concepts underlying our analytical framework

By definition, uncertainty cannot be determined in advance, as it concerns the unknown and unexpected. The research challenge then becomes the need to understand what conditions contribute to uncertainty, and how do people understand and deal with it, and what is the role of HIS in shaping these dynamics. Understanding uncertainty in practice requires empirical studies of what people do in situated contexts and the resources they rely on to conduct their everyday work. However, dealing with uncertainty in daily work of health care, requires more prospective strategies and improvisations. Important, arguably, is the ability to understand a situation where we do not know, and the reliance solely on numbers to a large extent becomes irrelevant. The totality of the situation needs to be taken into account, and how the everyday experience of doing work helps to get you through situations even when you do not know. Our research seeks to understand these practices of how people identify and understand uncertainty, and organize their everyday practices to deal with these conditions.

Disease surveillance related HIS in low-resource settings are viewed as a socio-material system of collective work, and it is useful to conceptualize uncertainty as a phenomena, which is experienced through individual as well as collective practices. Conditions of uncertainty are often characterized by a complete or partial, lack of something, such as experience, information or choices. We take Appadurai's view of seeing uncertainty through the lens of aspirations and hope which carry with it the potential of change, rather than as a feeling of insecurity and fear experienced by individuals. Since we view uncertainty as conditions for action that occur from circumstances of not-knowing, which is different from not doing, conditions of uncertainty affect the decisions, people make, just like information does. Unlike information that can be measured and accounted for, the unknown tends to be ignored or not articulated in guidelines for practice as well as in HIS development. We seek to not try to eliminate it, but instead to articulate it, to help understand the boundaries of action, and with it the possibilities to create new imaginaries of the future.

Conditions of uncertainty are context dependent and situated, being shaped by a range of structural factors, such as institutions, technology, and capacity. These conditions are emphasized in developing countries who are subject to significant resource constraints. Uncertainty is most often seen as a constraint, but arguably can also be see it as resource. Therefore handling it is not only about describing it but also about strategies to deal with it as it emerges. This requires special skills and mindsets that need to be supported.

The lens aims to place uncertainty in the domain of HIS by providing means to articulate conditions of uncertainty and place them into practices of information sharing and use. Equipped with this analytical lens, we hope to be better able to address the research questions of what conditions contribute to uncertainty. How do people deal with it? What can be the role of HIS in shaping and addressing uncertainty?

The empirical arena for our analysis is disease surveillance and more generally in HIS design and development. This is a task, which involves re-conceptualizing the linearity of the relationship between information and action, but taking steps towards their reorganization based on a practice based lens. It is challenging because the linear structure is intellectually comforting contributing to a sense of ontological security. Relationships are clear, where one step leads to the other, and it implies movement towards something new and improved. Factoring in uncertainty challenges this sense of comfort and security, and action is about identifying conditions of uncertainty and building practices that help to respond to the circumstances around you. While information plays a role in shaping these practices, they may not be explicit and formal, but rather based on relationships, prior experiences, and largely not explicit in nature.

3 Methods

This research aims at providing empirical insights from a situated perspective into the global agenda of disease control through improved surveillance. With the rise of global health efforts into large-scale programs such insights, usually obtained through qualitative research, are much needed in order to understand the social realities where interventions of surveillance and response are taking place (Feierman et al., 2010).

As the focus of the research is to understand the relationship between information and action, we have adopted a practice perspective for the research. This perspective allows us to focus on the relationship between what people do and the system(s) they are part of (Nicolini, 2012). Specifically, we wanted to understand work practices and the role information plays in shaping these practices, we adopted an interpretive approach to the research. Interpretive approaches build on the idea that people give meaning to the world they live in through their interpretations of their experiences. These methods give scholars occupied with human interpretations and meanings a base for doing so

(Walsham, 1995). Interpretive methods are rooted within ethnographic and anthropological traditions where data gathered through interviews and observations are viewed not as facts per se but as constructs of the informants and reinterpreted by the researchers based on their notes, observations, discussions and photographs (Walsham, 1993). These assumptions support an interpretive analysis of the context of human interaction through information, which is what disease surveillance and response ultimately is about. Also, a practice perspective is relevant since uncertainty cannot by definition be pre-determined, and only an interpretive lens (Walsham, 1993) helps to understand what people see and do in context.

Both researchers are part of the health information systems (HISP) action research program, which aims at building sustainable HMIS for low-resource setting through the development of the DHIS2 software through global networks of action (Braa et al., 2004). DHIS2 was implemented in Burkina Faso in 2013, and the research has been carried out in an after implementation period, where no specific implementation activities were carried out.

3.1 Data collection

Prior to data collection, the research was approved by the Ministry of Health (MoH) in Burkina Faso, and access was granted by the Secretary General, MoH. Consent, oral or written, to participation was furthermore obtained individually from each of the participants prior to interviewing them. They were promised of complete confidentiality of their responses.

The paper presents an in-depth case study of the dengue outbreak in Burkina Faso in 2016. In order to place this very particular case within the health sector context in Burkina Faso in general and the disease surveillance and response system in particular, the study also draws on data from a longitudinal study of use of health information and IS design in the health sector in Burkina Faso. Below we present a schematic time line of the research.

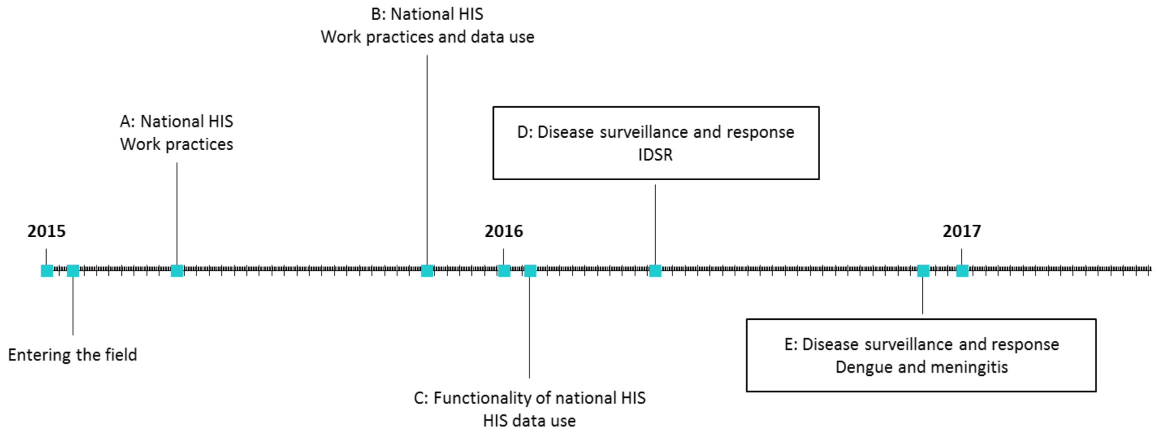


Image 1: Time-line of fieldwork

The table below summarizes the key activities undertaken during each period.

	Key activities	**Area of focus**	**Organizational level**
A+B	Participant observation	Work practices of configuration and national level data use	National (IT department and statistical department)
	Interviews and observations	Data collection and processing	Regional, District, Facility

C	Interviews with health program directors	Evaluation of functionality and the use of data from national HIS	National, Regional, District
D	Interviews and 4 weeks observations of work practices in two districts	Work practices in disease surveillance and response, IDSR in general.	Regional, District
E	Interviews and observations	Work practices in disease surveillance and response, dengue and meningitis.	National, Regional, District, Facility

Specifically, we draw on the data collected during two periods (D and E) for this analysis. The first period (D) was an open-ended study of practices of disease surveillance and response more generally without a focus on any specific disease. The second period (E) followed immediately after the 2016 dengue outbreak carried out in the capital of Ouagadougou where a majority of the dengue cases was reported from August 2016 through to January 2017. Two other regions reported some cases during this period. With 1061 probable (RDT positive) cases out of 1266 suspected cases, and 15 reported deaths, the central region was the main site of the outbreak. This outbreak provided an empirical site to study the role of information in the detection and management of the disease. It must be pointed out these figures come primarily from the public sector facilities and do not include the private sector, who typically do not report. The empirical research also focused primarily on the public sector reporting.

The aim of doing the fieldwork was to understand the time lag between when the first cases began to appear until the official declaration of an outbreak was made by the ministry. The time lag begged the question of why available information was not used, although it was available? To try to answer this question, we collected data through interviews, observations and document analysis.

The interviews were done between January 2016 through June 2017. They involved health workers and managers at facility, district, regional and national level. The table below summarizes the interviews done in these two periods including the type of health functionaries we met, and also the different administrative levels at which they operated.

	Health workers	**Managers**	**Data managers**	**Directors**	**Other**	**Total**
Facility	3	5				**8**
District	5	3	7			**15**
Regional	1	2	2			**5**
National			5	10		**15**
Academic					4	**4**
International		1			4	**5**
Total	**9**	**11**	**14**	**10**	**8**	**52**

Table: Number of interviews done and corresponding level

The majority of the interviews were done using semi-structured questionnaires. In the first period (D), we asked about with the general functionalities of the disease surveillance and response system, while the second period (E) focused on the dengue outbreak, primarily seeking to understand what information was available to whom and what they did with it during the initial period of the outbreak. After each interview, notes were taken in order to keep a record of key points and to track observations such as the physical setting and the reactions of the respondents during the interview. All interviews were recorded and transcribed, except in very few cases where the interviewees refused to be recorded. Not included in the table are informal interviews and talks done with health care workers during observations or on site-visits.

Further, in the second phase interviews were carried out very soon after the outbreak became publicly announced, which ensured a fresh memory of actions and response, which otherwise would have been hard to obtain (Rasmussen, 2017). However, talking about the lessons learned in an environment where the system has not performed optimally (LeFaso.net, 2016a, 2016b, 2016c) was at times sensitive to discuss for some interviewees. In order to respect this sensitivity, we have anonymized the research sites and identity of interviewees.

Various secondary data, such as disease surveillance bulletins, site investigation reports, directives, case notification sheets, and newspaper reports were also studied. Taken together, these sources gave important clues both about the formal practices or directives for surveillance and response; the type of information that was processed in the surveillance system – including the specifics of the practices concerned with data collection and dissemination (weekly reporting, case notification sheets, and site investigation reports); and the official communication about the outbreak (newspaper reports). All together the data from these sources were also helpful in building a narrative of the events during the timeline of the outbreak.

3.2 Data analysis

Due to the longitudinal character of the fieldwork, analysis and data gathering were carried out in an iterative and ongoing process, which allowed for some ideas and themes to develop based on the first round of interviews and to be then explored further in later interviews. For example, in the initial period, a question was how the staff gets prepared for something largely unknown, such as an epidemic. Nevertheless, it was not until the dengue outbreak emerged, we could observe and engage in conversations on what people did in such situations. The longitudinal timeframe also made it possible to return to some participants to follow up on details or to get confirmation of the initial interpretations made. An example of this was the timeline of the outbreak detailing the availability of information as well as the actions taken. A rough sketch was developed after the initial interviews, which were detailed and sharpened in subsequent interviews.

All interview transcripts and observation notes were coded using a qualitative software (NVivo). The initial coding process was open-ended to allow the data to "speak for itself", and for new themes to emerge. The codes were used to map the practices and to establish patterns, or particularities of the different elements of practice. Many codes concerned information and practices.

For example sequences coded as "data quality", "diagnostics", "processes for validation" where pointing towards themes such as reliability or availability of data. When further analyzed it often seemed to be the case that information was only partially available. With these themes in place, an experienced lack of information could be identified and related to the concept of not-knowing from the theoretical findings. Leading to the identification of not only lack of information but "not-knowing" as an observed condition of uncertainty. Another example was codes used to describe the practices health workers engaged in. Such codes could be "Being prepared", "bottlenecks", "experience", "knowing what to do", and "guidelines". These codes led to the identification of the theme "knowing-in-practice", which would be guiding the analysis of engaging in practices that have not been experienced.

The challenge of coding is that the data becomes deconstructed into a large number of small pieces that through the loss of contextually and relations removes the analysis from the field. Such process of reduction and abstraction are necessary parts of the analytical process. However, following one of Myers and Klein's (2011) principles for interpretive research the micro and the macro should be related throughout the analysis. Placing the themes back into the context became an issue of creating thick descriptions, which are important to develop understandings of what people do in a specific context (Walsham, 1993, 1995). From the field notes based on observations small descriptions of key situations or functions of the surveillance and response system were developed. These descriptions were used to build the narrative of the case study, which was crafted so it would display the events in a chronological order but still under the developed themes that would allow for conditions of uncertainty to be described.

As the findings were emerging in these various forms, they were continuously shared and discussed between the two authors of this paper, and with other colleagues.

4 Case context

4.1 Burkina Faso: Risk and health

Burkina Faso has been known as a politically stable country despite its high levels of poverty. During his 27 of rule, former president, Blaise Compaoré, managed to steer the country free of other conflicts in the region. In 2015, there was a successful popular uprising against Blaise Compaoré, leading to his resignation and ultimately a transition to democracy through peaceful elections for a new government. In recent years, however, the political instability in the neighboring country of Mali has started to spill into Burkina Faso. Areas along the Malian border are especially affected by small but frequent extremist attacks on public services such as police stations and schools, leading to great uncertainty amongst the population about their future. The capital of Ouagadougou has also seen two larger terror attacks in the past one and a half years, targeting mainly Westerners, adversely affecting tourism, leading to loss of employment and business opportunities. These contribute to a general uncertainty about the future.

According to the UNDP Human Development report Burkina Faso is among the lowest ranked countries in the world, with up to 40 percent of the population living below both national and international poverty lines (UNDP, 2016). Amongst adults, the biggest burden of disease are lower respiratory infections and malaria (WHO, 2015). Human resources for health are quite limited with for example one medical doctor per 15.836 inhabitants (Ministère de la Santé Burkina Faso, 2016). In contrast the are three to five medical doctors per 1.000 inhabitants in many European countries (WHO, 2017b).

Following recent large-scale epidemics in the West African region, there also has been a strong focus on strengthening surveillance and response capacity of the health system. Being located in the middle of West Africa, Burkina Faso borders six other countries, making it vulnerable to communicable diseases that easily can spread over the borders. Burkina Faso has responded to these threats by adopting both the IDSR guidelines as well as committed to the Global Health Security Agenda, emphasizing the “one health” approach (CDC, 2016). These commitments have led to a number of national and regional initiatives, including those to strengthen the HIS supporting disease surveillance and response.

4.2 The generic practice of disease surveillance and response

In the IDSR-guidelines, disease surveillance and response is defined as a core set of activities (Kasolo, Roungou, & Perry, 2010). These functions and activities are; Identify, report, analyze and interpret, investigate and confirm, prepare, respond, communicate and evaluate. They can be thought of as the generic practices underlying disease surveillance and response.

In a non-epidemic situation, the purpose of surveillance is to identify if there is an outbreak underway, identified through yes/no questions, such as are there any suspected cases of those diseases under surveillance? If the answer is “no”, an overview is made and reported, and no immediate action is taken. In the event of the answer beings "yes", the initial response required is to report the case to levels above and to determine the nature of the case. This implies gathering more information to confirm or not the suspect case, through additional testing such as for dengue, through a rapid diagnostic test (RDT) followed by a laboratory test. Other questions such as who is the population at risk, how well does the population know the protective measures to be taken or when to seek treatment, also need to be answered. Such information is gathered through site investigations, usually done by an investigative team visiting the facility where the suspected case was detected.

If the cases can be confirmed and a certain threshold is reached, an outbreak can be declared. Once officially declared, communication is with the public about the disease, what and how to be aware of the disease and the required reaction such as using anti-mosquito products also during the day and to destroy vector breeding grounds. Internally in the health system, communication concerns whether the guidelines are well understood and if there is the proper equipment to take care of the sick. In the case of dengue while the treatment is not curative but only symptomatic, it is important to ensure access to medical care including management of body fluids and level of blood platelets. These measures can potentially reduce mortality from 20% to 1% (WHO, 2017c). After an epidemic, the response is evaluated in order to determine how surveillance and response could be improved.

In Burkina Faso the health sector is organized at three levels; National, regional and district. The Ministry of Health at national level holds the central responsibility for the national disease surveillance and response. The National Directorate for the Fight against Diseases, DLM (Direction pour la Lute Contre la Maladie), is the focal point for the disease surveillance and response across the disease specific directorates. At the regional level, the responsibility is with the Office for the fight against diseases, SLM (Service de la Lutte contre la Maladie). At the district level, the district manager, MCD (Médicin Chef du District) is responsible for surveillance and response. Health districts are responsible for the functioning of the health centers, CSPS (Centre de Santé et de Promotion Sociale). In 2016, there were 1.760 CSPS across the country, each serving an average of 10.000 patients (Ministère de la Santé Burkina Faso, 2016). They are the primary entry point to the health sector for most of the population. There are data mangers, CISSE (Centre d'Information Sanitaire et de Surveillance Épidémiologique), employed at both district, regional and national level, but not at the CSPS.

In Ouagadougou where more people can afford paying for health services themselves, the private part of the health sector also plays an important role, and there exist a number of private clinics and laboratories, both for profit and non-profit. Laboratories share premises and management with a clinic or a district, but are mostly managed independently. Laboratories are organized under another directorate at the Ministry of Health; The Directorate for laboratories and pharmacies, DGPML (Direction Générale de la Pharmacie, du Médicament et des Laboratoires).

5 Findings

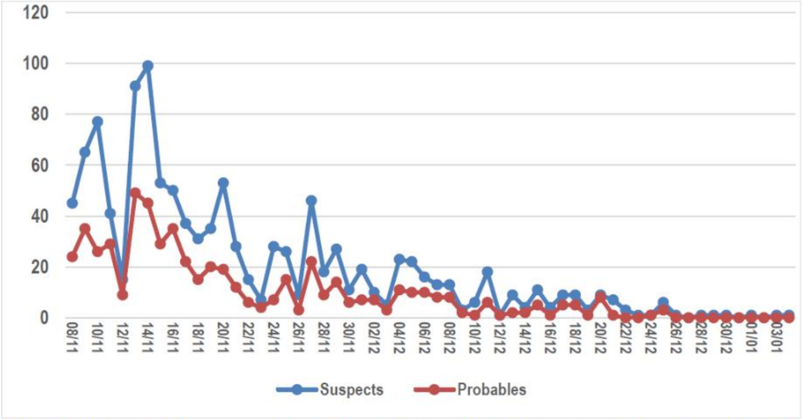
Although dengue is categorized as a neglected tropical disease, there is nevertheless a worldwide increase in cases (Herricks et al., 2017; Stanaway et al., 2016). The increase is biggest in Asia, but recently dengue has also started to develop into larger epidemics in West Africa.

In Burkina Faso, very few cases were detected since 1925, but since 2010 there have been cases reported, including a minor outbreak in 2013 (Ridde et al., 2016). The outbreak in 2016, however, was the largest to have ever hit Burkina Faso (ALIMA, 2016), but mostly confined to the Central Region and especially the capital of Ouagadougou (BBC Afrique, 2016; WHO, 2017a). With around

2000 registered cases and approximately 18 deaths, it was still relatively small compared to outbreaks that occur for instance in Asia. The dengue outbreak in Ouagadougou began to develop sometime between August and September, being officially declared in November 2016. By 2017, about four months after the first cases started to surface, the outbreak was under control. The curve of new cases had been broken in November shortly after the declaration and in January only very few new cases were detected. There existed a gap of about two months between the detection and reporting of cases. The timeline below gives a general overview of which information was available at what point as well as what action was taken during the outbreak. This is followed by a graph of the registered cases.

2016 **Before Aug**	**Aug**	**Sep**	**Oct**	**Nov**	**Dec**	**Jan**	**2017** **After Jan**
INFORMATION							
	* Some private facilities see rise in cases						
	Rumors from private sector are circulated						
	Reports of "palu dengue" on radio and TV						
		Public facilities see patients with unusual symptoms					
		Dengue suspected at public health districts					
			Dengue appears in MoH weekly bulletin by the end of the month				
				Dengue reported regularly			No new cases
							Evaluation with partners
							MoH continues analysis of outbreak
					Spraying of central sites in Ouagadougou		
					Number of TDR testing increases		
					National database established		
				* Outbreak officially declared			
				Assessments by district investigative teams			
				TDR being made available at some sites			
			Initial assessment by MoH and WHO				
			National committee to handle epidemics CNGE to meet regularly				
			MoH begins communication via the media				
			Dengue integrated in routine surveillance				
			New guidelines circulated				
			Training in regions and districts				
		Districts start to prepare and prevent informally					
Routine surveillance done via TLOH (dengue only part of monthly reporting)							
Research at selected sites							
ACTION							

Figure 1: Timeline of the outbreak



Graphique1 : Evolution journalière des cas de dengue dans la ville de Ouagadougou du 08 novembre au 04 janvier 2017

Figure 2: Number of new cases of dengue in Ouagadougou from 8th November to 4th January 2017. Source: MoH weekly report on dengue

It is interesting to note that the record of cases before the declaration is left out (prior to this date only cumulated data is available), as well as the drop that occurs is not long after the official declaration of the outbreak.

5.1 Giving the unknown a name

"The media, the radio, the TV, started to talk about cases of dengue. That there were some who had died. They explained that some had died from bleeding and so they started to suspect that there was a disease called the 'palu dengue'."

District data manager

Most interviewees stated that they became aware of the unusual situation when news of an unidentified disease causing high fevers had started to spread informally in Ouagadougou during August and September 2016. The uncertainty about what was going on led the public to employ the term 'palu dengue' (which translates to 'malaria dengue') to describe this unfamiliar disease. Later, when the cause of the outbreak was confirmed to be dengue, it was important that it should no longer be confused with malaria, and this term was refuted as a popular analogy in the media by the director of DLM at the ministry of health (BBC Afrique, 2016).

One national data manager explained that the radio stations, who ran programs where the situation was discussed by hosts with listeners calling in to voice their concerns, not only helped to inform about the disease, but also spurred a growing anxiety. High fever symptoms might not normally attract much attention in a country where malaria is endemic, but as the West African Ebola epidemic had emphasized, that high fever symptoms that could not be diagnosed as malaria or did not look like meningitis naturally caused concern.

As the disease started to manifest itself in Ouagadougou, the lack of ability to recognize it caused uncertainty among the population and also in the public health facilities itself. Health workers at the facility and district levels stated that although they did not know what it was in the beginning, they saw the symptoms being very similar to malaria, without it actually being malaria.

"Voila, before September there were often cases were we received a patient and treated correctly for malaria. Afterwards we send the patient to do a malaria control. The malaria was negative but the fever persisted. We tried to investigate to understand what was wrong, we did a review. But we didn't get the idea to search for dengue. [...] We thought about other things than dengue, it was new to us."

District head nurse

They realized this through a trial and error approach and noticed that in spite of high-fever symptoms and headaches the malaria tests were either negative, or as in other cases that the malaria treatment simply did not work. It was also clear that a lack of knowledge or awareness of dengue meant that this cause was not investigated initially.

Before the dengue outbreak, knowledge of dengue was limited to the national level. However, managers at some health districts, who were participating in a research project aiming at mapping the prevalence of dengue, also knew about the history and prevalence of dengue in Burkina. Apart from this, dengue was not widely known, either to the general public or to the staff at the clinics (CSPS) where majority of the patients are seen. This could be attributed to a lack of experience. If you do not know what to look for, how do you know you will recognize it, when you find it? This uncertainty created some of the initial difficulties with recognizing dengue, which created a series of unintended consequences.

5.2 The power and problem of protocols

"As we did not have the surveillance in our TLOH, we did not transmit data about dengue. It was malaria and so on."

National data manager

Not only was there uncertainty about what to call the disease, but also on how to report it. When the rumors began to appear, dengue was not included as a notifiable disease in the weekly routine surveillance system. For the thirteen diseases under surveillance, there are only two options to fill out; number of cases, and number of deaths. The national IDSR guidelines spell out definitions of what qualifies as a case, providing a reference for comparison with collected data, and for generating aggregate statistics and mapping prevalence. However, in a situation where the health system have to deal with an emerging disease, such as dengue, which they are not able to recognize, there is a need for a place to display this uncertain information. This information requires more solid knowledge than a rumor, and therefore it is not possible to record instances of "palu-dengue" or other non-identifiable diseases in the TLOH (expand). The TLOH actually does have a line labelled "Observations", which can be used for noting such other things, but we found it be not used.

"*From the beginning we did see some cases [of dengue], but we did not notify. Not until the district told us to report.*"

Facility nurse

In some cases, the lack of reporting was due to the limitations of the protocol, which only focused on the thirteen diseases. Simultaneously at the laboratories, the lab technicians had started to notice that something unusual was happening. The vice president of one laboratory said he started to see that numbers of patients asking for dengue tests were increasing, but he did not share this information with the district as no one asked him to do so. This way of thinking can be explained by extreme formality and rigidity in the procedures for reporting where the laboratories are not expected to send their routine reports to the districts. Instead, test results are sent to the CSPS via the patients, who then report to the district via either a line list, or monthly or weekly reports. If the patient does not return to the facility with the results, results are never reported. Given the existing protocols, the lab vice president said that there was no demand for his data from the district as health workers came by only in November, two months after the rumors started, to see his records.

Protocols are powerful in guiding practice, producing certainty by their very formal outlining of responsibilities, of what to do, how, and by whom, providing a sense of ontological security. The national IDSR guidelines ensured a robust information flow from the CSPS to national level, but only for those diseases included in the flow. Lacking the ability to register the unknown, the routine system was not designed for handling uncertainty inherent in dealing with a disease not previously experienced. This was a weakness both formally in the design of the TLOH, as well as informally by the reluctance of health workers and lab officials to act outside the protocol when it came to reporting on something they had not been instructed to report.

5.3 Improvised information sharing and local guidelines

"As we are just next door to the laboratory, often they informed us, they raised our awareness and directed our attention to certain possibilities. […] It is next door, so we just go there when they call us. And they come to tell me, as there is another priest who works there, we sleep in the same house, we eat together, we pray together, we do everything together. So, already at the table we tend to those things. And me too, I start to discuss with the other colleagues if there is something we can do to raise the awareness."

Head nurse of CSPS

In the absence of official information, information is instead spread through other informal channels, rumors and the media. Through this, some interviewees did have access to such information because they had informal types of relations with laboratory technicians. Informal information exchange also took place between health centers or with districts.

"*Automatically, when there are health centers, which are close by, automatically, you call them to say; be careful because there are some cases that we have verified. […] or else it will make the others look bad.*"

Researcher and former district manager

Contrary to the reluctance to share information without having an official mandate to do so, unofficial channels existed and they were very valuable. The information shared was not hard data and statistics, but rather a more generalized type of information or advise to be alert. This enabled some action to be taken around handling the outbreak and treating of patients at district and CSPS levels.

"*No, we don't wait for the declaration. But yet we have to attract the attention of the administrative authority. Long before measures might be taken to contain a situation, to investigate a situation that might be an epidemic, we are obliged to do so. […] Yes, but now it is clear that our actions are limited, because there are the actions that require support from the administrative authority.*"

District health manager

One district manager had even made his own protocol for his district, in order to take some initiative to raise awareness locally.

"*We had made the directives. I did it when I began in 2015 before the [official] directives. See, this is a study that was done here in 2014. It shows that there were some cases in some of our sectors. So, we took this to attract the attention of the head nurses. But the directives came later.*"

District health manager

He was able to do so because his district had been involved in some research on dengue prevalence. Normally access to such international research was difficult to obtain for several reasons; limitations in accessing journals, and low levels of English literacy. However, the research done on site had resulted in a report in French, it became a valuable piece of information to guide the district manager, in a context of uncertainty about the protocol. Also at the regional level, some action was initiated to get more exact numbers before the declaration to do so was officially made.

"*It's because in the city the people were complaining that someone were having dengue, there is the dengue. That's what alerted us, even the Ministry. But we had already asked the districts to give us the dengue cases in the TLOH, when the rumor was big, because we needed the numbers to alert the Ministry. And it coincidenced with the Ministry going on its mission.*"

Regional health manager

A couple of things stand out. The information sharing practices were more informal but almost an integrated part of work between district health managers. Information sharing was enabled through contingencies and building on relationships and connectedness between colleagues in the health sector. It is important to note that it was mainly managers, district and regional, who had existing authority and responsibility, who took the initiative in this regard. People who already had some kind of authority and responsibility. These people were engaged only locally, and only as long as there were no official, national protocol.

5.4 Price and value of information

“As we don't always have the means, the tactic that we use is the case definitions, which allow us to act. Because in our country, if we have to wait until everything is confirmed, that will be after the death of many patients.”

District health manager

Managing an outbreak is both about seeing, declaring and communicating, as well as treating those already affected by the disease. It might appear that these two key activities rely on the same information of confirmed cases derived from proper diagnosis. But in a resource constrained setting this is not always the case. The diagnosis of dengue follows three steps, which is reflected in the categorization of cases as either; suspected, probable, and confirmed. A suspected case is identified based on the patient’s symptoms only, done by health workers at the point of care. A probable case is identified through a positive RDT. A confirmed case is defined through the results of a laboratory analysis of a blood sample, carried out only in the reference laboratories. In fall 2016, hardly any public clinics or hospitals had RDTs to do the test for probable cases. The analysis determining a confirmed case could not be done in Burkina, instead the blood samples had to be sent to the “Institut Pasteur Dakar” (IPD) in Dakar, Senegal. During the outbreak, capacity was established first in Bobo-Dioulasso, and later in Ouagadougou. This lack of laboratory capacity furthermore constrained the acquisition of exact information, because it was time-consuming or not possible to get results.

When it comes to treatment, which cannot wait until a result returns from Senegal, a strategy to deal with this uncertainty is to work based on symptoms.

“But well, the para-clinical examination to say if it is a probable case, or a confirmed case. That analysis is not available locally. We take care of the sick based on suspicions. As the symptomatology for dengue is similar to other pathologies such as malaria, or typhoid. When we exclude these pathologies, we suspect, and on that basis, we begin to take care. We are at the operational level, so we begin to handle it. Well, it is like that.”

District health manager

Although this strategy is not optimal, it might be necessary.

“We didn't have the RDTs for dengue, so we send the sick to do the test at the laboratories, but that's expensive. In the beginning, they were fifteen thousand CFA, twenty-two thousand, but that's not within reach, so it was a bit difficult for our patients. We also didn't have the reagents in place as we do for malaria. We didn't have that. Even now we don't have that.”

Head nurse at CSPS

“When the people come for a consultation, we do the RDT [for malaria]. Often it is also positive. We start the malaria treatment with peripheral venous line. Because the headaches are often severe and the fever very high, we put the person on serum. You do the treatment for severe malaria, and when you do the treatment correctly in principle after 48 hours you should be able to liberate the patient and change to oral treatment. But often the headaches and fever persist, and often it is even the patients themselves who ask [for a dengue test]. As it is an expensive test.”

Nurse at CSPS

The RDTs were not available in the public sector before the outbreak as dengue was considered a neglected tropical disease, and testing cost of an RDT was very high ranging from 10$ and 24$. This was extreme in a setting where a doctors consultation at private non-for profit facilities costs around 1$, and in public facilities 0,35$. Most patients pay for health services out of their pockets and can thus not afford a test at such a high price. In addition, there is no curative treatment for dengue, and many of the interviewees stated that from a patient's perspective it is not really worthwhile to invest in a RDT, as it does not add to the treatment the patient receives. The main reason for testing from a patient or point of care perspective is to exclude other diseases.

From a public health perspective, this uncertainty created by such practices is unfortunate as the main data source for mapping the prevalence of the disease then becomes very uncertain. From a patient's perspective, however, this uncertainty is acceptable as it does not make a big difference to the treatment. The initial uncertainty is captured by the registering of suspected cases, which allows for notification of something not certain. However, moving on from that to a probable case and ultimately to a confirmed case, which would be the last level eliminating uncertainty, remains challenging. While tests are not affordable to most, or not seen necessary for treatment, the practices for collecting this data is influenced by the willingness and ability of patients to be tested. Data to support knowledge on where to focus the response will be flawed, and yet decisions are made on those grounds. For the development of a HIS to support public response this would be a challenge as the problem is not lying within the data itself, but on the practices to support the data collection.

5.5 Public/private fragmentation of health service delivery

"There were many cases in the private facilities. Especially, when I look at one of the big clinics, which had maybe 800 cases in October-November. And you see, they didn't tell us anything, whereas normally they depend on us. They should give us the information."

District data manager

Even if the routine surveillance system had included dengue, only a fraction of the cases would most likely have been visible in the public routine surveillance system, as patients tend to opt for private clinics. The private clinics are obliged to report to the district via the TLOH, but many do not do so.

"There are private facilities that really collaborate with the district. They send their monthly reports and they even call to give the information for the TLOH, but it is not all the facilities."

District health manager

For other diseases, such as meningitis, public facilities do have the testing capacity, but in the case of dengue, only the private facilities that had capacity to do RDTs in the beginning of the outbreak. Consequently, patients suspecting dengue consulted with the private sector or were advised to do so. The main data that should be reported via the TLOH was largely available at the private clinics who did not report, and this data was lost to the formal information channels.

"[…] often I sit down and listen to the radio or watch the TV. The minister [of health] is doing a press conference; he says that we have a certain number of cases of dengue, deaths. One asks oneself how did they get that number. The cases. Because we transmit those we know to the [district] CISSE. The cases that go through the private sector or those that are not diagnosed, those we don't know, and that means that it is underestimated. We do have some cases, but when we have one we call the

CISSE to inform, it is very tiny compared to the cases in Burkina. It is difficult to have an exact prevalence, it is based on estimates.”

Head nurse of CSPS

With such fragmented information, it became impossible to determine the prevalence of diseases, especially at the peripheral levels.

5.6 Declaration and systematic action

At the national level at the DLM and at international agencies such as WHO, the outbreak situation was also discussed, and it was decided to undertake a collaborative assessment of some of the sites where many cases had been reported. The investigation was done using RDTs, and it confirmed that there was indeed a significant number of cases in Ouagadougou, leading to the declaration of the outbreak.

As soon as the outbreak was officially confirmed, more systematic action rapidly started to be taken. The national committee for the management of epidemics, CNGE (Comité National de la Gestion des Épidémies) started to meet on a weekly basis. A national response plan was developed. Dengue was integrated in the routine surveillance system and the reporting rate was increased for the Central Region, where facilities and districts became obliged to report suspected cases every day. Other regions should report each week as usual. In collaboration with partners, RDTs were made available free of charge at (selected) public clinics and hospitals. Hospital care for severely sick patients was also made free of charge. Preventive measures were also taken. As there is yet no vaccine available, prevention was done through personal protection and destruction of breathing sites through for example public spraying. The ministry organized information campaigns and printed folders on dengue for distribution. Spraying of central sites in Ouagadougou was also conducted.

In order to manage information regarding the outbreak, the DLM established a database during the outbreak. This database contained data on the number of cases, suspected, probable and confirmed. The analysis of the material is ongoing and will be used to improve understanding of the development of the outbreak in order to improve guidelines so that prevention is better done in the future. According to a national data manager, the database has proved useful already to develop specific answers for questions that would be posed during the CNGE meetings.

However, the completeness of the information in the database is still suffering from the lack of diagnostic capacity and lack of incentives analyzed in the previous section. The use of RDTs were still mainly taking place in the private sector, which led to persistent data gaps. This also led to a discussion on whether dengue surveillance should be passive (based on routine surveillance tools) or active (based on laboratory confirming) (Runge-Ranzinger, Horstick, Marx, & Kroeger, 2008).This is a challenge both to the national database but also to the CSPS and the districts who lack contextualized information about the situation at their level.

5.7 Summary

The case details some of the reasons for the delayed declaration of the 2016 dengue outbreak in Burkina Faso for several reasons. First, dengue had not previously been seen in big scale in Burkina Faso. Second, the primary symptoms of dengue are high fevers and headaches, which are the same as for malaria, which is present by high rates in Burkina Faso. Many health workers did not know how to recognize dengue and mistook it for malaria. Third, dengue was not included in the formal weekly surveillance system (TLOH), and therefore the first cases could not be captured in a structured manner and circulated to the national level. Fourth, RDTs are expensive and they were by and large only available at private clinics and laboratories. Last, many private facilities do not report disease surveillance data on a routine basis to the public system. This meant that the majority of cases were registered in the private facilities but this information was not shared systematically with the public system. Altogether, these factors created uncertainty about what was going on and how to deal with it.

The evolution of the 2016 dengue outbreak in Burkina Faso became very much a narrative of the introduction of dengue to the national health system as well as to the population. During and especially after the outbreak the routine surveillance system was strengthened to limit some of the uncertainty in the dengue surveillance and response. A new system and routines have been put in place, and practices has thereby been formalized. They system is now able to detect dengue. The unknown has been made known, and the ability to recognize dengue has been sharpened. For example the amount of new cases of dengue is rising again in 2017, but the ministry of health has been communicating proactively in the press already when cases were detected (Burkina24, 2017). However, in the case of other emerging diseases it is less sure that the health system is better equipped to recognize those. In that case new unknowns and uncertainties are to be handled. We will turn to this question and explore it further in the two last sections of analysis of the findings and a discussion of their implications.

6 Case analysis

Our empirical research questions are concerned with the identification of conditions that contribute to uncertainty; how people deal with it; and the role of HIS in shaping and addressing uncertainty. These questions are motivated by a more general interest to build better understanding of how bounded or alternative rationalities influence information use practices within the public health domain in resource constrained contexts. Uncertainty used as an analytical tool helps to foreground the condition that we don't know, and urges us to examine alternative ways of acting based on appropriately designed HIS.

Our first research question concerned identifying conditions that contribute to uncertainty in the context of disease surveillance in a low-resource setting. The empirical analysis identified the importance of having ***prior experience*** with a disease. In such an absence, the protocols defined do not recognize the disease, and data on that disease even if detected does not get reported. The problem then tends to remain invisible, and outside the remit of formal channels of action taking that rely on the routine reports. Compounding this problem of invisibility concerns the ***lack of resources*** for carrying out testing for the disease. Diagnosis takes place through syndromic (based on symptoms), presumptive (based on clinical analysis) or laboratory testing, with the laboratory confirmation being the most accurate. Since in resource constrained environments, laboratory testing equipment and reagents for emerging diseases are largely unavailable in public facilities and, in the case of dengue, relatively expensive to access in private facilities, most cases go undetected. Furthermore, as there is no curative treatment for dengue, patients believe that the fever will anyway run its course with or without care, and so they tend to opt out of testing which they anyway find ***too expensive*** to afford. While these dynamics are observed in the case of dengue, the same would most likely be expected in the case of other emerging diseases such as Zika and Ebola. Since in low-resource settings the health care providers are dealing with real and visible everyday challenges, they have ***limited capacities and bandwidth*** to engage with a problem, which is unknown and where the probability of consequences remain marginal. Routines are an important lens to understand conditions or not of certainty. Routines reflect knowledge in action, and the absence of knowledge (for example, of how to deal with a case of dengue) then reflects and also magnifies conditions of uncertainty. The use of protocols (for example, on what data to report on) in themselves serve as a routine, but also help guide other routines such as what data to collect, when and how to report.

Absence of protocols for registering dengue, as well as ***absence of adherence to the protocols*** regarding data sharing between the public and private sectors further contribute to the conditions of the MoH not knowing about the prevalence of dengue.

While our empirical work has highlighted the above conditions contributing to uncertainty, this list is not exhaustive and in other settings there may be other conditions at play. Often, there may be political reasons certain interest groups have in keeping data invisible. Sahay et al. (2017) highlight some of these situations giving examples of Mbeki in South Africa denying using statistics that HIV leads to AIDS. A state government in India deliberately withheld information of a plague outbreak so as to not adversely affect tourism and business development in the state.

Turning to the second question regarding how health workers and managers dealt with conditions of uncertainty. In the context of a disease surveillance outbreak, the health staff do not have the luxury of not acting even if they don't know. Action needs to be taken even though information was missing, incomplete, or uncertain. Uncertainty was recognized as the situation being unusual both by personal experience through the observation of sick patients as well as through secondary information such as rumors, shared by colleagues and reported through the media. In absence of the ability to diagnose, which would be the standard way to verify and make sense of the unusual situation, alternative strategies were used to make sense. One such strategy was ***exclusion*** of the knowns, such as malaria. Another was the reliance on ***social relationships*** for a continuous discussion of what was going on and the sharing of experiences. These relationships provide a forum to place different experiences into context and the ability to share learnings around diagnosis and treatment. These took place at first when the disease was not known and later when it was known, but resources were constrained. These interactions helped to initiate improvisations where the formal hierarchy could be bypassed. For example by making and putting into action a local district level protocol for the handling of dengue. This ***introduction of structure*** outside the formal hierarchy through improvisations reflects the solidarity that exists between health workers and their desire to do their best and give primacy to the health and wellbeing of individuals over the need to follow formal rules and protocols, and displays the motivation to take ownership of the future. Likewise, reducing uncertainty by the production of local guidelines shows aspirations to act rather than wait.

Summing up the nature of these improvisations, they are interesting as they did not rely on quantitative information, which could not be obtained. Instead, they made use of the more fluid information which could be obtained in the moment. Strategies to obtain and use such type of fluid information were recognizing by exclusion, sensemaking by interaction with colleagues, and introduction of structure as the creation of local intermediate guidelines and protocols.

The third question concerns the role of HIS in identifying and dealing with uncertainty, and takes us to discussion of the more practical implications of our findings. HIS can be seen both as an object of and also an enabler (or constrainer of) certainty or uncertainty. While disease surveillance models and algorithms help guide the design of the HIS, they raise the question of do they reflect the "correct" reality, especially in conditions where we do not know. In their current design, HIS are not well equipped to handle uncertainty as they represent systems for the collections of "facts". They are storage places for information, not for information that is not there. However, they are also systems that should support action. Since action relies on more than facts, a design challenge concerns how to make HIS to be both systems of information and of action?

This requires to make the HIS very responsive to changes in the environment, by enabling significant flexibility into design. For example, there needs to be mechanisms in place where new indicators can quickly be put in place in the system. In our case, it would imply the ability to include the reporting of dengue immediately as the first cases started to become known. This however, assumes that we can detect dengue cases, and have the ability to record the case, but report it because of design limitations.

Leading from the above is to enable the HIS configuration to include more room for the uncertain and unstructured information. This could for example be free-text fields where uncertainty could be voiced as small notes. Reporting should be able to include both suspected and confirmed cases, so that health workers do not feel fear in reporting something which can be a wrong diagnosis. Repeating patterns of free text entry or provisional diagnosis could help flag unusual activity and raise the need for a closer scrutiny of the situation. This could help inscribe the HIS with characteristics of an early warning system.

A more radical approach would be to try and design the HIS as an enabler of conversations instead of tools of documentation. When health workers do not get solid information, they talk to and learn from each other. Most HISs represent one-way communication, with data flowing upwards with limited feedback. The argument being made is not about HIS replacing face-to-face communication, but additionally also providing more possibilities for informal, confidential communication with peers or colleagues.

In summary, in answering the three research questions we have highlighted the concept of uncertainty and its need to be situated and contextualized in conditions of providing health care in low resource settings. Uncertainty helps to explore some of the boundaries of information and its role in action, when some of the issues may be unknown while others are more known. The most important insight is that uncertainty is important to consider, and finding out ways to do so. However, the concept also has some challenges. Accounting for uncertainty is also a way of describing it, even though it is not an activity that assumes it can be reduced, it is still a process of rationalizing it. If we seek to manage or organize uncertainty, are we falling into the same trap of trying to make something that is not known to be known, while remaining open towards the conditions of uncertainty. These findings challenge our traditional notions of designing HIS for action. In cases of emerging outbreaks, information is not always solid, or cannot always be obtained, and action needs to be based information that cannot be verified or is not optimum. The expectations and mindset around a HIS needs to be redefined, and be able to acknowledge that there is always the unknown which has to be considered, so the design must leave spaces for the unforeseen and not-knowing.

7 Discussions and Concluding remarks

For the purpose of this study we have taken up the call made by Appadurai (2013) and others (Haram & Yamba, 2009; Whyte, 1998) that challenges anthropology to focus more on the future and the agenda for change. Appadurai argues that this involves creating imaginaries of the future and aspirations about a better life. Although we are not anthropologists, we find this call to be particularly inspiring and reflecting a parallel with issues around HIS. The idea that we rely heavily on numbers and calculation of risk to describe the future, resonates with the underlying assumptions of HIS, where information use is seen as the optimal path to strengthen health services delivery. As a result, improvement is often sought in the collection of more and more precise data and its speedy distribution, for example through the use of mobile phones. Realizing the challenge in this approach, we found the call by Appadurai to focus on uncertainty instead of stubbornly trying to reduce it to be intriguing.

Taking the concept of conditions of uncertainty as our analytical tool we identified reasons contributing to uncertainty, including lack of prior experience, inadequate resources, ill-designed protocols and institutional constraints. The information for action principle is limited in giving directions for what to do under such circumstances. However, we saw health staff cope actively with these conditions by relying on improvisations such as making tentative diagnosis based on exclusions, exchanging and discussing rumors through social relationships, and informally structuring practices by the making of local protocols. While this might not be an optimal solutions, it is better than waiting for official instructions that are delayed. These findings point towards action being based on both information and non-information, and the importance of strengthening practices in situations of not-knowing.

The findings are on one hand very specific to the health system in Burkina Faso. They carry practical relevance for the efforts to strengthen the national HIS to also support disease surveillance and response based systems. Furthermore, an implication for practitioners is that HIS do not work as isolated sources of information but comprise larger socio-technical systems. Making these strategies and visions more vocal on not only the possibilities but also the limitations of HIS, could inspire an agenda of better coupling between the HIS and the surrounding practices.

One the other hand, alongside the specific story of the disease surveillance and response system in Burkina Faso, there is also a more general story of knowledge and action in health care provision in low-resource and vulnerable settings. The need to rely on not-knowing and partial information is integral to social life and human interaction, and not-knowing becomes also an important enabler of social change and ICTs being a change facilitator. Data then is not the only change agent, and its scope should also include the dimension of non-data, leading to more varied imaginaries of a future free of diseases.

An obvious limitation to this study is that it is based on one case in one country, which leaves us with unanswered questions regarding how the concepts of uncertainty and not-knowing are relevant in other disease cases and countries? This ‘uncertainty’ calls for more studies looking into dimensions of uncertainty and not-knowing in health care delivery, and also in HIS design. It would be interesting to see if and how these concepts can be applied in other contexts and diseases.

Furthermore, imagining the future is in a way a contradictory task. Whether such imagination is based on facts or something else, it is hard to hold free of some sort of speculation, chance and maybe just luck. In any case, understanding how good the imagination was, would require looking at the past. However, we think that it is not a matter of foreseeing the unforeseen but a matter of providing different strategies for doing so than the one based on data and measurements.

This research is a first attempt to unpack which information health care work also relies on. The ‘also’ concerns does not refer to data as an opposition to more qualitative data collection, instead it should be seen as a supplement to other factors also in play, that only manifest themselves in daily practices. Incorporating these findings into HIS requires a rethinking of the information for action premise, which directs attention to many factors not directly associated with the HIS and decisions based on this information. However, we do believe that building attention on uncertainty will help forward HIS as tools that strengthen information use not only based on predefined facts, but also through a dynamic adaptation to the uncertainties that occur in practice.

8 References

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Appendix 4: Paper 4

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RESEARCH ARTICLE

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Plans and “off-plan activities”: Exploring the roles of data and situated action in health planning in Burkina Faso

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Abstract

Implementation of health management information systems (HMIS) has gone hand in hand with a growing global demand for high-quality data. While this has sustained HMIS implementation, it has also promoted a data-centric assumption that better data leads to better action on health. An example is health managers envisaged using HMIS data to make action plans for health service delivery. The paper draws on an in-depth study of practices of health data use in Burkina Faso to explore this relationship further. In this context, deviation from the agreed plan is not seen as problematic. Local action plans are often overruled because of requirements of higher levels, unexpected developments in diseases, or sudden provision of fresh funding. Health managers organize work under these uncertain circumstances through situated action. The concept of “off-plan activities” is used to handle unforeseen events. Mobile phones are used extensively to make and remake plans. It is argued that the findings invite us to consider a less data-centric approach to the role of HMIS data in health service delivery, where HMIS data are seen less as a tool to discipline local practices than as one element of the dynamic practices undertaken by individuals in the organization of daily work.

KEYWORDS

data use, HMIS, planning, situated action, uncertainty

1 | INTRODUCTION

District health managers in Burkina Faso are in charge of the day-to-day functioning of health districts, which involves making plans for the delivery of health services. However, their work comprises a whole range of functions. They work in the field, in clinics, and hospitals, where they carry out supervision, training, and vaccination campaigns, and where they can exchange information directly with health workers. They work in meeting rooms, where they present and discuss progress reports and strategies. Furthermore, they work in offices, where they engage in meetings, finalize reports, and sign off a wealth of papers, ranging from medical prescriptions via annual action plans to displacement permits. These offices are usually welcoming spaces with comfortable chairs and air-conditioning. Their walls are seldom bare, perhaps displaying key district health statistics, clinical guidelines, photos of an official visit to the district, or certificates that the health district manager has been awarded. One item, always on display, is a large institutional calendar with a standard display of each month of the year in columns and spiced up with photos and headlines about larger donor-driven projects. One day, I was studying the landscape of these office walls in more detail than usual, as the district manager I interviewed had to take a long phone call. It struck me that these calendars were almost always empty. I started to make note of this when I visited other offices and noticed that, although there were calendars everywhere, they had hardly any notes on them, if any at all. Why would you put a calendar on your wall if you were not going to use it? Maybe, they were simply used to tell the current date, or were there because they were nice to look at or as a courtesy to those who had donated them? However, it could also be that they were left empty in acknowledgement of the fluidity of day-to-day planning, which I had also started to observe. If you start the week by reworking your weekly plan, it might not make sense to note it down.

Broadly speaking, health managers use data to assess the prevalence or nature of health issues in the population within the geographical area they manage. By using data, they can determine the burden of disease and initiate long-term or short-term preventive action. In low- and middle-income countries (LMICs) health management information systems (HMIS) are often implemented to support this work through the provision of timely and accurate data (Braa & Sahay, 2012; Lippeveld, 2001). Health managers at all levels of the health system are envisaged using data to analyze the health status of their country, region, district, or health facility in order to draw up adequate action plans for how to improve health (Aqil, Lippeveld, & Hozumi, 2009; Heywood & Rohde, 2001; Lippeveld & Sauerborn, 2000). In this view, plans are supposed to act as structuring devices to guide action, while managers are seen as analysts who make these plans based on HMIS data.

Such assumptions about the ability of HMIS data to determine action are challenged as HMIS are now passing the pilot stage in many countries, and it is seen that data are still not used as much as envisaged (Nicol, Bradshaw, Uwimana-Nicol, & Dudley, 2017; Sahay, Sundararaman, & Braa, 2017; Wickremasinghe, Hashmi, Schellenberg, & Avan, 2016). This lack of use is often ascribed to low data quality or lack of capacity to analyze and work with data locally (Braa & Sahay, 2012; Nyamtema, 2010). However, it has also been shown that not only data and plans, but also social dynamics structure action in the health sector in LMICs (Nicol et al., 2017; Sahay, Sundararaman, & Braa, 2017; Wickremasinghe et al., 2016). The latter observations are interesting as they identify the challenge of lack of data use to be more than just a challenge of lack of capacity and poor data. Instead, they invite us to reflect further on the role HMIS data plays in action.

In information systems (IS) studies, this gap between work itself and representations of work, exemplified by plans or guidelines, has been a central issue because IS have traditionally been designed in accordance with formal representations of work, thereby not acknowledging how work is actually done (Hirschheim & Klein, 2012). In ICT4D research, similar gaps have been defined (Heeks, 2005). Alternative approaches to IS design have been developed through practice-based studies (Suchman, Blomberg, Orr, & Trigg, 1999). A well-known example is the work of Suchman (1987) on how people interact with an advanced photocopier that was not as easy to operate as expected. She showed that plans are not simply followed. Instead, action is situated in the sense that it is also shaped by material and social circumstances. In the context of LMICs, such material and social circumstances include different rationalities (Avgerou, 2000) and individual efforts taken to organize daily life under circumstances of high uncertainty (Appadurai, 2013). These insights invite us to reflect on what we can learn from LMICs rather than mainly on what we can bring (Walsham, 2017).

The aim of the paper is to discuss alternatives to the dominant data-centric approaches to HMIS development and implementation by exploring the functions of HMIS data and action plans in the context of the health care delivery in a LMIC. For this purpose, I am applying the following research question: *How do health managers in Burkina Faso balance data and situated action in the organization of their work?*

I engage with this question through a qualitative study of health managers and their planning processes. The analysis draws on a qualitative interpretive study of health data use carried out in the health sector in Burkina Faso over a period of 3 years. The analysis shows that there is gap between the data-driven plans, which are indeed drawn up, also on the periphery of the health sector, and the actual activities that are carried out during the year. Changes to the plans are introduced because of unforeseen developments in diseases such as outbreaks, or initiatives introduced by the national level of the health system or the donors. The local practices that are used to bridge this gap are examples of situated action. In conclusion, therefore, it is argued that they should be included, not omitted, from the conceptualization of health data use, as they are equally instrumental to data-driven plans in shaping the future.

2 | THEORETICAL LENS

The focus of this section is to propose an alternative framework for how to understand the relationship between work and representations of work in relation to public health and health-service delivery. First, I discuss the need to adopt a different approach to HMIS data use. I then outline different aspects of plans in relation to action before finally proposing some alternatives to the data-centric understanding of plans and action.

2.1 | HMIS and the data-centric approach

The recent relatively successful uptake of HMIS in LMICs has enabled increasing amounts of data to be collected in a uniform and structured way before being disseminated locally and globally (Sahay, Sundararaman, & Braa, 2017). These advances have gone hand in hand with global agendas emphasizing accountability in foreign aid and the evaluation and monitoring of development progress first with the Millennium Development Goals and now with the Sustainable Development Goals. However, in spite of the advances, it remains a challenge to ensure that data provided through HMIS are used in countries, especially at the peripheral levels of the health sector (Nicol et al., 2017; Sahay, Sundararaman, & Braa, 2017; Wickremasinghe et al., 2016). This lack of use is often linked to poor data quality (Braa & Sahay, 2012; Nisingizwe et al., 2014), to a lack of the skills needed to work with data (Braa, Heywood, & Sahay, 2012; Kumar, Gotz, Nutley, & Smith, 2017) or to HMIS mainly being set up as a tool to support the registration of data rather than its dissemination (Madon, Krishna, & Michael, 2010). While making these links is not wrong, it does tend to neglect the fact that data do not represent a single driver of action, which in turns means adopting a data-centric approach to social change. Such approaches are problematic, as they do not capture the treatment of data, nor how it is enacted and incorporated into broader organizational practices (Kelly & Noonan, 2017; Kelly, Noonan, & Sahay, 2013). Furthermore, such data-centric approaches do not sufficiently acknowledge the different rationalities that might coexist with social change, and consequently LMICs are often seen as “problematic hosts” for ICTs and IS (Avgerou, 2000). Within ICT4D research, there is a growing recognition that this view should be changed so that IS researchers, instead of being experts who bring solutions to beneficiaries, adopt the role of co-contributors also reflecting on how local practices can benefit successful IS design and implementation (Sahay, Sein, & Urquhart, 2017; Walsham, 2017).

2.2 | From plans to action

Generally speaking, plans are a central aspect of human action. They can function as maps or guides for how we intent to act. They can function as predictions of the future (Appadurai, 2013) or as calculations of risk by, for example, visualizing the best ways to arrive at a certain point (Suchman, 1987). The relationship between plans and human action has been discussed widely in relation to human behavior and organization studies, as well as in the field of IS. In these contexts, plans are central both as descriptions of processes and practices that the system should support and as guides for how to use the system. Suchman originally studied the claim that computer interfaces could be designed to be intuitive and self-explanatory but came to the conclusion that they had to be learned by users in specific use situations (Suchman, 1987; Suchman et al., 1999). She articulated this conclusion through the concept of "situated action," which she derived from ethnomethodology and used to point out that action is not only defined by predefined structures or rational plans, but instead, it is based on assessments of what is rational to do in a given situation. Based on this empirical analysis, Suchman described situated action in terms of how users readjust their plans in encountering an advanced photocopier and colleagues—or in other words, the material and social properties of the world that surrounds the use of the photocopier.

Suchman is careful to point out that, although action is not predetermined, it is not random either (Suchman, 1987). This is an important point as it calls for a further examination of what situated action entails in practice (Suchman et al., 1999). In a West African context, a similar conclusion has been reached regarding bureaucrats' practices that are shown not to be irrational just because they do not follow the official rules of the public sector. Instead, they take a quite rational approach to the contextual circumstances of their work by applying "practical norms" (Bierschenk & Olivier de Sardan, 2014). Instead, they argue that the gap between official and practical norms and procedures is an area that needs further exploration. In the context of HMIS in LMICs, related observations have been made regarding gaps between the formal rules setting out documentation criteria, based on national policies and plans, and the informal constraints at the point of service delivery, where care is seen as more important than reporting (Piotti, Chilundo, & Sahay, 2006).

2.3 | Organizing practices

Lastly, I will draw further on the discussions above to sketch an alternative to the data-centric way of thinking. In doing so, I would like to complement them with a suggestion articulated by Appadurai (2013). In his rich and complex analysis of the functioning of financial markets, he argues that we mostly rely on tools to analyze the past, while lacking the tools to envisage the future. He draws on a range of work in economics and other social sciences to develop a distinction between risk and uncertainty, where risk can be measured and calculated because it has known elements, while uncertainty is characterized precisely by its lack of these elements. This distinction can help us be more precise about how we handle the future—not only as something that is planned and foreseen, but as something that is produced and designed deliberately by people through their daily practices. As it would go beyond the scope of this paper to engage fully with Appadurai's work here, I will simply adopt his suggestion to treat the efforts individuals employ to produce everyday order as a resource equivalent to high-level planning and design. In doing so, the gap between different representations of work can be understood as a matter of integrating plans drawn up at higher levels of the health system into the production of locality by the capacity of more peripheral health managers to produce order through everyday activity.

As the readings above suggest, representations of action cannot fully determine action. Consequently, attention should also be paid to what people do in context and why. In this perspective, it is not irrational to depart from the plan. On the contrary, it can be quite rational as an effective way to get work done. Understanding these deviating practices means accepting them as something that should be appreciated rather than avoided. A less data-centric approach to HMIS data use considers these factors.

3 | METHOD

The study was conducted by adapting an interpretive methodology emphasizing the social and often less visible parts of organizational life (Orlikowski & Baroudi, 1991; Walsham, 1995). Production of thick descriptions is seen as a tool to convey this understanding to others (Walsham, 1995). In the following, I outline how I collected and analyzed the data for this paper.

3.1 | Data collection

In IS research, there is a long tradition of studying work practices through adaptations of ethnographic techniques (Blomberg & Karasti, 2013). The method adopted for this work draws on such an approach. The data are drawn from a long-term study of data-use practices in the health sector in Burkina Faso conducted over a 3-year period. The author lived in Burkina Faso throughout the study and conducted fieldwork related to use of health data in different parts of the health sector. The research was thus multi-sited as the aim was to study the dynamics of data collection and its use across organizational levels. The Ministry of Health in Burkina Faso approved the research prior to data collection. Oral or written consent to

TABLE 1 Overview of interviews

	Clinic	District	Regional	National	Other
Health worker	7	5	1	0	0
Manager/Director	6	9	2	9	0
Data manager	0	8	4	7	0
Other	0	0	0	0	7
Total	13	22	7	16	7

participation were obtained individually from each informant prior to interviews or observations. Table 1 presents a list of interviews that were recorded and transcribed during the whole research period and which lasted between 30 and 90 minutes.

The analysis in this paper draws in particular on 3 weeks of observational studies carried out in one urban health district in Ouagadougou, the capital of Burkina Faso. Prior to this, I did participant observation over a period of several months in the directorate for information technology in the Ministry of Health as well as I had done occasional visits to health districts. Observations and interviews from these earlier periods of fieldwork also contributed to the shaping the core ideas presented in this paper. In the urban health district, I followed daily life in more detail especially focusing on the activities of members of the health district management team. This included participation in weekly coordination meetings at district level, observation of daily information meetings, and participation in outreach activities such as training and supervision visits. I collected data through field notes describing activities I had participated in, observations I had made concerning HMIS data and its use, including documentation of unstructured interviews I had done during observations. As the work evolved, I also conducted structured interviews with key informants from the health district, which gave me an opportunity to discuss my observations regarding data use and planning in more detail.

3.2 | Data analysis

Data were analyzed by means of an interpretive approach where themes and ideas are developed in an iterative process of collecting data, organizing it, and relating it to theory (Walsham, 1995, 2006). As these steps are not done sequentially, they mutually inform each other, allowing the researcher to develop ideas and to go back and assess them further in the field or by relating then to theory.

I used coding as a means to organize findings before developing them into brief narratives and thick descriptions detailing the practices of HMIS related data use. Concepts are already developed as empirical material is gathered where the researcher starts to mentally organize it, for example when notes are taken (Walsham, 2006). This was the case, for instance, with the concept of “off-plan activities,” which I noticed and described in very early field notes, and then explored more deliberately in later observations and interviews. Interview transcripts and field notes were coded following an open-ended coding principle. This process outlined the specifics of the data-use process, such as “tools for planning,” “accounting,” “funding,” and “activités hors plan” (“off-plan activities”). Later, these codes were developed into more substantial ideas. This was for example the case with the action plans, which I first coded “tools for planning” but as the analysis evolved also labeled “tools to negotiate future possibilities”.

As Walsham notes, interpretive research evolves in the mind of the researcher through a discussion with the material, supplemented with the minds of others (Walsham, 2006). As the study was conducted over a long period of time, I was able to discuss observations made during data analysis with health managers and workers in the field. During the research period, I also discussed the narratives shaping the thick description and an early version of the paper with colleagues from the IS research field.

4 | CASE STUDY AND ANALYSIS

In the following, the organization of the health system in Burkina Faso is briefly outlined before describing the development of action plans and their multiple uses. Then, the concept of “off-plan activities” is discussed, followed lastly by examples of how health managers organize activities through situated action.

4.1 | Case study context

Health service provision in Burkina Faso is largely undertaken by the public sector. Although most health services are subject to user fees, the health sector is heavily dependent on external support. This creates dependence on the continuous support of donors (Maclure, 1995), which requires a considerable amount of coordination between the latter and the health system. A cornerstone in facilitating this coordination is the 2020 national plan for health development (PNDS), which sets out Burkina Faso's strategic health priorities.

The Ministry of Health manages health services in Burkina Faso, while the actual delivery of health services is organized through a three-tier organization consisting of district, regional, and national administrative units. There are approximately 1600 health facilities across the country, administered by 70 health districts organized into 13 regions. A management team consisting of a district health manager and a team of eight people run each district. The responsibilities of the management team include ensuring the delivery of health services, planning, monitoring, and evaluating the district's health-related activities (Ministère de la Santé Burkina Faso, 2010).

Since 2013, a centralized national web-based HMIS has been functioning countrywide. It is running on the District Health Information System software version 2 (DHIS2, https://www.dhis2.org/). Aggregated health data regarding health service delivery are collected routinely every month in a paper-based report at the 1600 health facilities. Designated data managers enter the reports into the web-based HMIS at district level, which is then available countrywide. The content of the HMIS covers most of the national health programs, and these data primarily form the basis for the production of the annual health statistics as well as the action plans for health service delivery.

4.2 | Action plans as tools for negotiating future possibilities

In December each year, the disease-specific directorates of the Ministry of Health, the health regions, health districts, and health facilities, begin to draw up their annual plans, which should be based on an analysis of health data from the previous year.

> "Each year the district elaborates what is called the action plans. [...] They have to know the meningitis prevalence of last year, measles, and prevalence of malnutrition. So it is based on this that they can say that this year our health challenges will be 1, 2, 3. They list the health issues based on the reports of the previous years. And then based on these issues they do the planning." *(Researcher/former health district manager)*

The action plans are made using data from the HMIS, which the data manager extracts and shares with the district management team for further analysis and manipulation. It was observed that excel spreadsheets are used for this purpose as they are easier to work with than the interface of the web-based HMIS. Mangers at each administrative level from health facility to the national level make an action plan, and it is ensured that these plans correspond with the national strategic plan.

In addition to their approval, the action plans have to be financed. Health care activities undertaken by the districts are funded in three ways: (1) the health district's own funds, raised from the drugs sold at public pharmacies in the district; (2) government funds, coordinated by the government's central program for health development, some which might come from external donors; and (3) direct funds from donors, with whom the health district negotiate funding agreements directly.[1] The district managers referred to raising funds from donors as "advocacy." At the time of the fieldwork, they would engage in this by presenting the needs of their respective districts in meetings with the donors. These meetings were essential to drawing up the plans, as only funded activities should be included in the final annual action plan. In this regard, planning health service delivery is a matter not just of identifying health problems, but also of securing the resources to do something about them. This relationship challenges the data-centric logic, as it shows that it is not the data-driven plan that potentially facilitates action; it is only the activities in the plan that are eligible for funding. In this sense, data use becomes less a question of making a plan and more a question of being able to justify this plan to other actors in the system. Realizing this shift, the national directorate for health-sector statistics held training sessions to facilitate this type of advocacy.

> "[The advocacy] is actually often missing. So last time we arranged a workshop on data use with one of our NGO partners. It was a really interesting workshop because we brought together the decision-makers from the regional level. [...] We showed them how to use the data. Apart from planning, the data can be used for advocacy, and we did some exercises. How can it be used to talk to the authorities about administrative policies and to partners in order to mobilize resources to fund activities? [...] How can you communicate in order to actually convince a partner or a political or administrative authority to support an activity?" *(Manager, Ministry of Health)*

Using data just to make a plan versus making a plan that can be negotiated might appear to be a subtle difference, yet, as it is exactly this process of negotiation that determines which activities are included in the final plan, it is rather important. It changes the plan from being a locally relevant tool outlining the key activities of the year to being a document that should be of global relevance by complying with donor strategies and visions. Rather than being a tool to envisage the future, the HMIS data become a tool to negotiate the future.

4.3 | Off-plan activities

Once the well-structured planning process has been completed, health districts have a solid foundation for the following year's activities. However, from my observations of daily work in one such health district, it appeared that it was not the action plans that guided which activities were done each week. Instead, I began to hear statements along the lines of "We were told to do this activity by the government last week," or "The breast-feeding workshops we are doing is this week is an "activité hors plan"." The phrase "activité hors plan" was also used in the health district progress reports. "Activité hors plan" can be translated as "activity outside the plan." However, as it is used more like a fixed concept that everyone knows and uses consistently, I will adopt the translation "off-plan activity." This makes it possible to refer to it as a concept, similar to the way it is used by the health managers. When I began to inquire about off-plan activities, it turned out to be a concept that was consistently used to describe the various discrepancies between planned and actual activities.

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[1] While the fieldwork was taking place, this funding process was subject to an effort to centralize coordination further and to introduce results-based financing. While this change will most likely impact the way district planning is carried out, it would go beyond the scope of this study to discuss this further.

> "Right now there is an activity that was not in our action plan. It must be executed, it is urgent because it is a national decision. It is an off-plan activity. Apart from that, there may be some donors who have come to find that our plans of action were already closed, but they say that they can finance some activities, and the state knows that, in any case, it will do us good to do this activity. And then it comes as an off-plan activity and we do it." *(Head mid-wife, health district, Ouagadougou)*

The informants explained that there were different reasons for off-plan activities. For example, they could be caused by donors proposing projects at the last minute.

> "Often they come with their money, they find that the action plan is already closed, but they want to get into it—what to do? […] It's trainings, capacity building, it's equipment, it's supervisions. Should we refuse because it has not been planned? Well, it actually disrupts the planning of our work schedule. But we have to deal with it because we are in a country where resources are limited. […] We count on foreign aid. But you can imagine a partner who comes like that and presents something to the politicians, for example, and the technicians say, we're not going to do you it. You see what it does. It is difficult to defend." *(Manager, Ministry of Health)*

Several informants stated that it is difficult to say no to funds, even when these funds are notified at very inconvenient time and thus risking to distort the data-driven plans and priorities.

As the organizational hierarchy in the health sector is very strong and must be respected, activities initiated from a higher level always have priority over the plans from the level below. Therefore, action plans of the peripheral levels will always be bypassed by the national plans. This type of off-plan activity may be aligned with the overall health challenges of the country, and thereby indirectly be data driven. This indicates that there is a hierarchy in HMIS data use, where the interests and the priorities of the donor who is initiating the activities are overruling the priorities of the district or regional health manager.

In addition, off-plan activities can also be caused by issues that emerge during the year and require action more or less immediately.

> "If the resources are there and we've seen that there is a problem that really requires action, then we can take action directly concerning the root cause of the issue. In order to try to solve it we will do this activity, but it has not been planned due to difficulties with identifying when to do it, and you must do all you can do to solve it. This we do not plan, so we have to execute it as time goes by and as they come along. That is off-plan activities." *(Head mid-wife, health district, Ouagadougou)*

Health emergencies, such as outbreaks of infectious diseases, also cause off-plan activities. These off-plan activities are by nature difficult to foresee. However, for some diseases, such as meningitis, it is well known that epidemics are more likely to occur during the dry season, and therefore proactive action is planned when this season is approaching. Such activities are included in the action plans. However, for other diseases, such as dengue, which until the fall of 2015 had not been seen on a large scale in Burkina Faso, this proactivity is hard to plan, as it cannot be fully foreseen at what moment an increase in cases might occur.

On the one hand, the off-plan activities were seen to disturb the work, making it difficult to execute the action plans. On the other hand, no one wants to complain about an activity being financed, even when it happens outside the normal funding procedures. Instead, the more or less neutral concept of off-plan activities had been developed. This can be seen as a concept allowing for flexibility in the work, as it bridges the tension between the fixed plan and the actual possibilities that arise during the year. It functions as an integrated concept in the planning, which itself functions by means of this concept, as the idea of off-plan activities makes it possible to talk about and account for the unexpected in a uniform way.

4.4 | Organizing with flexible plans

One effect of the off-plan activities is that they often create delays, as they lead to some activities being postponed. Other factors, however, also contribute to uncertainty about when activities can be done.

> "Normally January is a quiet period because the financing has not been harmonized in advance. Because in January we start with the new action plan to search for financing. So when the allocation of funds is ready, at that moment the activities can be launched." *(Head mid-wife, health district, Ouagadougou)*

As the example above shows, some delays will most likely be processual and thus return each year. However, at other times, the overall stability of the country as a whole also plays a role. The first period of the fieldwork took place shortly after a terrorist attack was carried out on a popular restaurant in Ouagadougou killing 30 people. This event followed a popular uprising against the president of 30 years, resulting in an interim government and finally a failed military coup before a new government was elected. Altogether, these events created a general sense of insecurity about the future. In the government's first year, it led to major delays in the negotiations between the government and the donors while some donors reconsidered how to continue their support.

> "Yes, the funding—for example, this plan of action—is planned to start in January. You cannot wait until April or May to release the resources. We have consumed how many months, four months? It is not possible. So the money does not come because the partners do not fund anymore. It seems that there is no more money in Europe. Is it that, or is it because Europe does not want to give us money anymore?" *(District manager, health district, Ouagadougou)*

For the district managers, this tension between planning, monitoring, and actual possibilities creates some complications in the daily management of health service delivery. It becomes the district manager's job to continue delivering health services despite these adverse circumstances. One effect of the insecurity regarding funding and the function of the action plans as process-monitoring devices is that some activities are deliberately excluded from the action plans.

> "As they [a donor] do not have the money right away [but] they find that the activity is very important. Often they tell you, 'Well, you can hold back a little. We do not have the money, but we will try to search.' At some point, we'll say that we prefer to remove it. Because if we do not remove it, and then evaluate, there will be many activities not carried out. So we take it out [of the plan]. In the meantime the [partner] finds the money, they come back and they say to go on with the activity, as the money is there. Now it [the activity] is no longer programmed. It was not kept in the plan, so automatically it is necessary to register it as off-plan." *(Manager, Ministry of Health)*

This is an example of a practical norm that arises when everything needs to be accounted for by the end of the year. It is then better to keep the plans clean of activities when funding is not secured. This means that, although the action plans are officially finalized by the beginning of the year, they are still kept open in the minds of the health managers, so that they can add activities once they receive finance.

On a day-to-day basis, other strategies are adopted. Once the annual action plan has been drawn up, it is broken into more manageable entities, meaning that the health district manager will make a rough monthly plan and then a more specific weekly plan. Putting this plan into action every week requires a lot of coordination and phone calls to see who is available to undertake the activities as they come up during the week or maybe even the day before they should be done. One Monday morning, a district manager explained how the regional director had called him the night before, on a Sunday, to inform him of a 4-day workshop that required the attendance of three nurses from the district, and that it would start that Monday morning. In such cases, he said, you do not refuse; you simply start calling around to see whom you can find to go. In such cases, the activities in the manager's weekly district plan might need to be postponed, or he or she might need to find other health workers to do the work at the clinics.

Plans are even adjusted during the day just when they are about to happen. In making appointments with either the district or the national levels of the health sector in Burkina Faso, you should quickly learn the practice of renegotiating a plan. For example, if you want to make an appointment with someone, it is good to talk about it a week beforehand to provide information about the nature of the appointment and to make sure that the person you want to meet is not going to the field the week you propose to meet. On Sunday evening or Monday morning, you should make a call to see which day of the week is the most appropriate. On the day of the appointment, you should make another call to confirm the appointment and set a specific time. Even attending the weekly district management committee meeting, which is scheduled to be held every week on Thursdays at 1 o'clock, requires a similar process of confirmation.

These practices of modification are facilitated technologically by mobile phones and practically by the fact that it is not seen as unusual to answer a phone during a meeting or to interrupt a conversation to take or even make a call. Most health workers have more than one phone number, usually two or three, one number from each of the main service providers. This is to be sure always to have coverage from the network and because it is cheaper to call numbers with the same provider. One of these phones is usually the "FLOTTE phone," which is typically a basic cell phone without an internet connection. Instead, the government pays a flat rate that allows unlimited free calls to be made between the FLOTTE phones in the same group. In this way, cell phones become devices of flexibility that allow the action plan to be constantly fine-tuned.

In summary, this further examination of the planning processes shows that they are more organized than appears at first sight. A possible reason for this discrepancy is that they are organized quite differently from the assumptions underlying the data-centric approach. Although health managers do make data-driven action plans, they do not use these plans to organize the day-to-day delivery of health services. Instead, they organize these activities in a much more situated manner, which enables them to take into account the adverse circumstances of unexpected events and the lack of resources that characterizes health service delivery in Burkina Faso. It is a context in which directives from higher levels frequently bypass local plans, where there are insufficient resources to maintain a constant alert and preparedness system to tackle emerging epidemics, and where there is constant insecurity about financing. To be able to get things done requires an ability to deal with these contingencies and to be able to react swiftly to changes. Health managers do this by adopting a flexible and situated approach, where, instead of laying out detailed plans for when to do what, they make plans that are more tentative and can therefore easily be adjusted. They maintain this sense of the tentative both physically, as plans are not written down, as well as in their minds, as there is always an expectation that the daily schedule might have to change. This flexibility is also institutionalized, as the changes have a specific name: off-plan activities. By giving the unplannable this specific label, it becomes easier for health managers and health workers to operationalize it because it can be talked about and integrated into the plans at short notice.

5 | DISCUSSION

The present case shows that health managers use HMIS data to make action plans that serve at least three purposes: to plan activities, including preparing for emergencies, to negotiate finance with the state and external donors, and to monitor progress. These findings show that plans have multiple purposes and serve multiple interests. Health managers use action plans to envisage the future, but this representation is not particularly used to determine actual actions on the ground. Instead, it is used to negotiate the future by asking for funds. Later, the action plans will be used to account for the past through their function as process-monitoring templates. In other words, the action plans based on HMIS data are devices of visibility and accountability to the higher levels of the administration, rather than drivers of action.

While the action plans still function to organize activities, they are often bypassed by unexpected events. Handling these events as they emerge is not about following a plan, but instead about being able to modify the plan. Health managers find ways to create daily order in real time through situated action, such as constant modifications, and practical norms, such as the handling of off-plan activities to smooth accountability. These practices enable most activities to be done despite delays, uncertainty about funding and postponements due to off-plan activities.

In practice, these findings invite us to rethink the function of an HMIS as more than just a data repository but also as a hybrid system consisting of several complementary technologies, in this case the web-based HMIS as well as mobile phones. They accompany each other in supporting communications about what actions to take. The findings could also prompt donors and high-level planners to revisit what they demand of health systems. On the one hand, the expectation is that data should be used to drive local actions, while on the other hand, top-down initiatives are often introduced in a manner that bypasses local analyses. Currently, the health managers at the peripheral levels are balancing these two situations in their daily work. Maybe, it should not be their responsibility alone.

6 | CONCLUSION

The findings of this paper are in line with previous work suggesting that data and plans are limited in their capacity to predetermine human action. However, the analysis also contributes by providing a thick description of how this limitation is managed in a resource-constrained context like Burkina Faso. It appears that the health managers are deeply engaged in creating daily order and that this work is neither irrational nor random, but instead comprises a continuous effort to order and structure daily life by taking into account the adverse circumstances as they emerge. While HMIS are used in these efforts, they are used a little differently than commonly envisaged. HMIS information in the form of plans is not driving action; instead, the plans are actively used to negotiate possibilities for action. However, these possibilities may be hampered by plans from higher levels, suggesting a hierarchy of data use. Technological devices that provide more flexibility than a web-based HMIS, such as mobile phones, and the practical concept of “off-plan activities” are used to navigate beyond the fixed plan in order to adapt to the contingencies health managers experience in their work. In this perspective, the link between data and action is not a matter of the data alone, but also of the human flexibility that is required to create order under adverse circumstances. A practice-centric approach to web-based HMIS helps to identify the effectiveness of these locally developed practices. It reminds us that HMIS design should also aim to support this and that this might include combining a web-based HMIS with other technologies that facilitate discussions around data.

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Stine Loft Rasmussen is a PhD fellow with the HISP network at the department of Informatics, University of Oslo. In her research, she is focusing on exploring health data use as a social practice in the context of the national health sector of Burkina Faso and in particular in relation to the topic of disease surveillance and response. She has extensive experience as a health information systems practitioner, including 6 years of electronic health record development and standardization of clinical content across the 15 University Hospitals in the Capital Region of Denmark. Her research interests include the relationship between technology and social change, sociology of technology, and ICT4D.

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Appendix 5 : Autorisation de Stage

MINISTERE DE LA SANTE
-=-=-=-=-=-=-=-=-=-=
SECRETARIAT GENERAL

N°2015 № -0466 MS/SG

BURKINA FASO
Unité-Progrès-Justice

Ouagadougou le : 23 FEV 2015

AUTORISATION DE STAGE

Je soussignée, **Docteur Djénéba SANON/OUEDRAOGO**, secrétaire générale du Ministère de la Santé, autorise **Mme RASMUSSEN Stine Loft** à effectuer son stage de terrain à la Direction des services informatiques et de la télésanté dans le cadre de ses travaux de recherches doctorales sur l'optimisation des systèmes d'information en santé.

Cette autorisation est délivrée pour servir et valoir ce que de droit

Ampliations:

- CAB (ATCR)
- DSITS
- Intéressé

La secrétaire Générale

La Secrétaire Générale

Docteur Djénéba SANON/OUEDRAOGO

Appendix 6 : Autorisation d’Enquete

MINISTERE DE LA SANTE
-=-=-=-=-

REGION DU CENTRE
-=-=-=-=-
DIRECTION REGIONALE DE LA SANTE DU CENTRE

BURKINA FASO
Unité-Progrès-Justice

Ouagadougou, le 03 JUIN 2016

N°2016- 0745 **/MS/RCEN/DRSC**

AUTORISATION D'ENQUETE

Je soussigné, Directeur Régional de la Santé du Centre, autorise **Stine Loft RASMUSSEN,** étudiante doctorante au programme **« Health Information System Programme » (HISP)** du département informatique de l'Université d'Oslo en Norvège, dans le cadre de ses travaux de recherche à réaliser une enquête sur le thème « **Utilisation des données ENDOS : Exploration des pratiques d'utilisation des informations sanitaires du système d'information sanitaire du Burkina Faso »** dans les districts sanitaires de Baskuy et de Bogodogo dans la région du Centre.

Par ailleurs, je vous invite à déposer un exemplaire du rapport d'enquête à la Direction régionale de la santé du Centre.

Aussi, le document final validé pour l'instance pédagogique de votre institution nous sera-t-il indispensable pour le service de documentation de notre structure.

La présente autorisation est délivrée sur demande de l'intéressée.

Le Directeur régional de la santé du Centre

Dr. Landaogo Soutongonoma Lionel Wilfrid OUEDRAOGO
Médecin de santé publique

Ampliations :
- Districts sanitaires (5)
- Intéressée
- Archives/chrono.

Appendix 7: Invitation DLM

MINISTERE DE LA SANTE

SECRETARIAT GENERAL

DIRECTION GENERALE DE LA SANTE

BURKINA FASO
Unité-Progrès-Justice

N°2017__826__MS/SG/DGS

#. - 8

Ouagadougou, le 12 MAI 2017

Le Directeur général
de la santé
A

Monsieur le Directeur des services informatiques et de la télésanté

- OUAGADOUGOU -

Objet : Echanges et collecte de données sur la surveillance des maladies dans le cadre d'une étude sur les systèmes d'information en santé au Burkina Faso

J'accuse réception de votre lettre à la date du 26 avril 2017, relative à une demande d'échange et de collecte de données sur la surveillance des maladies dans le cadre d'une étude sur les systèmes d'information en santé au Burkina Faso et vous en remercie.

Par la présente, je marque mon accord et j'invite Madame Stine Loft RASMUSSEN à prendre attache avec la Direction de la lutte contre la maladie pour les aspects pratiques.

Ampliation:
- DLM

Le Directeur Général

Dr Salifou KONFE
Chevalier de l'Ordre National