# Working papers in Information Systems



# HANDLING UNCERTAINTY IN DISEASE SURVEILLANCE AND RESPONSE

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#### Handling uncertainty in disease surveillance and response

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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 notknowing? 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 identifies 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.

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# 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 behavioural economics have dealt with the concept of rational behaviour 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 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 behavioural 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, behavioural 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 behaviour 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).

Behavioural 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 behavioural psychology within economics and challenged the idea of rational behaviour 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 wellconsidered 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 unfold 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 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, are many LMICs now in charge of their own data via national HIS repositories that they own and control (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, thereby making methods more, such as through the use of 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 favour 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 everyday 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 becomes 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

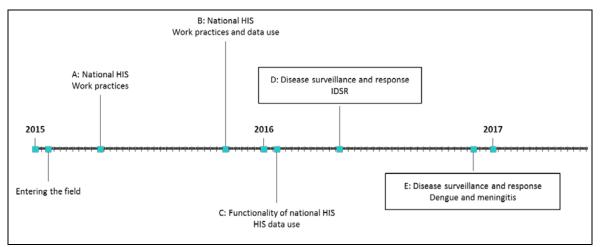


Figure 1. Timeline of Fieldwork.

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
С	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
Е	Interviews and observations	Work practices in disease surveillance and response, dengue and meningitis.	National, Regional, District, Facility

Table 1. Summary of Key Activities.

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 2.** 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

3/2017

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 antimosquito 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 Laboratories).

# 5. Findings

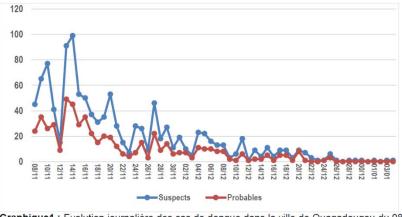
Although dengue is categorized as a neglected tropical disease, there is nevertheless a worldwide increase in cases (Herricks et al., 2017; Stanaway et al., 2016). The increase is biggest in Asia, but recently dengue has also started to develop into larger epidemics in West Africa.

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.

INFORMATION								
	* Some pr	ivate facilities	see rise in cases	5				
			ctor are circulate					
	Reports of	"palu dengue	" on radio and T	V				
	Public facilities see patients with unusual symptoms							
		Dengue s	suspected at publ					
			Dengue ap	pears in MoH w				
				Dengue re	eported regularl	у	No new cases	
2016		_	_		_	_	2017	
Before	Aug	Sep	Oct	Nov	Dec	Jan	After Jan	
Aug								
							Evaluation with partners	
							MoH continues analysis	
					~ .		of outbreak	
	Spraying of central sites in Ouagadougou							
						of TDR testing in		
		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							
				egrated in routir	e surveillance			
				lines circulated				
		·		regions and dis				
			start to prepare a	1	mally			
	veillance done	e via TLOH (d	lengue only part	of monthly				
reporting)								
Pecearch at	t selected sites							

Figure 2. Timeline of the Outbreak.



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

#### Figure 3: 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 highfever 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 "paludengue" 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 would 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 lowresource 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 rumours through social relationships, and informally structuring practices by the making of local protocols. While this might not be an optimal solution, 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 notknowing and partial information is integral to social life and human interaction, and notknowing 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 notknowing 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' is not meant 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.

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