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EPISTEMIC CULTURES OF THE MENINGITIS SURVEILLANCE SYSTEM IN BURKINA FASO

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Epistemic cultures of the meningitis surveillance system in Burkina Faso

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Abstract:
Health information systems are instrumental in promoting the vision that availability of data improves decision-making. However, such a view tends to ignore the multiplicity of rationalities that underpin the information system, and assumes the system should support a truth. The notion of epistemic culture refers to the machinery that produces scientific knowledge, as a way to understand the gap between the world, the multiplicities involved, and the words we use to describe them. Through an analysis of the practices of meningitis surveillance in Burkina Faso, we trace this machinery. In particularly we use the concept of circulating reference to open up different processes of translations and to understand the changes of both substance and information that unfolds through these translations. We find that not only is knowledge shaped by different rationalities, it also relies on more than one epistemic culture, significantly defined by its origins of either information or substance. Furthermore, these flows are based on different temporalities – short and long term – which carry varying tolerances to data precision. This entails questions of how to balance such different cultures in a HIS, as well as to the limits of the HIS to simultaneously support these different cultures.

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1. Introduction

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

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

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

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

We take the domain of disease surveillance and response as our analytical focus to explore this bridge between the world and the depictions of it made in the health system. In the wake of recent large scale outbreaks in the African region, calls have been made to strengthen information systems to support disease surveillance and response (Gostin and

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

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

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

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

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

2. Theoretical Framing

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

2.1 Circulating Reference

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

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

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

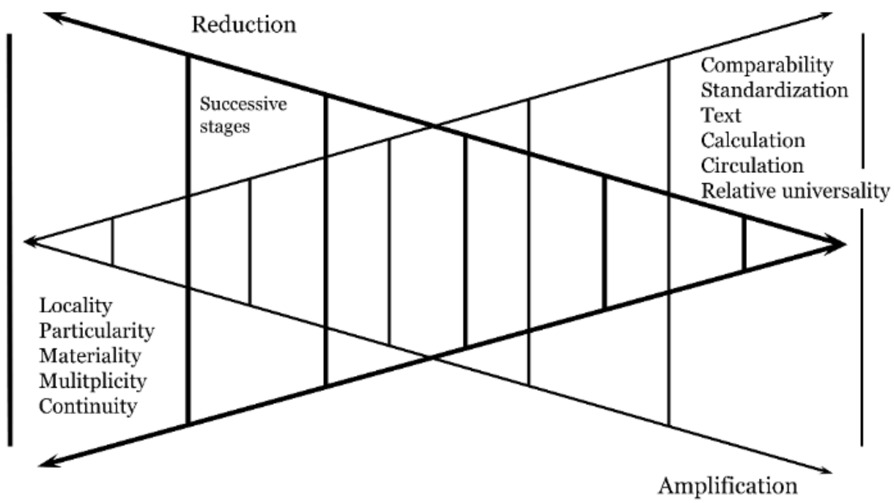

Figure 1: Latour's (Latour 1999a: p. 71) depiction of trade-offs between gains and losses in an information producing process.

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

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

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

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

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

3. Method

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

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

3.1 Data Collection

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

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

Table 1. Number of interviews done and corresponding level

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

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

3.2 Data Analysis

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

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

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

4. Case context and description

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

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

4.1 The Integrated Disease Surveillance and Response system in Burkina Faso

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

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

4.2 The MenAfriVac in Burkina Faso

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

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

5. Case Narrative

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

Regional health data manager

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

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

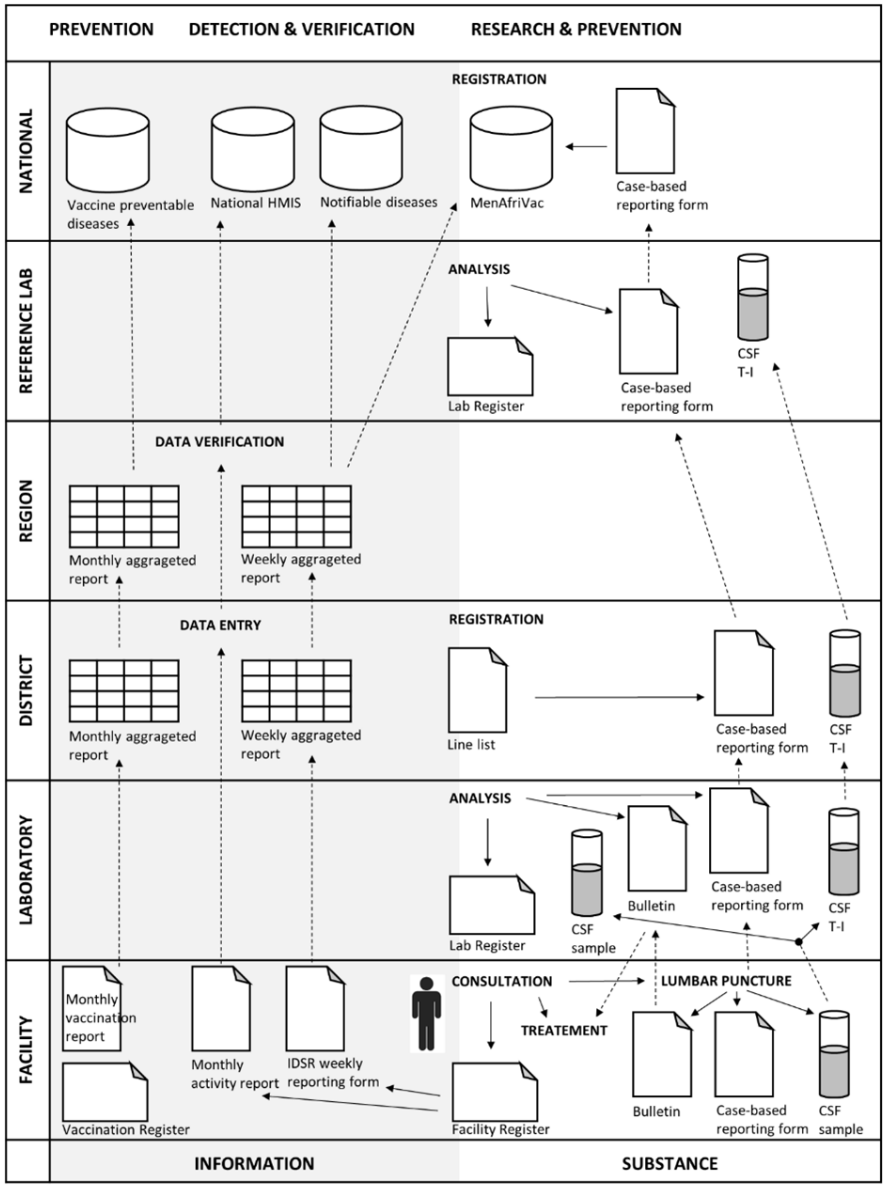

Figure 2: Schematic overview of meningitis-related data flows in the health system of Burkina Faso from health facility to national level

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

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

5.1 Information Flows

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

Researcher/Former district manager

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

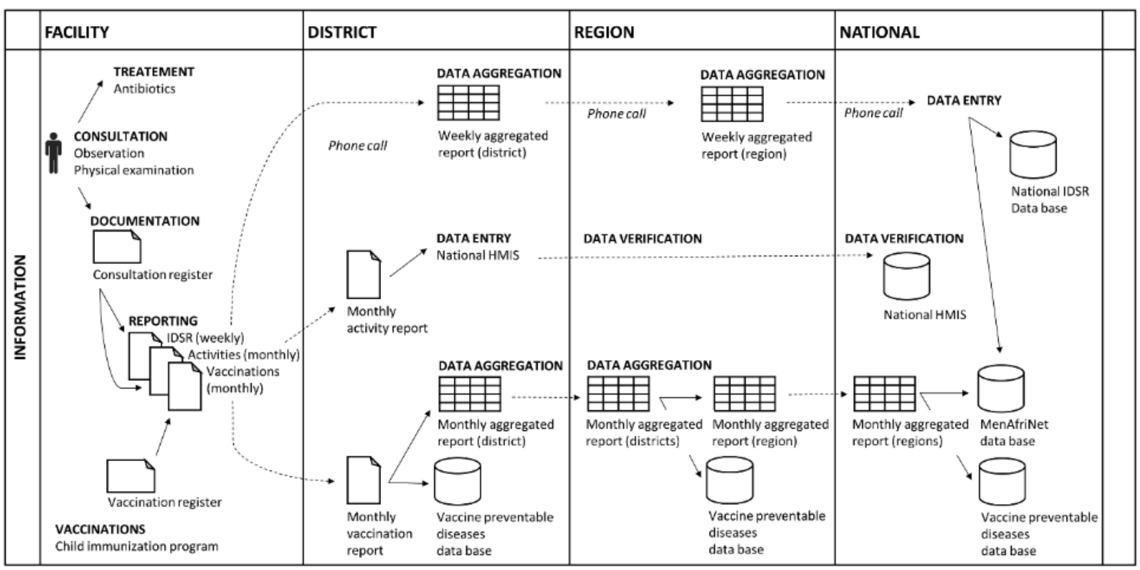

Figure 3: Schematic overview of flow based on information

Health facility level

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

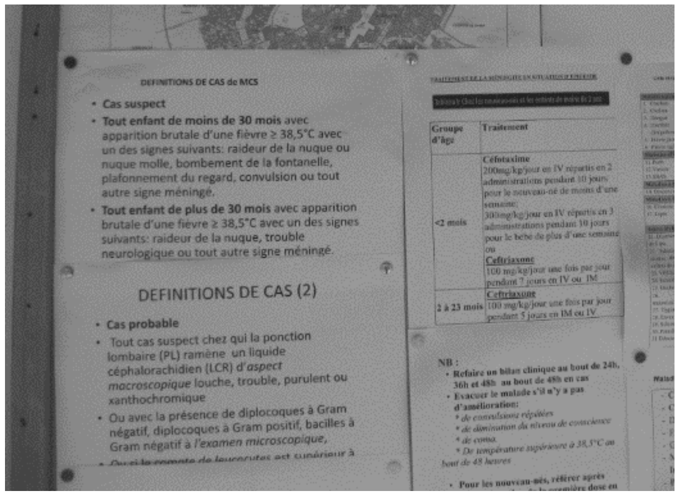

Image 1: Standard case definitions for cerebrospinal meningitis (MCS) as displayed at a health facility

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

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

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

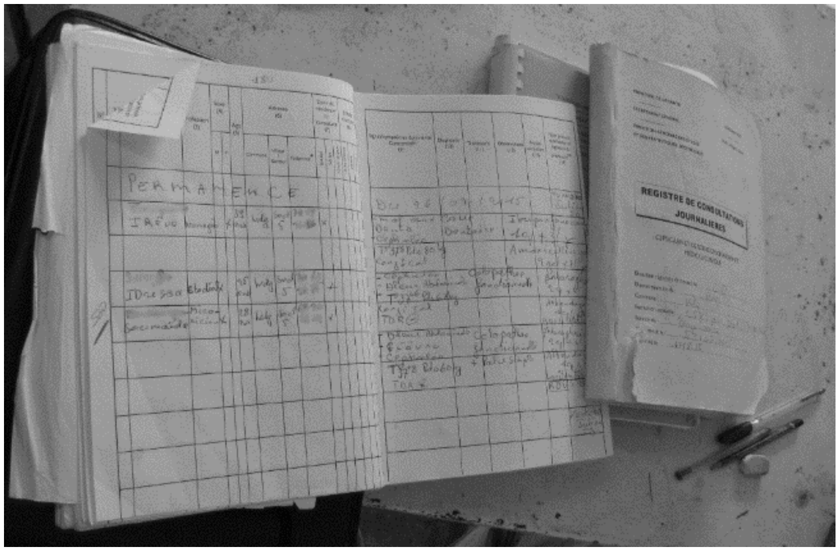

Image 2: Health facility consultation register

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

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

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

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

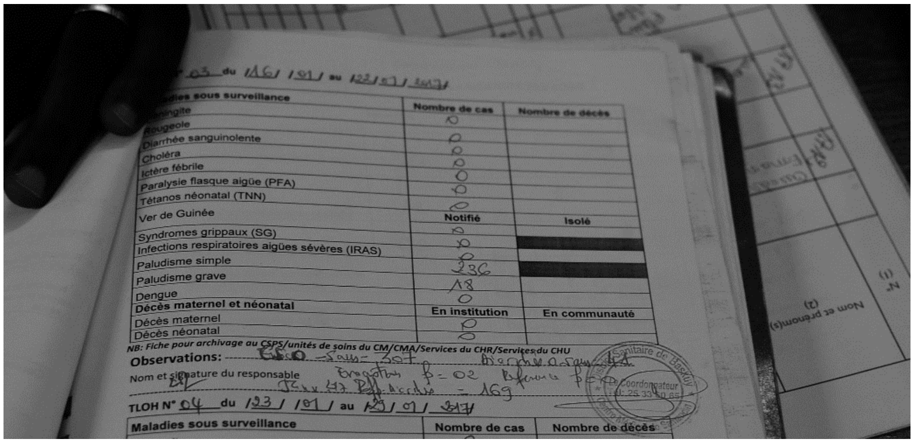

Image 3: Weekly aggregation of suspected cases and deaths of diseases under epidemiological surveillance

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

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

Image 4: Compilation of a monthly health facility report

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

Furthermore, the nurse uses a little sheet to keep track of the aggregations, as it is easy to skip numbers when for example flipping a page.

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

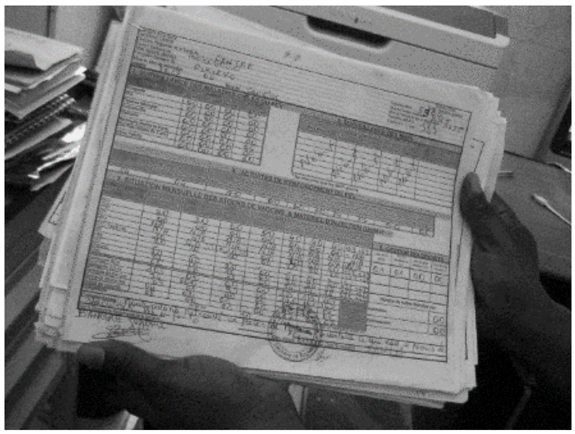

Image 5: Vaccine report compiled monthly by the health facilities.

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

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

District level

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

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

District data manager

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

TELEGRAMME LETTRE OFFICIELLE HEBDOMADAIRE

	REGION	DISTRICT	ANNEE	FORMATIONS SNITAIRES	Semaine	Méningite		Rougeole		Shigellose (Diarrhées sanguinolentes)	
						Cas	Décès	Cas	Décès	Cas	Décès
347	Centre	Baskuy	2016	CNSS	4	0	0	0	0	0	0
348	Centre	Baskuy	2016	CSPS Pogbi	4	1	0	0	0	0	0
349	Centre	Baskuy	2016	CSPS Secteur 03	4	0	0	0	0	0	0
350	Centre	Baskuy	2016	CSPS Secteur 08	4	0	0	0	0	0	0
351	Centre	Baskuy	2016	CSPS Secteur 10	4	0	0	0	0	0	0
352	Centre	Baskuy	2016	CSPS Secteur 12	4	0	0	0	0	0	0
353	Centre	Baskuy	2016	Disp. J.L. Goarnisson	4	0	0	0	0	0	0
354	Centre	Baskuy	2016	Disp. Larlé	4	0	0	1	0	0	0
355	Centre	Baskuy	2016	Lycee Zinda	4	0	0	0	0	0	0
356	Centre	Baskuy	2016	Lycee Nelson	4	0	0	0	0	0	0
357	Centre	Baskuy	2016	Lycee Bogodogo	4	0	0	0	0	0	0
358	Centre	Baskuy	2016	Lycee Bambata	4	0	0	0	0	0	0
359	Centre	Baskuy	2016	Lycee Mixte	4	0	0	0	0	0	0
360	Centre	Baskuy	2016	Lycee Kolog-Naaba	4	0	0	0	0	0	0
361	Centre	Baskuy	2016	Lycee LPRC	4	0	0	0	0	0	0

	Choléra		Fièvre Jaune(Ictère fébrile)		PFA		TMN		Ver de Gui		IRAS		Palu Simpl	Palu grave		Syndromes grippaux	Décès maternels	
	Cas	Décès	Cas	Décès	Cas	Décès	Cas	Décès	Cas notifiés	Cas isolés	Cas	Décès	Cas	Cas	Décès	Cas	Ds les FS	Ds la
347	0	0	0	0	0	0	0	0	0	0	0	0	36	0	0	0	0	(
348	0	0	0	0	0	0	0	0	0	0	0	0	201	20	0	0	0	(
349	0	0	0	0	0	0	0	0	0	0	0	0	56	1	0	0	0	(
350	0	0	0	0	0	0	0	0	0	0	0	0	98	24	0	0	0	(
351	0	0	0	0	0	0	0	0	0	0	0	0	61	0	0	0	0	(
352	0	0	0	0	0	0	0	0	0	0	0	0	68	5	0	0	0	(
353	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	(
354	0	0	0	0	0	0	0	0	0	0	0	0	35	4	0	0	0	(
355	0	0	0	0	0	0	0	0	0	0	0	0	15	0	0	0	0	(
356	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	(
357	0	0	0	0	0	0	0	0	0	0	0	0	13	0	0	0	0	(
358	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	(
359	0	0	0	0	0	0	0	0	0	0	0	0				0	0	(
360	0	0	0	0	0	0	0	0	0	0	0	0	3	0	0	0	0	(
361	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	(

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

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

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

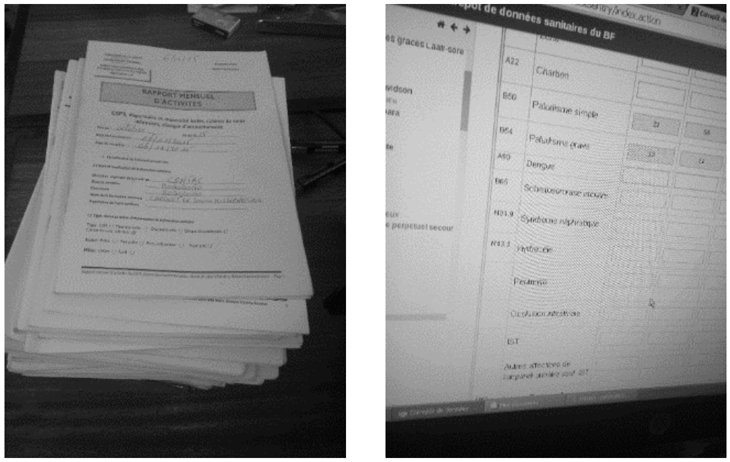

Image 7: Monthly reports from health facilities (left). Data entry screen of national HMIS (right)

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

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

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

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

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

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

Regional level

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

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

National level

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

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

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

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

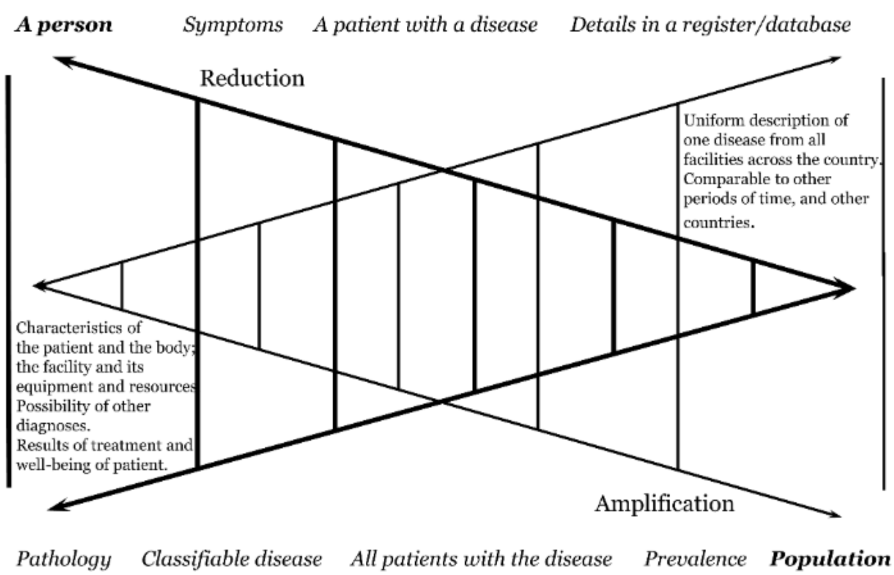

Figure 4: Summary of losses and gains in the information-based flow. Based on Latour's (Latour 1999a) dichotomy

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

5.2 Substance Flows

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

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

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

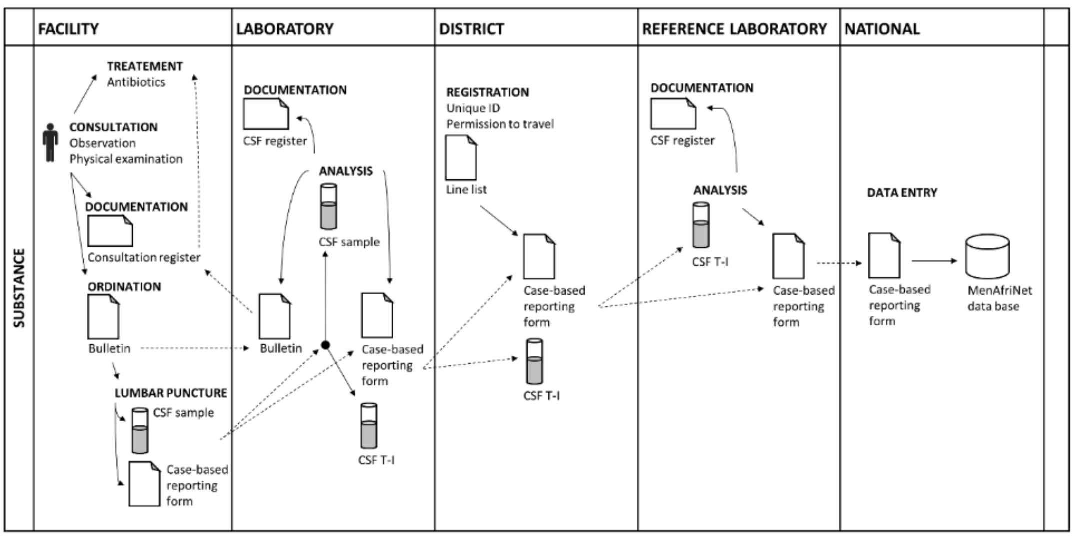

Figure 5: Schematic overview of flow based on substance

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

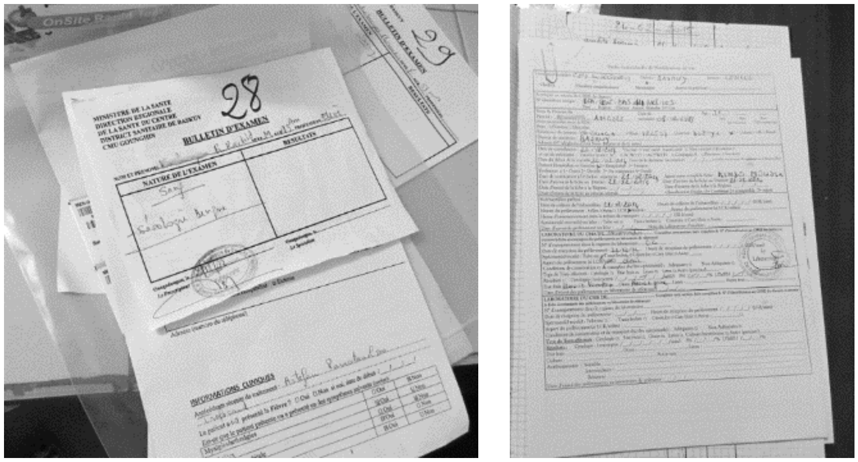

Image 9: Examples of request slip (left) and notification sheet (right)

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

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

Image 10: Kit for doing a CSF sample

To be able to retrieve the sample, the nurse asks the patient to lie down on either side with the back curved. With an injection needle, the nurse withdraws a small amount of CSF (cerebrospinal fluid) from the patient's spine. The sample is stored in a sterile tube. This is the first translation taking place in this chain. Mediated by the testing kit, the CSF is translated from being part of the patient's body – a biological ecosystem – to a sample of a specific fluid that can be further analyzed. It is reduced to a small sample losing its ability to support the body of the patient but on the other hand gaining the ability to transmit further information about bacterial meningococcal disease. If the patient is suffering from meningococcal disease due to bacteria, the sample will contain these bacteria. This can be suspected already when the liquid is withdrawn from the patient.

Cerebrospinal fluid from a patient who is not sick is clear, while it is cloudy when infected by bacteria. This information is recorded on the notification sheet.

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

Health facility laboratory

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

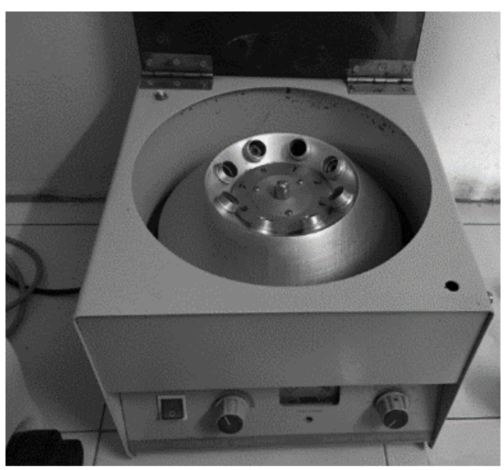

Image 11: A centrifuging machine

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

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

Health district

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

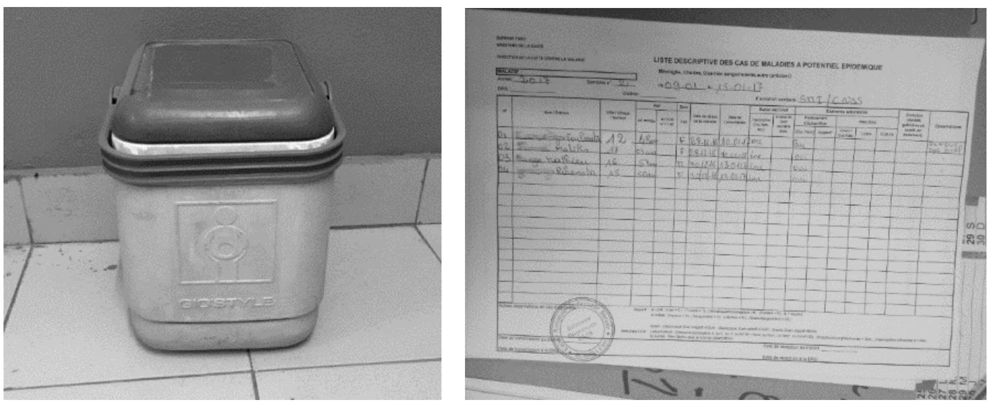

Image 12: Transportation box (left). Generic district line list (right)

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

Reference laboratory

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

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

Ministry of health

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

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

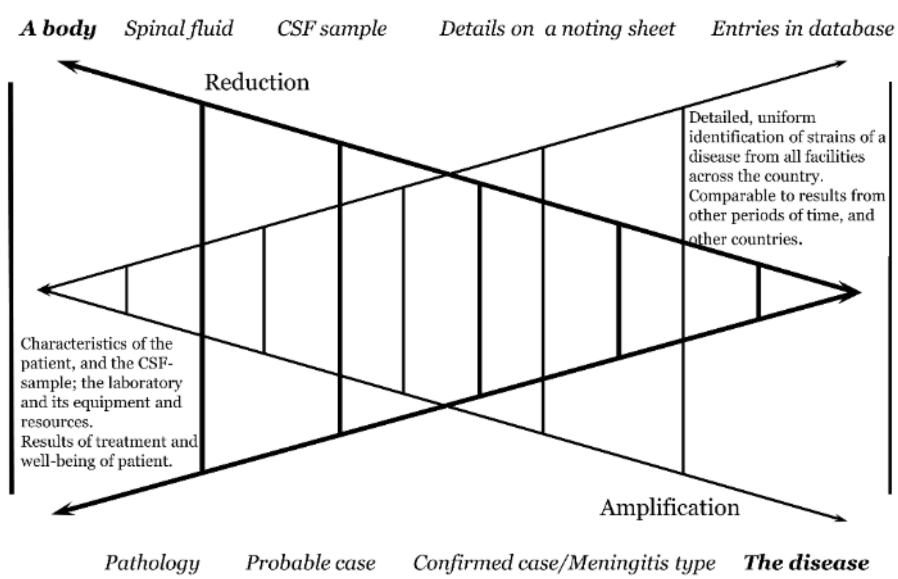

Figure 6: Summary of losses and gains in the substance-based flow. Based on Latour's (Latour 1999a) dichotomy.

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

6. Analysis

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

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

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

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

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

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

7. Conclusion

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

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

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