Community network or community-based health insurances (*mutuelles*)? An exploratory study of family illness and *Couverture Maladie Universelle* in Northern Senegal

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The relationships formed with many participants is one stronger than "study participation" can describe. Intimate knowledge and experience of livelihoods and home lives combined with the wonders of mobile communication has made for connections that endure the separation of space. I am so privileged to have the opportunity to know such people.

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Long before I ever thought of Norway for a master's degree, I was regularly reading and speaking the phrase *Kjøre på,* as a Boy Scout thanks to my scoutmaster. The lessons about carrying on whether in the middle of Theodore Roosevelt National Park or typing in a socially-distanced student apartment have taught me to keep at it and drive on.

Abstract

Across the world and especially in the Global South, governments are rapidly transitioning their nations and health care sectors, in the pursuit of Universal Health Coverage (UHC). As international aid organizations and decision makers advocate for a future where all have financial protection and accessible care of good quality, researchers and anthropologists are attentively taking account of how this progression meets and intervenes in citizens' lives. With great promise for its potential and high priority in the Republic of Senegal´s current administration, the pursuit of Universal Health Coverage is an agent of change. Senegal´s UHC program focuses on *mutuelles* (community-based health insurance) schemes and user fee exemptions. I conducted fieldwork over a five-month period of fieldwork in the rural town of Linguere to investigate the unfolding of UHC policies on the ground. Over the time I lived in town I came to know and participate in the lives of different community members as they pursued treatment for ill health. Study participants included key health persons, such as health care providers and mutuelle scheme leaders, and various members of the informal sector. During these months and over the course of data analysis it became evident that uncertainty is confronted time and again in the process of treatment and that it is an essential part of life for Senegalese families interacting with the health system. Uncertainty also dominated people´s experiences of local *mutuelle* insurance schemes, user fee exemptions, financial means for treatment, and the form of treatment the illness demands. It is apparent, through my research, that the state's priorities for UHC actually play a limited role in the ways many Senegalese pay for medical treatment and healthcare costs, and that levels of uncertainty in these different options must be weighed and navigated before and throughout the treatment of the ill. Finally, the limited role of the state points to how a scenario where achieving high levels of *mutuelle* membership may be reached, but shortcomings in its implementation must be addressed before it can seriously be considered.

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Abbreviations to be used:

Abt Associates	The Company offers services in the fields of social policy, clinical trials, economic and health policy, international development, research and evaluation, data collection and management, and strategy planning. (Abt Associates Profile, Bloomberg Web Accessed 10 July 2020)
CBHI	Community-Based Health Insurance
CMU	*Couverture Maladie Universelle*, The Universal Healthcare Coverage Program under implementation in Senegal
DECAM	Decentralization of Health Insurance (*Desentralisation de l'assurance maladie*)
MDGs	Millenium Development Goals
SDGs	Sustainable Development Goals
SAPs	Structural Adjustment Policies
UHC	Universal Health Coverage
UN	United Nations
USAID	United States Agency for International Development
WHO	World Health Organization

Keywords: Social Protection, Universal Health Coverage, Senegal, uncertainty

Chapter 1. Introduction, research objectives and questions

Universal Health Coverage was defined in the 2005 World Health Report as access to necessary health services with protection from financial risk. In recent years, Universal Health Coverage (UHC) has been discussed extensively in the global health and economics literature. International goals like the Millennium Development Goals and Sustainable Development Goals continue to focus on improving health for the world's population, and UHC was included in the SGDs in 2015. Recommended by the World Health Organization (WHO), across the world, different governments have proposed and implemented various policies to bring improved health coverage and quality of care to their country's people. Africa has been a focus of international policies, such as the African Union's Africa 2063 Agenda, a document signed by members of the African Union stating that by 2063, "African people (will) have a high standard of living, and quality of life, sound health and well-being" (Agenda 2063, 2015, p. 2). The WHO Regional Office for Africa is advocating that by 2030 Member States "will have health systems that are performing optimally for effective delivery of an essential package of health and related services" with "at least 80% of their populations utilizing the identified services" (WHO Africa, 2017). In Africa especially, the shifting economics and demographics of the continent establish a need for new health priorities. Financial coverage and financial protection have been a key part of the move towards UHC. Health systems depend on mechanisms of financial support for users to ensure sustainability and services as well as facilitate campaigns and change (Garret et al., 2009, p. 1294). One method of extending health coverage in different countries, such as Senegal, has been through the expansion of health insurance programs such as Community-Based Health Insurance (CBHI) or *mutuelles* as they are known regionally and locally.

Having previously lived in Senegal for 10 months through a volunteer program based in the practice of accompaniment, I already had a basic understanding of society and numerous contacts. During this time, I lived with a host family and was learning the local Wolof language. The time immersed in a different culture was a positive experience that helped me to live in community and one simpler than that in my home of the United States. The chance to reconnect and strengthen these relationships by returning to Senegal for ethnographic fieldwork on people's use of community-based health insurance was a rare opportunity.

In this introduction, I will present Universal Health Coverage and the context of moves towards UHC internationally. Financial protection and health insurance have figured prominently in these historic moves, and such is also the case in Senegal, where I have conducted my research. My research began with a focus on community health insurance and household treatment of illness, aiming to offer evidence of how these insurance schemes work (and do not) for ordinary people in situations of ill health.

1.1.1 Steps Towards Universal Health Coverage on the African continent

The road to Universal Health Coverage (UHC) is being pursued in different ways by various countries around the world. This has been further shaped by the 2019 United Nations General Assembly, where it was agreed that countries would approach UHC differently, finding their own way and their own strategies forward. The push for UHC has been underscored by the international community through Sustainable Development Goal 3 of the post-2015 development goals and the 2013 release of the Africa Union's "Africa 2063 Agenda." SDG 3 maintains the broad focus of healthy lives and well-being for all people at all ages. This idealistic concept is broken down into categories for focus. SDG 3.8 outlines the goal of UHC to include financial risk protection, where catastrophic health expenditures are avoided, in addition to access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all. Universal health coverage (UHC) is thus defined by the WHO that all people and communities can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship (World Health Organization, 2010).

A variety of actions have been proposed and implemented to realize UHC, but have not been met without criticism (Sanders et al., 2019). These moves and policy pushes occur in an African context that has experienced a variety of global health approaches (Prince, 2014), most of which focus on single-disease programs. Moves towards UHC are more ambitious, aimed at the whole population. However, in the wake of "structural adjustment" policies (SAPs), African governments are often ineffective and inefficient at providing health services to their citizens (Prince, 2014), particularly as they operate under severe resource scarcity.

UHC proposes a new direction in funding health systems in Africa. In retrospect, the World Bank has acknowledged that previous SAPs recommending users pay into the health systems of poor countries were regressive, entrenching many communities further into poverty (Soors et al., 2010). Policies of international donors and global financial institutions have been implemented in postcolonial African countries as a result of shifts in global and national economies (Prince, 2013, p. 115). A look at recent history is required to have perspective on these policy decisions. Mkandawire has pointed out that, “In the first two decades after independence, health, education, and social protectionism became a central part of the nation-building project and a central demand by the public of their government” (Mkandawire, quoted in Prince, 2014, p. 18-19). However, this period of investment coincided with oil and debt crises of the 1970s that resulted in the IMF making loans to African governments, which were presented on conditions that governments downsize capacities and encourage privatization of health services. Western governments and international institutions thus imposed structural adjustment programs, and policies of neoliberalism in poor countries when the country governments accepted IMF-Wall Street-US Treasury money during financial crises (Harvey 2005). During this spread of neoliberal policies in the 1980s and 1990s, “responsibility for health development in African countries increasingly shifted out of the hands of ministries of health and into a globalized policy environment, dominated by the World Bank and IMF” as Janes has pointed out (Janes 2004 quoted in Prince, 2014, p. 23). Through acceptance of these policies, governments agreed to dramatic privatization and commodification of public assets, such as social welfare provisions and healthcare (Harvey, 2005, p. 160). For members of the informal sector around the world – that is, people who do not have formal employment –an increased burden of healthcare financing has been placed on the poor through the removal of healthcare protections and spread of user fees (Harvey, 2005, p. 171).

International policies have had effects that can be seen at national and local levels. Research in Senegal showed that decentralization through the ‘Bamako Initiative’ altered the financing schemes of health facilities, such that the government played a lesser role, while in-house pharmaceutical sales was chosen to play a large role in each facility’s financial stability (Foley, 2010). These policies were implemented in the midst of decentralization in national policies which have shaped the context of decision making and dynamics of power. Turshen has argued that decentralization can lead to an expansion in power among local elites, where prevailing inequalities are increased (Turshen, 1999, quoted in Foley, 2010).

In Senegal, different levels of power and wealth have been integral to the country’s history from precolonial caste systems to colonial times, to current differences seen through location and employment. (Foley, 2010, p. 10). As health policy is rolled out, it may take a different shape in these local environments of socio-economic inequality. Meanwhile, community management, participation, and state-citizen partnerships for health have become key points in Senegal's national health policy (Foley, 2010, p. 60). The categories of civil society or community can obscure varieties of social inequality, class, ethnicity, and gender, as Janes argues (2004 cited in Foley, 2010). It is of interest to me how UHC in Senegal, claiming to include the community, and claiming to have 'universal' reach, addresses health financing and financial protection for Senegalese citizens. Below I discuss Senegal's approach to UHC (known in French as *Couverture Maladie Universelle* or *CMU* for short), focusing on moves to expand health insurance programs.

1.1.2 UHC financial mechanisms and health insurance programs

One method of addressing a nations' financial health hurdles has been through the implementation of health insurance schemes. 'Financial protection for healthcare is the main aim of health insurance. If a range of health outcomes improves or death rates decline for the insured, it is possible that we can attribute better health outcomes to health insurance' (Acharya et al., 2012, p. 260). Such policies are important in working towards UHC, but more opportunities for health financing do not guarantee that other shortcomings in the UHC terrain are solved. Financial coverage of a benefit does not ensure delivery or quality of care; patient demand for and availability of the service are also necessary (Lagomarsino et al., 2012, p. 940). As UHC policies are implemented and endure, the role of health insurance-centered approaches to UHC (if any) on quality and delivery of healthcare will be questioned and explored. Components of current policy that set it apart from previous examples of health insurance and coverage are likely to have meaning, given past trends.

Many health insurance rollouts assume that, as opportunities for health financing grow and gain traction, health measures will improve. However, empirical research findings have not always shown that population health systematically improves in response to enhanced risk pooling and prepayment (Moreno-Serra, 2012, p. 918). Challenges with implementation and enrollment also loom large. 'Although insurance schemes can have an important role to play, so far they have been unable to contribute substantially to universal coverage in low income countries, and millions of people remain excluded from access to health services (Oxfam, 2008, p. 18). Particularly, poor people and members of the informal sector often do not participate in community based health insurance programs (Soors et al., 2010, p. 85), even when these programs are designed to include them. ‘Enrollment seems to be related to perceptions, education, and cultural factors rather than to factors related to health and health care’ (Acharya et al., 2012, p. 261) in addition to economic factors. Internationally, Community-Based Health Insurance schemes (CBHI) have accrued little success, as not all of the population can utilize these programs, and participation in them largely depends on one’s relation to scheme leaders, and thus on forms of trust and social connection (Soors, Devadasan, Durairaj, & Criel, 2010, 7).

As health financing via health insurance is suggested as a means of achieving UHC, this study will explore how relevant these general critiques of health insurance are to Senegal’s context, and to the ways ordinary people in Senegal access health services, health insurance and other forms of economic support when faced with illness and health crises in their families. It will do so by embedding research in people’s lives and in following their pathways of accessing healthcare through an in-depth qualitative study. Before I give details of the research design and methods, I will first examine Senegal’s moves towards Universal Health Coverage and its landscape of community health insurance schemes.

1.1.3 UHC: free initiatives and health insurance schemes in Senegal

The Senegalese Universal Health Coverage program (*Couverture Maladie Universelle* or *CMU*) was announced in 2013 by President Macky Sall. The office was under operation in 2017 (*Agence de la CMU*) with formal rollouts of the program taking place. The CMU Program relies on three pillars, which include free initiatives, and multiple formal systems of health insurance, tailored to formal and informal workers (*Ministère de la Santé et de l’Action Sociale*, 2012). Free initiatives include kidney dialysis, caesarean sections, and user fee exemptions which include consultation ticket exemptions at health facilities for children under 5 years, and free consultations as well as medical tests for adults of 60 years or more. Health insurance schemes are not new in Senegal and target people both earning a living through working informally and through formal employment. Formal social health insurance schemes that support individuals who have formal, regular employment and their families have been in place since the 1960s and 1970s. Currently groups of the employees and government schemes provide coverage to these formal workers. Schemes to meet the rural populations, farmers, and informally, irregularly employed populations have been rolled out in recent years under the name *Les Mutuelles de Santé*. The *Les Mutuelles de Santé* (shortened to *mutuelles*) or community health insurance schemes, refers to local insurance schemes that are developed in concert with an NGO partner or private organization, which are currently being connected to the government via the *CMU* program. The term *mutuelle*, however, also refers to health insurance schemes more generally such as those for government employees and private schemes made up of different members of the formally employed, as discussed. This terminology can be confusing, and in my discussion of these *mutuelles* I therefore explicitly differentiate the community level local scheme and better established national schemes. The most well-known *mutuelle* scheme in Senegal and one subject to much research is a community health insurance scheme in the major city of Thies, where a scheme between the Catholic hospital and the community has enrolled significant portions of the population (Mladovsky, 2014).

Individuals with irregular employment make up roughly 80% of Senegal's working-age population and have been left behind by previous health reforms (*Ministère de la Santé et de l'Action Sociale*, 2012). Across Senegal, *mutuelles* are being established and joined in and by an increasing number of communities with the aim of reaching 90% of the population by 2022 (*ibid.*). Many *mutuelles* schemes are community run, meaning that they are decentralized and the services, dues, and memberships function through the local scheme organizers and vary by community, with enrollment based upon the head of the household. The 2013 shift in political will concerning *UHC* has placed the state at the forefront of *mutuelle* scheme development, which was previously conducted to a large degree by NGOs and international donors (Mbengue, Sene, & Camara, 2014).

These policies have been implemented in a context still very much encountering effects of colonial systems and SAPs. Meanwhile decentralization of the healthcare system, which was implemented in 1997, has had detrimental consequences for health equity (Foley, 2010). During these policy changes, budgeted funds rarely went towards the development of health facilities, instead being caught between local health committees and health employees with access to pharmaceuticals. This sea change of decentralization included the use of new buzz words, such as participation, community management, and state-citizenship partnership for health (Foley, 2010, p. 60). The effects of decentralization along with the Bamako Initiative (introduced above) shifted the idea of a patient to a consumer who chooses to utilize a health service (*ibid.*). These free market ideologies were developed as power and the flow of resources transitioned from national leadership to a regional and local environment apt to exploit local inequality and power dynamics (Foley, 2010, p. 61). This has occurred even though people in

Senegal face constant economic constraints, and some severe economic hardships. This trend towards divestment and resource scarcity combined with long-term consequences of SAPs has weakened the health system (Foley, 2010, p. 69). As insurance schemes are organized and created under the auspices of UHC, it is in this context that these fragmented financing mechanisms look to contact the population and enter citizens into these systems (Mladovsky, 2020).

Various members and groups of the population are affected differently by the implementation of insurance schemes. I am interested in the extent to which these insurance schemes actually help people during illness events and crisis. As these policies are put in place, people still seek care and treatment from various sources, including the public system, private providers, NGOs, and traditional practitioners. I am interested in the therapeutic itineraries (Foley, 2010, p. 111) people follow. Considerations of cost, efficacy, and accessibility (geographic and social) are factored into therapeutic itineraries (*ibid.*). Government and government affiliates are advocating the current financing mechanisms of insurance and user fee exemptions to the general population. It is of interest to me how *mutuelles* factor into these therapeutic itineraries and to what extent *mutuelles* provide social protection. This is an important question because the *CMU* largely depends on voluntary recruitment into *mutuelles* to reach the greater informal and underemployed population. As citizens are recommended to enroll, reports of insufficient funding by the state and limited availability of services covered at health facilities have been reported (Mladovsky, 2014). Strengthening forms of financial support through *mutuelle* membership occurs in a context in which there already exists various forms of financing illness treatment, including, in some cases, NGO care provision or assistance, but more commonly family contributions, and money pooling groups derived from people's social networks.

There are several studies that have investigated the functioning and effects of *mutuelles* in Senegal. Quantitative studies to date have accounted for the effects of financing healthcare through community participation on healthcare access (Jütting, 2003) and the influence of social capital (e.g. one's relationships and social networks) in *mutuelles* enrollment (Mladovsky, 2014). Qualitative studies have examined the factors that influence enrollment like 'social capital', that is how 'the information, trust and norms of reciprocity inhering in one's social network' (Woolcock, 1998 cited in Mladovsky, 2014) influence the level of scheme participation with dropout (Mladovsky, 2014), meanings of leadership and outside decision making (Mladovsky, 2014). Investigations of terms and benefits which increase *mutuelles* adherence (Ndiaye et al., 2015) and quality of care have also been made (Sagna et al., 2016).

While researchers have considered definitions of solidarity, willingness to pay, and social capital as related to *mutuelles* and how effective *mutuelles* implementation has been, little has been done to assess the actions people are taking to seek and engage economic and social support when negotiating health dilemmas. People make complex decisions and undertake diverse actions in their communities, often and seemingly far removed from the effects of global neoliberal and national policies. Research for these published studies has occurred in years past, hence is rather out-of-date, and the need for a qualitative understanding of the Universal Healthcare Coverage program in Senegal that has developed over the past couple of years is evident. Qualitative understandings of the ways people interact with policy rollout, like health insurance scheme use, must be considered as governments radically reshape the structure, organization and financial underpinnings of their health systems (Foley, 2010, p. 80).

In designing, conducting my research, and analyzing research findings, I have drawn heavily on approaches and methods from medical anthropology. Medical anthropology is well-positioned to inquire about the concept of UHC, including how individuals encounter the concept and policies entering into their daily lives (Prince, 2017; Abadia-Barrero & Bugbee, 2019). Ethnography is the study of naturally occurring phenomena in their natural context by understanding social relations, normally through long-term immersion (Princeton Anthropology Website, 2020). It is particularly suited to gathering local practices, perspectives and understandings, as its iterative, immersive nature creates opportunities for daily routines to be considered and the nuances that accompany them to show through. Regular interaction with people in the context of their lives allows the researcher to intimately understand others' livelihoods and responsibilities. Understanding how these day-to-day experiences intersect with sudden and timely needs such as that of illness and healthcare leads to data collection more closely representing lived lives. Perspectives of individuals and their support network navigating the various treatment establishments over time have been absent from the primary research literature on UHC in West Africa. This study has focused on the understanding of individual treatment trajectories and the considerations of insurance scheme staff as Universal Health Coverage is rolled out in Senegal. As different policies are implemented by national and international interests, developing contextualized accounts of how people on the local level and in the informal sector are affected, becomes increasingly necessary.

Having lived in the rural northern town of Linguere, Senegal for a year (in 2017-2018), and studied the Wolof language during my entire stay, I decided to return to Linguere for this exploratory study, and this is where my findings are located.

1.2 Local Context: health care and *mutuelles* in Linguere

I carried out my fieldwork in a market town in rural Northern Senegal called Linguere. Due to previous time (in 2017-2018) in this town as a volunteer with a church program, I selected this *department* town. The town is the head of a *department* which is similar to the county level of government. A variety of resources and services accompany the town of approximately 10,000 inhabitants, including different health structures, educational opportunities, and offices. In this section, I focus on the health system and health-care facilities available to people living in Linguere.

When seeking treatment, the ill may go to the health structures or pharmacies, (where they may partially pay via a *mutuelle*) and/or traditional healers for remedies and care. In the Senegalese public health system there are four levels of structures. Health huts serve as the lowest level, followed by health posts, health centers, and hospitals. The population of Linguere and the surrounding area are served by a health center and a primary level hospital. Services available in the hospital include general surgery, maternity care, obstetric-gynecological, emergency & trauma, dental, ophthalmological, pediatrics, and primary care. Services at the hospital and medications are currently purchased out of pocket, unless one fits the criteria of the *CMU* program's free initiatives (see above) or one pays a percentage through membership in a *mutuelle*. There is also the social service in a different office and independent from the oversight of the CMU and local *mutuelle* scheme discussed here as *La mutuelle de la ville*. Its role is to cover treatments that the poorest patients cannot afford, through the social worker's discretion. Linguere hospital has a social service, however not all hospitals contain a social service to assist treatment and far from all treatments are covered, as the budget is limited (I did not get a number from the social worker or hospital staff). A consultation with a physician at the health center (1,000 cfa, $2 USD) is less costly than a consultation at the town hospital (1,500 cfa, $3 USD). Public pharmacies at the health center and the hospital sell subsidized pharmaceuticals. When inventories are out of stock, however, patients must visit one of the two private pharmacies in town, which sell pharmaceuticals (as well as powdered milk and personal care products) at higher prices. A Senegalese NGO with an office in town, funded by

American and Canadian religious organizations, also participates in the health system - distributing pharmaceuticals to surrounding health huts, discounting medications and health products to the poor, as well as putting on educational and social events. Patients requiring treatment beyond the services provided locally may be referred to regional hospital facilities or to hospitals in the capital, Dakar. Regional hospitals are in Louga or Touba, each 2,500 cfa ($5 USD) by car one way at 130 km and 115 km respectively. Psychiatric services are available in Touba or the capital city.

In Linguere, a *mutuelle* was established by USAID and Abt Associates, an international contractor often cooperating with US foreign aid, in 2002. This private *mutuelle* is subsidized (but has yet to receive funding) under the auspices of the Senegalese government's *Couverture Maladie Universelle* (CMU) program for Universal Health Coverage since being brought into the scheme in 2017. A membership booklet costs 1,000 cfa, and this is purchased by the household head, who is termed the "beneficiary." Each family member must be enrolled individually under this beneficiary's membership booklet at a cost of 3,500 cfa ($7 USD) per person. There are currently approximately 3,000 beneficiaries and 7,000 members enrolled, including citizens of surrounding villages that can make regular visit on market days. Membership has increased under recent solicitation since 2019 by the mayor of Linguere (who is also the interior minister of the current administration). His interest in the program led to the creation of the "2,000/2,000 Program" where the Ministry of Health covers 2,000 cfa ($4 USD) of the yearly membership dues for the first 2,000 individuals to enroll each year. The scheme pays for 80% of service costs when patients seek care at the state health center and 50% of service costs at the state hospital. *La mutuelle de la ville* covers 80% of pharmaceutical costs when purchased in the hospital or health center. An agreement with one of the private pharmacies covers 50% of pharmaceutical costs up to 7,500 cfa ($15 USD), excluding medication for diabetes and hypertension. According to the scheme president, this scheme is aimed at serving the poor (who have irregular and minimal income) as shown by its low cost to enroll and the portion rather than full coverage of the different services it covers. A manager carries out day-to-day work associated with the *La mutuelle de la ville's* functioning in a simple office located at the local health center. She is the only employee of *La mutuelle de la ville*. Here, the manager enrolls patients and furnishes *La mutuelle de la ville's* guarantee letter – a form torn from the register, which indicates that the patient has a valid *La mutuelle de la ville* membership, and is entitled to receive discounted services on its behalf. The manager furnishes this form to *La mutuelle de la ville* members seeking care at the health center or pharmaceuticals from private pharmacies. The manager completes this for the patient and then writes the total expense and cost covered by the *La mutuelle de la ville* in a ledger. *La mutuelle de la ville* also has an elected president, who is tasked with leading meetings of *La mutuelle de la ville* assembly and the control committee, as well as approving treatment at the hospital for members referred there for care. The community based nature of this *mutuelle* means that there are representatives from the 13 neighborhoods in town who make up the 'general assembly' which votes on who will serve in positions on the control committee including president, general secretary, treasurer and 3 at-large members. This kind of representation and structure makes it community based, with both men and women taking part.

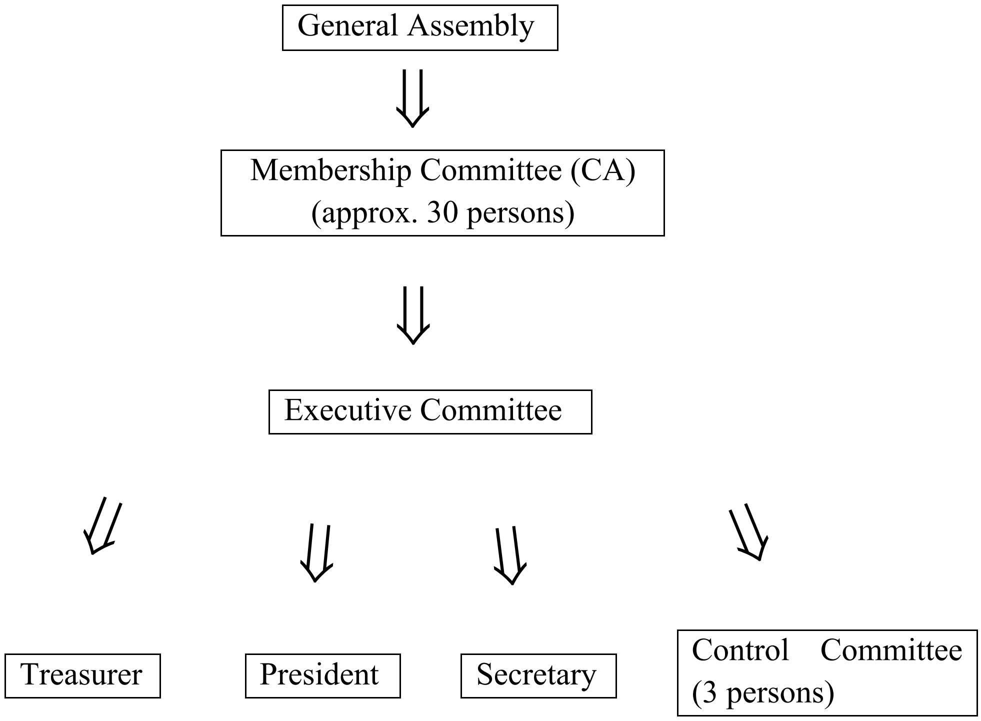

Figure 1 The leadership structure of *La mutuelle de la ville*. Every organization and neighborhood selects members to represent them in the General Assembly. The General Assembly then votes on the following committees and groups. The mutuelle manager was appointed independently.

Other forms of health insurance for town residents are provided through employment. These include *Institute de Prevoyance Maladie* (IPMs) for the privately employed (which have a central leadership in the capital rather than being community run), government health insurance schemes for those employed in the formal public sector, and other types of private *mutuelles*, which groups of employees have set up independently of the state and employers. I was able to learn more about the Catholic teachers' *mutuelle* and a private *mutuelle* created by teachers in town who work in the public schools. Coverage can vary from 50% to 100% for each benefit from hospitalization to pharmaceutical purchase. For those in formal employment, monthly membership fees removed from one's salary each month are the most common form of contribution. Enrollment in these different schemes depends on how and if the household head and family members are employed.

Like the rest of Senegal, a large percentage of people of working age are unemployed or underemployed in Linguere. Teachers, government office jobs, and health workers (or workers at healthcare structures) include the more reliable job opportunities, while being a shopkeeper, farmer, herder, craftsperson, or maker of foods and drinks are some other common livelihoods. Linguere does not have a well-developed formal economy, and it is common for only one person in a household of various (5-8) extended family members (rarely a nuclear household) to have regular formal or informal earnings. Others may contribute with small jobs known as *tabba tabba* in Wolof, where one sells juices, foods, home products, or clothing from their home or walking around the neighborhood. Illness treatment is often dependent on the incomes earned by family members, as demonstrated by participants in this study.

Outside the formal health care system, traditional healers are the most common practitioners consulted by the ill in Linguere, according to my informants. These specialists are regularly visited, especially given that Senegal's formal health system is not accessible to all of the population due to cost or distance. A similar outlook exists in other African countries (Akyeampong, 2013). The fact that these practitioners offer patients and their families more time and a local understanding of illness serve as additional reasons to consult such practitioners. In Senegal, the population is largely Muslim. Muslim healers called *marabouts* or *serignes* are a type of local healer in Senegal. The ill may be brought to the *marabout*, or a family member may pay them a visit. Over the course of fieldwork, I have learned that many Senegalese approach the spiritual world as another dimension of our world, which we cannot see or inhabit. Well and ill-intentioned spirits, exist here, not so different from the intentions of people, whose actions in the spiritual world have consequences in our world. In this understanding, illness may arise from any of four different manifestations in the spiritual world. A *jinn* is a malevolent spirit, a *rab* is a malevolent ancestral spirit, a *ndeum* is a witch that can eat people's souls, and the final cause is *liggeey* which translates to 'work' and is the result of someone's ill wishes, whether that be a relative or another known person. A *rab* or a *ndeum* is experienced as a type of wind that brings on illness, when one's body gets hot. Consultation with the *marabout* is followed by the preparation of a medication for the ill which may be drank or poured over one's head like a shower. Other services or follow-ups may be suggested depending on the illness. Steps of treatment always have some financial cost, whether that is for ingredients or just the time consulting the healer. Participants in this study reported payments ranging from 2,000 cfa ($4) to 50,000 cfa ($100), paid at the time of treatment or upon the cessation of illness. I gathered this information because it is necessary to account for the variety and breadth of treatment available locally and what people are utilizing in the context of UHC programs.

1.3 Research Objectives:

This study explored the experiences of the ill and their family members in a pluralistic medical system, where the ability to pay determines the level of care that the ill may receive. While acknowledging the existence and value of religious healers, the study focused on the use of the formal health care system, and the economic costs, government or non-governmental aid programs, and social support networks involved in accessing these services. The size and strength of one's support network influences what forms of care and treatment are possible in cases of serious and chronic illness. Using an approach versed in ethnographic methods (which I explain further in Chapter 3), research focused on the treatment trajectories of Senegalese and the socioeconomic context within which they occur.

My research objective was to understand the ways in which Senegalese families relate to, negotiate, and engage social and economic support in cases of serious and chronic illness. An additional objective of this research was to better understand how Senegalese families perceive and experience (if at all) the *CMU* Universal Health Coverage program, specifically the community health insurance schemes (*mutuelles*). These larger aims were broken down into specific research objectives. Over the course of fieldwork and analysis these developed into what are my final research aims and objectives.

- To build an understanding about the sources of economic and social support that members of the informal sector rely on in seeking to act on episodes of ill health
- To explore how *Couverture Maladie Universelle* including *Les Mutuelles de Santé* is experienced and perceived by members of the community.
- To explore the perspectives and understandings of health professionals about economic support of the sick in cases of ill health and the use of *mutuelles*
- To investigate treatment itineraries and how ill health factors into health expenditures

The case studies of Djiby in Chapter 4 and Ramatoulaye in Chapter 5 comprise 2 of the 3 findings chapters in the thesis. These cases contextualize livelihoods of the informally employed and the actions available in the event of illness. This was of interest to me due to the central focus of reaching the informal sector underlined in the CMU, specifically the *mutuelles* (community-based health insurance schemes). The role that social networks and family can (or cannot) have in the treatment of the sick is central to the two case studies of Maimouna, Djiby's mother, and Aissata, Ramatoulaye's aunt. The accounts of other participants in the study also confronted the challenges and opportunities in seeking treatment; however I found the experiences of Djiby and Aissata as the most meaningful, due to already well-established relationships with them and the time frame of the respective cases. These instances of illness involving Dijby and Aissata's families were unfolding during fieldwork. While multiple participants shared illness experiences that were recent, personal or which involved a close relation, these had already occurred, and thus I could only gain retrospective accounts, although these accounts were important in developing my understanding. The experiences of Djiby's mother and Ramatoulaye's aunt, and the observations and other data created during fieldwork, helped form strong data about the events that follow in serious cases of ill health.

As the local context is considered, including the communities and services in Senegal, we must also give attention to the previous scholarly work that has been conducted in Senegal on healthcare and the health system. These efforts by the state to provide Universal Health Coverage take place within this context of development and healthcare provision. Previous studies have ethnographically attended to illness and treatment itineraries (Foley, 2010). More recent focus on the meaning of Universal Health Coverage has been explored. These include studies of the current health financing methods of user fee exemptions and community based health insurance (*mutuelles*). The following section accounts for this recent scholarship in Senegal, and points to how the insurance schemes and the Universal Health Coverage program have not been received without critical reception.

Chapter 2. Positioning the study

2.1 Knowledge Gap

Previous studies have investigated the functioning and utilization of *mutuelles* (community based health insurance schemes) in Senegal. Quantitative studies have accounted for reasons of membership in *mutuelles* and related effects on healthcare expenditures and healthcare utilization (Jütting, 2003). Findings have shown that it is challenging for the population to pay membership fees and that one's religion, education, and income are important determinants of scheme membership. Jütting theorizes that community participation or local ownership and trust will be fostered in insurance schemes that are locally based and managed (Jütting, 2003). Locally-run and structured programs of primary care provision emphasize the immediate surrounding community, although these do not go without their critiques. Such foci in health policy have been subject to local power relations and criticized for driving inequality (Foley, 2010).

Qualitative methodologies have also been applied in producing knowledge about the *mutuelles* of other African countries aside from the context of Senegal. Qualitative studies in Mauritania, the Democratic Republic of the Congo, and Ghana have investigated low membership (Waelkens et al., 2017), influence on quality of care and affordability (Criel et al., 2020), and inequity in membership (Jehu-Appiah et al., 2011). Qualitative research has also investigated values and visions of the *mutuelle* schemes from the perspectives of leadership and citizens. Alenda-Demoutiez has explored the influence and demand of internal and external actors in the use of *mutuelles* to achieve Universal Health Coverage. Findings of their work have pointed to the unclear direction of *mutuelles'* role as one of the Social Solidarity Economy (SSE) or one of financial protection through insurance coverage. Uniting these schemes under one subsidized network, as the Senegalese government is currently doing, challenges each scheme's identity and may reduce the diverse actors, communities, and ideals present (Alenda-Demoutiez, 2017).

Qualitative studies have also explored *mutuelles* in other respects, such as reasons which influence enrollment, including social capital (Mladovsky, 2014), as well as level of scheme participation with dropout (Mladovsky, 2014), and meanings of leadership and outside decision making (Mladovsky, 2015). Social capital is defined by Woolcock as "the information, trust, and norms of reciprocity inhering in one's social network" (Quoted in

Mladovsky, 2014). This is one way in which local *mutuelle* schemes have the potential to be inequitable, as recruitment into such schemes often moves by word of mouth and social connections. One's place in regard to the *mutuelles* schemes has also been found to have significance following enrollment, as dropout and low participation have been observed, although the nature of cross sectional studies renders the cause and effect unclear (Mladovsky, 2015). The *mutuelles* are a major piece of the *CMU* program in addition to user fee exemptions.

Recent studies have also investigated portions of the Senegalese *CMU* program which provides user fee exemptions to citizens over 60 years of age and on consultation tickets for children under 5 years. These studies have pointed to the high fragmentation of the Senegalese healthcare system with multiple practitioners and forms of payment being utilized (Mladovsky, 2020). This goes for the user fee exemptions, various *mutuelles* and employer based insurance schemes (*institution de prevoyance maladies*, IPMs) which are community or employment based, while healers and private practitioners are not included in these programs, and in the case of private practitioners their own insurance schemes often operate. The inequitable potential of this policy is also emphasized, where poorer citizens may not know about or demand for programs which they are indeed eligible for (Mladovsky & Ba, 2017). User fee exemptions have been bolstered with the *CMU* program, although complaints of slow to arrive or lack of promised subsidies handicap the program (Wood, 2020). The release of these funds varies by each local government and hospital, as the Linguere health care facilities have not experienced such withheld funds pertaining to the user fee exemptions.

While researchers have considered the concept and functioning of *mutuelles*, little has been done to assess the actions people are taking to seek and engage economic and social support when negotiating health dilemmas. As mentioned earlier, people make complex decisions and undertake diverse actions in their communities, often and seemingly far removed from the effects of global neoliberal and national policies. Additionally, fieldwork for these studies has largely occurred in years past, and there is a need for a qualitative understanding of the *CMU* program as it stands in the current moment. Recent studies have investigated the inner workings of UHC policy development in Senegal and different local and international interests that play roles, while other studies have questioned the use of UHC for political interests and how scheme staff fit into this dynamic relationship (Tichenor, 2020; Wood, 2020). Knowledge constructed through qualitative methods of the ways people interact with policy rollout, like health insurance scheme use, must be considered as governments radically reshape the structure, organization and financial underpinnings of their health systems (Foley, 2010, p. 80).

This is because, as pointed out in the introduction, the expansion of health insurance schemes (community-based health insurance, *mutuelles*) is a common means by which to provide countries' citizens with UHC.

Additionally, there are no published studies accounting for the treatment trajectories of individual patients in Senegal. Rather than carrying out surveys or one-off interviews, long-term interaction with participants undergirds this thesis. Previous studies concerning UHC and forms of support during illness have not drawn on ethnographic methods, leaving out many contextual details. Studies drawing on ethnographic methods stand to expand on navigation of the healthcare system and treatment itineraries, as these policies are situated in social relations and social conditions. Policies and reforms in countries and localities need to be accounted for, specifically how they meet citizens' needs. As UHC and primary healthcare occupy the spotlight and serve as the current destination of the Sustainable Development Goals (SGD3), anthropologists are well positioned to develop empirical findings that serve policymakers and the greater public sphere (Prince, 2017; Barrero and Bugbee, 2019).

To contribute to this field, this study used ethnographic methods, aiming to develop the understandings and perspectives of lay people and to explore the actions they take in cases of chronic disease and serious illness.

2.2 Uncertainty as a thematic framework

A theoretical perspective provides a lens to view and distinguish between empirical data (Hylland-Eriksen, 2017). Previous qualitative research has done so in the context of Universal Health Coverage in Senegal. Frameworks of critical realism and social constructionism have been used to analyze and place the user fee exemptions provided by the CMU (Mladovsky, 2020). A framework involving the community model of trust and solidarity was formed by researchers to categorize perceptions of solidarity in *mutuelle* schemes (Mladovsky & Mossialos, 2008). Foley pointed to the dramatic uncertainty of medical treatment by studying people's actions under neoliberal health reforms through the perspective of "practice theory"; and in doing so found that people's actions are greatly limited by local factors such as the power of high-ranking family members to make exclusive decisions that can hinder or halt the healthcare seeking (Foley, 2010). I will now visit the framework that came to be central to the findings presented in this thesis. This is the theme, or lens, of 'uncertainty'.

“Some [theories] are large theoretical frameworks, whereas others are more limited or specific theoretical schemes or propositions” (Moen & Middlethon, 2015, p. 366). The position of uncertainty in this thesis is a mode of being, such as that offered in ethnographies of other processes of change (Pratten & Cooper, 2015). The lens of ‘uncertainty’, as used by anthropologists, has been used to interpret and analyze the ethnographic material discussed in the following ethnographic chapters. This thematic reference point has been developed over the course of fieldwork and data analysis, as I came to understand that uncertainty holds a central place in people’s lives. During fieldwork, uncertainty came to provide meaning in the context of illness; I came to realize that participants and informants acted in contexts of multiple forms of uncertainty. Evident in the jobs and economic insecurity of participants, this became magnified in the case of a great need.

Pratten and Cooper draw on ideas of socially dependent action to frame ‘uncertainty’ in the collection, which they edited, “Ethnographies of Uncertainty in Africa” (2015). The contributors demonstrate how uncertainty is a phenomenon exaggerated by the intensive processes of change and development across the continent. The extent with which uncertainty has become a constant trope in the lives of Africans, leads to a world view which is structured by “instability, incoherence, and uncertainty” (Pratten and Cooper, 2015). This volume brings understandings of uncertainty into focus, as it is a feature of life that incites, encourages, and limits the choices and motions of interlocutors. As development work is pursued by national governments and NGOs, consideration of the complex and temporary moments in which people live, using concepts such as uncertainty, can provide clarity to what is influencing people.

Some key terms used in the Pratten & Cooper edited volume will be applied in findings chapters of this thesis. Actions and their progression defer to social contingencies, defined by Bledsoe as, “the social relations that define all aspects of life” (Bledsoe, 2002 cited in Pratten & Cooper, 2015). These relationships and their temporal nature have been spoken of as the ‘subjunctive mood’ by Susan Whyte, where people actively confront potentialities in happenings, circumstances, and relationships (Whyte, 2005 cited in Pratten & Cooper, 2015, p. 3). Embracing this way of being leads participants to invest in persons who are provisionally, proximally and socially close. These persons make up one’s ‘infrastructure’ which one comes to rely on (Simone, 2004 cited in Pratten & Cooper, 2015). The timeliness of the moment is what sets this perspective and resource apart from social capital or perks conveyed thanks to status.

The perspectives that these authors offer on uncertainty have helped to deepen my understanding of the individual's place relative to one's social network and family members, as I observed and followed treatment trajectories among study participants. These social relationships and networks are often mutually dependent in their direction and offer no guarantee, as various contingencies must align in one's moment of need.

From what I could observe and understand, for study participants, ill health led to uncertainty about where treatment would lead and where it would stand. Granted uncertainty is a part of illness decisions anywhere, but the extent to which economic insecurity and the absence of well-functioning services are ridden with uncertainty, makes it the central element framing treatment trajectories among study participants. Uncertainty defined the situation: whether health could return through hospital appointments and prescription use or if it becomes necessary to consult a traditional healer and look outside of the walls of 'cosmopolitan medicine.' Paying for treatment or healthcare was another topic of much debate: one's relatives were typically the first to be consulted when financial support was needed. The 'subjunctivity' of such relationships (whether they were supportive or not, but also whether one's relatives had any money or could access any) could spell the difference between getting well in a couple days and waiting for the funds and family members to arrive. Contexts of scarcity bring uncertain steps forward in the treatment of family members.

These understandings of uncertainty also carry weight in the development of the Senegalese government's *CMU* program through *mutuelles*. Uncertainty dominates experiences of seeking health care or financial support from *mutuelles* - where the government's undependable payments to schemes leave both staff and local health professionals wondering if the *mutuelle* will remain financially viable.

This framework will continue to be used in the following ethnographic chapters as questions arise of what support is realized and what improvements in health condition take place.

This study has explored the experiences of the ill and their family members in a pluralistic medical system, where the ability to pay determines the level of care that the ill may receive. The size and strength of one's support network influences what forms of care and treatment are possible in cases of serious and chronic illness. Using an approach versed in ethnographic methods, treatment trajectories of particular Senegalese families, and the socioeconomic context within which they occur, were explored together with participants by the researcher.

Chapter 3. Methodology

3.1.1 Ethnographic fieldwork, ethnographic methodology, and communication

The research questions I have been exploring in this study involve the understanding of people's experiences, behaviors, and knowledge in the context of illness and the support one draws on. I found that qualitative methods are well-suited to address these questions, which focus on contextual details of social and economic nature. Specifically, the study of critical medical anthropology has proven useful as it "seek[s] to answer practical questions about the nature of health, illness, healing systems, and related matters across cultural systems, populations, and social contexts" (Singer and Baer, 2007, p. 47). As I used methods steeped in this way of thinking I found that I could consider these questions situated in the lives of participants throughout fieldwork and the process of analysis. I have the good fortune of established friendships from an earlier long-term stay in Senegal, which allowed me to enter the lives of participants. Such interpersonal presentation and relations have great influence on the development of any ethnographic study. "It is on the basis of the personal qualities and the conduct of the researcher, rather than the topic of the research project, that rapport is usually established" (Singer and Baer, 2007, p. 44). The extended engagement with participants in the field and continuing to remain in contact with participants has allowed me to consider the research questions as life continues. "Over time ethnographic researchers are able to glimpse behind the public masks and front-stage performances of social actors to backstage and often hidden arenas of experience and social interaction" (Singer and Baer, 2007, p. 52). Interviews, focus group discussions, informal conversations, and participant observations helped me to better understand the lives of participants and learn about what roles social relations can play in enabling family members to receive treatment. This has contributed in allowing me to develop a 'thick description' of my research field (Geertz, 1973).

3.1.2 Locations and Relations

Shortly before beginning this master's degree I lived in Senegal for 10 months as a volunteer. During this time I lived in one rural host community with a host family. I did simple tasks at a health resource center which supplies area health huts with pharmaceuticals and provides some services for locals, such as persons living with HIV/AIDS, including educational and social events. I regularly filled out paperwork for visitors, and put together medicine requests at the pharmacy. I also taught English lessons at a primary school in the community. However, the greater part of my role was to share about life, people, and culture with my sending community in the United States through newsletters and blog posts. As importantly, I wished to have a positive influence on the Senegalese community representing the United States, where positive growth was possible together.

I was taken in as a family member and given a Senegalese name (I was named after a host uncle) as part of being welcomed into the home. Having a namesake is common in Senegal and a part of respect. The home was always full of activity with different generations and different things taking place. This introduction to the community lifestyle as well as the language barrier were challenging for me to get used to. I came to do well in this way of life, especially as sharing with others came to be normal and less selfish. I also joined the family at a point of significant changes in the family makeup, as my host grandfather died and the first born of my host parents arrived just before I moved into their home.

Living in the house as a young man, meant that I was given errands and occasionally helped with chores at my host family's home. This helped me to know the neighborhood and naturally meet local people. As I learned more about the language, I came to see how much people joke with it too. People were surprised and happy to speak Wolof together, and as my understanding got better I realized how much teasing one can do. This teasing diffused all daily activity whether when eating together or out purchasing something from a shop. Moving from a place of largely nonverbal communication to being able to have some conversations and accept the new way of life helped me to grow close with my host family. Living with the family helped me to learn how to be respectful and appreciative, indispensable lessons as I adapted to the new culture and its norms. Instruction about what one does or what one should not do created points of discussion and learning. During this previous year I came to know different members of the extended family who came to visit or lived elsewhere in town, and this continued upon my return. I remained in contact with them following my departure from Senegal.

One major piece of the program that took me to Senegal was about living simply, and this time with the host family involved doing just that. Having no control, but accepting other's meals and group activities came to be the new normal during these days. Being welcomed into someone's home surprised me and I continued to be surprised throughout my stays. I was astounded by the preparation that one would make for their guests, making an extra special effort to satisfy one's guests is profound. Connecting through the basic senses when culture and language are more difficult to understand was humbling. The local story goes that such acts will ensure your family stays well when they are traveling. The respect that people show each other is another lasting impression from my time there. Signs of respect filled daily communication from greetings to use of titles that invoked a wider sense of family. One commonly addresses others as their aunt, uncle, or as a mother or father. I came to realize that many of these interactions suggested that we are members of a large family. I came to feel that this could provide a refreshing sense of togetherness and common purpose with others who I did not know.

The opportunity to carry out my fieldwork in Senegal as part of the Master´s program was an opportunity to continue developing understandings, concerning religion, culture, and health. As much as I looked forward to building on these previous memories and relationships, I also looked forward to doing something more impactful than simply watching, smiling and nodding. I would be able to build on relationships that I had formed as well as continue to build on the language skills I had learned during the year volunteering there.

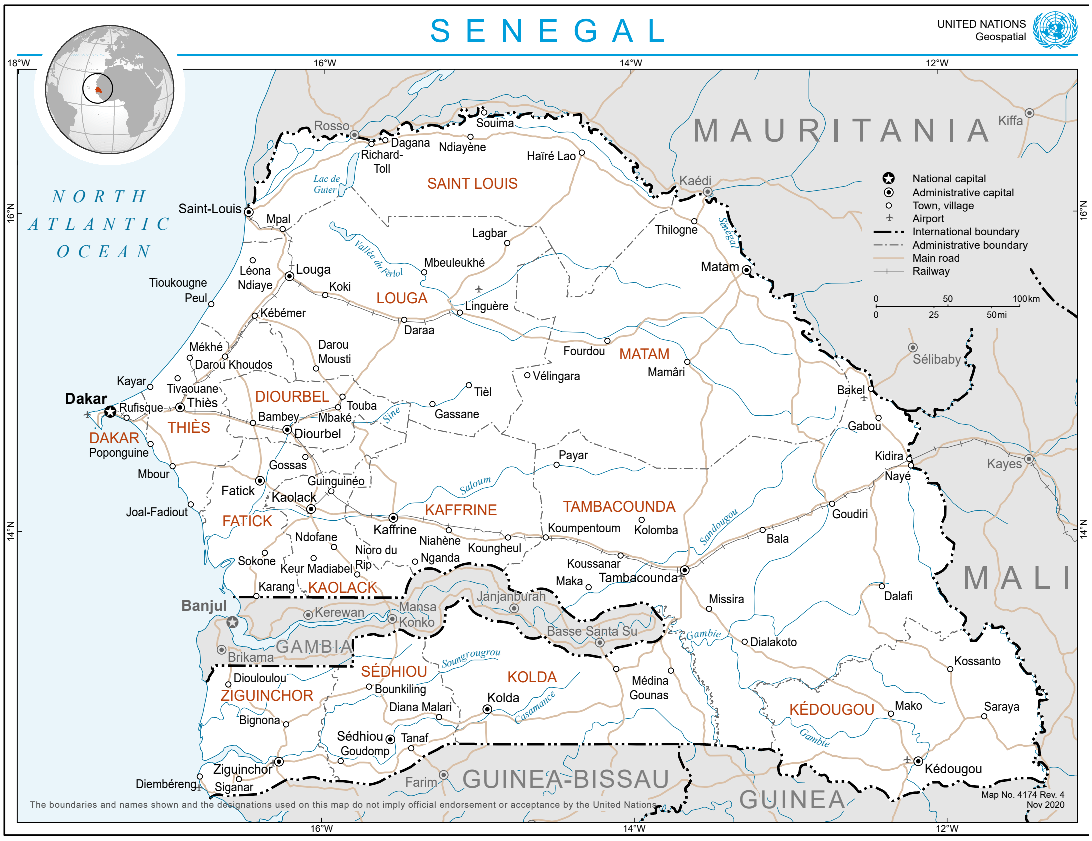

Figure 2. The nation of Senegal with the capital Dakar on the western-facing Cape Vert Peninsula. Linguere is located in the Louga region, and the north central part of the country. (from United Nations: Senegal country profile)

Fieldwork took place from Late September 2019 – January 2020, after receiving ethical approval from the Senegalese Ministry of Health. I spent three months of this time in the town I had lived in previously (a town called Linguere) collecting data, while two months of this period was spent in the capital Dakar, obtaining ethical clearance and transcribing interviews. A friend connected me with a family in Dakar, and I stayed with them at their apartment when I was in the capital. The other months in Senegal I spent with a host family in town. They were the same host family I lived with in Senegal the previous year, and I was welcomed back as a member of the family when the possibility of my return for fieldwork came about.

Over the course of fieldwork, I continued to uphold different identities from previous time in Senegal. I lived with the host family and again held a place in their home. I also resumed attending the church in town where I had been spending time. I did not, however, want to be confused as a missionary with the church in town either, as I would frequent the church and its offices. I was regularly introduced as a volunteer or student by my supervisors when meeting new people. It was challenging to maintain the different roles that form my identity. Returning, but with research and topics to inform conversations helped to continue discussions after introductions. Returning also showed people I already knew that I did not forget about them and that I have a continued interest in the community. My identity was more mysterious to those who did not know me and with whom I had not had an opportunity to visit. Answering questions about NGO projects and hearing about assistance ended up also being a part of the research. With time the guard and hesitation of some relaxed, and relationships could be built.

I am a native English speaker, but the use of English is rare by local people. Senegal was colonized by the French and French continues to be taught in schools and used in professional settings. English was rarely used by my host family, but a couple of family members had studied it while growing up. Use of French was needed in correspondence with the Ministry of Health officials to obtain ethical clearance for the research. Although my French proficiency is almost nothing, I was fortunate to have some friends assist me with the ethical application process and correspondence in French. While in the field, doctors and pharmacists largely preferred to speak French, but I was fortunate to work with a translator who could effectively communicate in multiple languages.

Different local languages exist with each of the ethnic groups in Senegal, but Wolof is the most dominant local language. Wolof is the language of Dakar, the capital, and is normally spoken in markets and the street. National news is televised in a Wolof, and in a French broadcast, while the majority of talk shows and national TV series are done in Wolof. Information relating to Islam, the religion of nearly all Senegalese, is also communicated in Wolof. Wolof and Pulaar are the two dominant languages in the town where I conducted fieldwork. Although a large group of the population identifies as Pulaar, many speak Wolof well which is most commonly spoken in Linguere.

Much of the culture and daily life is expressed in the Wolof language and using it helped to break down barriers wherever I went, whether that was through the use of appropriate greetings or simply naming something which frequently became a joke. There are also members of the population who have not studied in a school and do not speak French. The Wolof language was the selected form of communication to collect data while I was on fieldwork. My knowledge of it, the limited number of published studies using Wolof, and its almost universal usage, were sensible reasons to speak it during fieldwork.

I was fortunate to begin learning Wolof while in Senegal previously as a volunteer, because Wolof is the language in the home of my host family in Linguere. I used Wolof in nearly all of my daily interactions as I met new people and navigated daily life. During the summer of 2019, before going to town for fieldwork, I took language lessons in the capital during a two-week period while I completed the application for ethical clearance. Frequenting the university, neighborhood shops, and basketball courts in the capitol provided me additional opportunities to practice the language and learn about livelihood in Senegal. After moving to the town, Wolof was what I depended on for communication over the course of fieldwork. My notebook was a familiar sight for my host family and friends, and guessing which word or phrase I was writing down came to be a regular point of entertainment. As interviews were recorded and ideas were developing I worked with a translator to improve communication and in so doing my own language skills continued developing. Following transcribing interviews for the month of November I especially noticed a jump in my comprehension.

A young man who is completing a master's degree in English, Simon Ibou Diouf, agreed to serve as my translator and travel from the capital city to be in town. He came to the field for some weeks on three occasions - one in mid-October, one in early November and another during late December 2019. Due to the limits of resources and his commitments in the capitol this schedule was feasible. The translator was of enormous help and we continue to be in contact. His knowledge of the French and Wolof languages as well as his personable nature enabled many introductions, discussions, and clarifications. Our discussions and time together as peers helped me to understand aspects of life with a much more personal and intimate perspective. Without the translator, my language proficiency hindered long discussion with those aside from close friends and host family members, and this posed some limitation to my data collection.

3.1.3 Sample and recruitment procedures

Apart from immersing myself in family life and local culture, and conducting participant observation, I interviewed 23 participants including different community members, and key health persons including doctors, insurance scheme managers, and pharmacists. It was recommended that I speak with one doctor at the district health office in town about the ethical clearance and the research project. Upon his suggestion, I added pharmacists to the study sample, because pharmacists interact with patients regularly and their businesses are a major stop for the ill and their families. There was no inclusion or exclusion criteria apart from being a community member or key health person over 18 years of age. Recruiting participants of diverse backgrounds was envisioned to help create the richest possible data set. The proposed sample consisted of members of both the formal and informal sectors, including informally employed members of the local communal *mutuelle*.

Participants interviewed ranged in age from 29 years old to 60 years old. There were 10 female and 7 male community members that participated in interviews, while 4 male and 3 female key health persons participated. Members of the key health persons group included two insurance scheme managers, three doctors, and two pharmacists. Among the community members group, my sample included only one interview with a person who had formal employment (he was a security guard). Participants with a wide variety of informally employed roles were included: housekeepers, sellers of foods like peanuts and candies or baguettes with sauces, sellers of vegetables, sellers of sheep, or *boutique* merchants, who sold items used daily such as oil and tea.

Two focus group discussions were also carried out with community members. The focus group discussion included six women of various ages, while the second focus group included two women and two men from 38 years old to 55 years old. A member of the second focus group was formally employed as a night guard, while the other three members were informally employed as a laundry washer, gardener, and musician. These FGDs, as well as informal conversations that I had with different community members, provided diverse perspectives about the culture, livelihood, and the events that take place when illness in the family is addressed.

Five of the participants were ill or experienced illness themselves, while four participants had family members who were ill. Kleinman has pointed out that family members also experience the illness (1988). Previous work has demonstrated the significance of family members as decision makers and supports in cases of serious illness and complex therapies in the African context (Janzen, 1982). The influential role that persons socially close to the sick have in decisions of treatment location, treatment type, and duration cannot be understated, as Janzen has shown with Kongo society's creation of the 'therapy management group.'

Apart from interviews and FGDs, Participant Observation was used where possible with participants currently navigating health events. This meant accompanying people from home to clinic and pharmacy, to the offices of the communal *mutuelle*, to the NGO which provided health assistance, and to places of work, and visiting people in hospital. I also used informal conversations to collect data. Notes, recordings, and transcripts from these encounters comprise the collected data.

Recruitment proceeded through snowballing methods. This doctor at the district health office introduced me to other doctors working in clinical settings at the health center and the hospital in town. I shared with friends and community members that I would like to visit with people who are sick or have family that are sick and belong to the communal *mutuelle*. However, my attempts at recruitment were unproductive this way, because people just referred me to the *mutuelle* president. This also limited which cases I heard about. My friends at the NGO believed that they could not help me because they did not work with the *mutuelle* and I did not clarify this issue until late in the research, in part due to my developing language skills. I tried another approach, interviewing contacts that were healthy and did not have any illness (at least any illness that I knew of beforehand) in their family to better understand the context and illness support in general. Relationships with various local people I knew from time in town the year before served as my sample early on. These conversations then led to introductions and snowballing to recruit ill or recently ill participants.

Focusing on people in the informal sector: The experiences and knowledge of participants working in the informal sector form the data collected about family illness experience. Members of the informal sector are people who work in unsalaried employment. These forms of work typically involve payment per service or per day of work. The recruitment of participants through contacts in town did not reach members of the formal sector with current illness. I interviewed one friend who works in the formal sector, but he did not have any family members who were sick. However, he did explain how his *mutuelle* functions when his family is sick as well as his understanding of how support functions in Senegal and in town. Conversations and friendships with different teachers in town also helped me learn about types of *mutuelles* that serve the formally employed and how that affects members.

Efforts were made to include members of the government's *CMU* program staff in the study. I conducted 2 interviews with members of the local *mutuelle* scheme administration in Linguere. I could not conduct interviews with the government leaders in the capital, because the additional research clearance took time to obtain. By the time the appropriate access was obtained for these employees, it was not feasible to spend time in the capital city carrying out these interviews. I gained introductions and contact information, but I did not collect interview data from this group. The short conversations that we had together did, however, give me important insights, as these included the undeveloped nature of the *mutuelle* scheme for the informally employed in town, as well as the development of the *CMU* program in Senegal.

Neighborhood friends and host family members helped me to better understand the local goings on, cultural, social, economic and religious contexts. My time in the field focused on how these contexts influence illness, and more importantly how seeking treatment was largely dependent on social relations. I spent time getting to know individuals working in the market and my host family's neighborhood. Having previous contacts in town, I was able to quickly build on existing social networks. Weekly visits to the NGO where I had previously volunteered, the hospital, health center, as well as frequenting various sellers and shops helped me to familiarize myself with the community. Relationships with participants lasted at least two months in the field and contact has been maintained through WhatsApp and Skype calls with many participants throughout the writing and analysis process of the 2020 spring semester. Many of these relationships have become close friendships that have endured the distance posed by borders and flights. This continuous contact has enabled me to inquire further about individual illness cases, better understand the *CMU* program, and gain clarification about events that I witnessed or discussed. Through asking further questions and clarifications I have been able to better comprehend the data collected. This iterative research process has allowed me to learn more about the lives and forces that people in Northern Senegal address, especially during illness. Without the openness and patience shown to me by participants none of this research would have been possible.

3.2 Methods:

I drew upon the following methods in gathering material and data for this study.

3.2.1 Informal Conversations

Over the course of fieldwork my relationships with community members working as sellers, shop owners, or craftspeople developed. I came to know about the lives and society of the setting in which I was living. I was able to build links with various townspeople when I regularly visited a place or through the introduction of a mutual friend. As discussions, English lessons or cups of tea were shared questions of life and its day to day joys and challenges often came up. Health would occasionally enter these conversations or I would bring it up. Different places I frequented in town became natural points of discussion with friends and other passersby. I have kept in contact with my host family and multiple participants since fieldwork finished, and these conversations continue to contribute to my understanding of life and illness in a Senegalese context.

3.2.2 Interviews

I conducted semi-structured interviews at the home or business of participants. Interviews followed a specific agenda to collect information about a specific topic or theme (Kielmann, Cataldo, & Steeley, 2012). I arranged interviews with both key health persons and community members as I looked for answers to my research questions. Qualitative interviews are an appropriate method for participants to construct or reconstruct experiences so that knowledge can be produced (Mason, 2002). Interviews were the main form of data collection in the key health persons group, as doctors and pharmacists were often working, making for few opportunities to meet and converse. Interviews typically lasted one hour in length and an interview guide provided some structure to the interviews. I was fortunate to have the translator present for all but three of the 23 interviews during the final days of fieldwork. He was great help with making sure that the discussion went smoothly and clearly articulating questions. This method allowed for in-depth responses to questions regarding the way things are and function. These were particularly useful when visiting with participants with whom I had had previous conversations and knew well.

3.2.3 Focus Group Discussions

Focus Groups are a valuable method of comprehending common knowledge or shared knowledge of an area or group of people (Kielmann, Cataldo, & Steeley, 2012). This method of data collection was used early on to understand how things are. An FGD was then used late in fieldwork to confirm that data collected was based in reality and to challenge developing ideas. The translator was present for these discussions, which occurred at the home of the communal *mutuelle* president and in the courtyard of the NGO in town respectively. An interview guide was used to provide a structure to the conversation.

3.2.4 Participant Observation

Participant observation was conducted when possible. "Participant observation is a research strategy that aims to produce knowledge both on and through interactions between people" (Moen and Middlethon, 2015, p. 347). When the researcher spends extended periods of time with participants in the social context of study, they are able to engage in socialization and enculturation while functioning in the space under investigation (*ibid*.). This involvement of the researcher in goings-on combined with attention to how events are taking place helps the researcher gather a nuanced understanding of the context and its social contents (Moen and Middlethon, 2015, p. 348). I have described, above, how my stay with a large family, enabled my growing understanding of the social, economic and cultural contexts of health and illness, and of local culture, religion, and social relations, as well as the importance of language to understanding social fields and interactions. I also conducted participant observation in other contexts. For example, during the one week hospital stay of a family member of one participant I was able to spend time with the ill family member and the family both at the hospital, in the home, and while accompanying them seeking medications and assistance from the universal health coverage program (CMU). This was done by spending time in the patient's hospital room, accompanying the participant on errands, and visiting the patient and family in the home. I remained in contact with the participant for the remainder of fieldwork and conducted interviews with them.

3.2.5 Field Notes

I kept a journal during the course of fieldwork where I kept track of the day's conversations and activities. I also reflected about the development of recruitment and the study sample here. Over the course of fieldwork this came to be a place where I also reflected personally both about my place as a researcher and about life in general. "Fieldnotes inscribe the sometimes inchoate understandings and insights the fieldworker acquires by intimately immersing herself in another world…" (Emerson et al., 1995). Expanding and building on these throughout the course of fieldwork helps the researcher to track the development of forthcoming ideas and the progression of inferred meanings. Fieldnotes are a valuable place for the researcher to evaluate sketches, episodes, and lengthier anecdotes before preparing a final report (Frey, 2018).

3.3 Analysis

I translated and transcribed interviews in the field over the month of November with the translator. I spent more time in the capital than expected due to the work schedule of the translator. Upon return to Oslo I translated and transcribed remaining interviews conducted in December and January. I asked the translator or one Senegalese friend in Oslo about phrases I did not understand.

I began thematic analysis of the interview and focus group data in the field and continued in the spring semester upon return to Oslo. Thematic analysis involves the researcher comparing and contrasting different portions of data, and describing their thematic relations as pieces of text are examined (Moen and Middlethon, p. 358). An inductive approach allows findings to come through the data, as opposed to when using a specific framework from the onset of data analysis. These conjunctions in the data collected were developed systematically through the formation of codes, which were then applied to the rest of the data set. Research questions helped to shape the resultant themes, by providing a domain of relevance rather than a set of expectations about findings (Thomas, 2006).

Peer workshops as well as discussions with other students and supervisors helped to both question and justify themes induced from the data. My analysis also developed from the use of a field note diary and recordings of conversations and observations.

3.4 Challenges

Every research project has its challenges, and over the course of fieldwork I encountered different challenges. One attempts to anticipate challenges and prepare for them, but sometimes this is not possible.

I found the first focus group discussion to be particularly tricky to conduct. After receiving ethical approval from the CNERS I was in contact with the *mutuelle* president about hosting a focus group discussion. I was excited about the opportunity to get started and she had previous experience with students conducting research and wanted to share perspectives about the *mutuelle*. The *mutuelle* president had previously pointed out my weak language skills, so the translator and I chose to conduct the entire discussion translated through the translator. I had never met the women that the *mutuelle* president recruited, and short introductions were made. Informed consent took some time to go through and the *mutuelle* president grew impatient with the process. As we started some questions in the discussion some short answers were given from a couple of participants, but no discussion commenced. The *mutuelle* president continued to express her impatience, and despite the best efforts of the translator to reassure her and continue the discussion, no opinions or personal perspectives were shared.

I did not anticipate meeting such cool and closed participants at this FGD. Previous experiences in town with the health NGO and conversations with friends in the house were rich, but my language proficiency prevented me from understanding everything in these informal moments. I mistakenly thought that this level of openness would also apply to the participants that the insurance scheme manager recruited, because myself, my host family, and the NGO administrators I had lived with were well known. However, I was not as well known in the community as I had thought and these participants were skeptical of my person and research. Perhaps the formal structure of the FGD inhibited participants. This focus group discussion demonstrated the importance of having a relationship with participants before focus groups or interviews. It was the first time interacting with any of the women from the group. Future knowledge building activities would give greater priority to the use of language and trust with participants.

I continued to ask friends and members of my host family about doing another focus group discussion. It proved difficult to coordinate another group, despite assistance from my host uncle and namesake in recruitment. Potential participants were typically occupied with work during the day and at home with family members during the evenings.

These challenges with focus group discussions as well as the limited availability of my translator meant that I relied more upon informal conversations and interviews to collect data than on FGDs. I could do interviews with different participants and come to them at times that fitted them, rather than calling participants to all come to a common location. I could explain the research and participants could receive further clarification from the translator as well. The one-on-one setting made it simple for me to contribute and participate in the discussion naturally in Wolof as well.

These lessons learned were applied in the second focus group. During the first week of January I organized an FGD with a group of middle-aged adult community members that I knew. Individuals were not all members of a *mutuelle*, but they did have trust and were people that I had known for some time. This focus group discussion also occurred at the end of the research process, so my personal knowledge of treatment and the goings on could be posed and tested. Discussants did not talk about any serious personal or familial health events, but the general discussion challenged and confirmed knowledge and practices of which I had become aware.

After I started transcribing my interviews in November, I changed my approach from discussion of the mutuelles and health to life more generally. During this time, I came to better understand the context of life and livelihoods in the town, including employment opportunities, expenses, and what events affect them. I found that my intense focus on health early on was not needed, and that conversations about life in general with friends that I saw everyday was more beneficial to the study’s progression and to addressing the study´s objectives, that is to learn more about the economic and social contexts in which people experience illness and seek treatment.

3.5 Ethical Issues

Ethical approval was obtained from the appropriate bodies in Norway and Senegal before any recruitment or data collection began. A notification was received from NSD, the Norwegian Center for Research Data, in June 2019. The research project received ethical clearance from the *Comité National de Recherches Éthiques Scientifiques* (National Committee for Science and Ethics Research at the Senegalese Ministry of Health) at the end of September 2019. After returning revisions and obtaining the final approval from the CNERS, I began discussing healthcare in conversation with friends who are members of the community. The top ethical concerns involved data collected on the recorder and in the research notebook. A coding key with aliases was used with participants responses and notes. Codes and recordings were stored on the researcher's encrypted external hard drive and placed under lock and key in the researcher's accommodation. Recordings were then stored in the University of Oslo's TSD system upon return to Norway.

Informed consent was obtained before formal interviews and focus group discussions. An information form describing the study and data collection methods and a consent form were created for the study and included in ethical applications in Norway and Senegal. The form was translated into French for use in Senegal. The forms were shared with participants in advance of interviews or FGDs, and then further explained by myself and the translator before beginning the encounter. A few of the participants did not read French, in such cases explanation by a family member was common in addition to our explanation. Consent forms were signed by participants.

3.6 Limitations

I believe that the limited time that the translator was present as well as my novice level as a researcher were limitations over the course of this study. These factors meant that formal interviews and focus group discussions were less useful than anticipated. Early on I received quiet or short responses when bringing up the topic of health and what someone does when they are sick. This continued when the translator came to the field, where he cautioned me about asking any of the questions on my interview guide. He warned that the personal nature of these questions would be uncomfortable to discuss with people. The serious way that he responded to the guides surprised me. I remember many open conversations with my friends and bosses surrounding health and finance while I was in town with the NGO the previous year as a volunteer. It appeared, both from the translator´s advice and from my experiences, that formal interviews were not the best way to gain knowledge about how people respond to ill health and seek treatment.

I was introducing myself as someone who is researching health and I often explained some of my research if it interested others. This occasionally led to important conversations or introductions. Presenting myself as a health researcher interested in people's health experience may have limited how I was received by community members. Looking back on these early days, I wish that I had phrased my research as conversations about illness rather than discussing with community members about how the mutuelle in town was operating. This would have allowed other members of the community to feel more qualified to direct me. I believe that this would have created more community buy-in by members of the healthcare system in town. To some, I appeared as someone on a search for challenges and limitations of the health system.

Some of these reactions to my research and the way I (at first) conducted it, were cultural. In Senegal, it is not looked upon fondly to be someone who is too curious about the affairs of other people. Descriptions of my research and what people do often appeared as nosy or as searching for problems. As the translator and I discussed the research topic more and as we met people who had a level of trust in me and felt comfortable sharing their economic situations, he came to appreciate the work I intended to do. His understanding of the research aims and the conducting of sensitive interviews was instrumental in data collection. As we came to see, some people are more closed in discussing sensitive topics, while others had trust in me or were simply more forthcoming, which freed them to disclose. The translator and I were also concerned about the location of some of the conversations. When someone describes their challenges in an open place it is possible that others may hear what they have to say. Saying things out loud in the Senegalese culture may raise concern for what happens in the future, but through multiple encounters with participants these and other concerns came to be of less significance to participants.

In spending time with my host family, visiting different friends and frequenting various meeting points in town I sometimes felt that I spread myself too thin during the course of fieldwork. That is to say that encounters were made with many community members and healthcare staff in town, but the depth of many of these connections was not significant enough to establish trust. Other times relationships were formed and maintained, but data concerning the research questions was not obtained. This could be because the status of our relationships was superficial so the other individual never felt comfortable to share private knowledge or beliefs, or simply due to my limited proficiency with the language.

Transcribing interviews in the field was one especially lengthy time commitment which I did not anticipate. The days when the translator was available to travel and be in the field allowed us little time to transcribe data. The transcribing was completed during a month that I spent in the capitol city so that the translator could keep his commitments. It was not expected that this amount of time would be dedicated exclusively to transcribing and it took away from my time in the field.

3.7 Validity

Validity considers how credible a description, conclusion, explanation, or other sort of account is (Maxwell, 2013, p. 122). I considered validity in utilizing multiple methods for data collection. Focus group discussions, semi-structured interviews, informal conversations, and participant observation were employed during fieldwork. The use of multiple methods and triangulation is done to increase one's understanding of complex phenomena rather than complete a requirement stating that validity is attained (Moen and Middlethon, 2015, p. 487). Over the course of fieldwork rich data was collected through informal conversations and participant observation. Building understanding through different perspectives helped to question data collected and lead to more accurate takeaways. "Over time ethnographic researchers are able to glimpse behind the public masks and front-stage performances of social actors to backstage and often hidden arenas of experience and social interaction" (Singer and Baer, 2007, p. 52). The significance of trust and the long-term nature of relationships with participants in the production of knowledge cannot be overstated.

People in Senegal often remarked in Wolof that Senegalese people are *lëndëm* (dark, not clear) or that these are *sutuura* (secrets), when I mentioned my research interests. It was challenging to convince my translator of the need to include discussion of living arrangements and economy in interviews. He believed that many of my interview prompts demanded a lot about people's personal life and were far too nosy. I remember multiple candid conversations with friends and family members who called me a curious person, upon me explaining my study. This is generally not looked upon fondly in Senegal. However, as I maintained regular encounters with people and continued to question and discuss life, these boundaries often relaxed. The extent and duration of my relationships with the community and multiple participants allowed me to build trust over the long-term. It is often the researcher's person and not their topic of inquiry through which one establishes trust (Singer and Baer, 2007, p 44). Stopping by someone's house while on a walk was one way to stay connected with community members, but these informal interactions created opportunities for knowledge production as well. The translator commented on my relationship with multiple participants towards the end of fieldwork. He pointed out that the relationships I have with people are very strong. He knows this because of the time and conversations people were willing to share with me. Hearing his opinion about this was humbling. It is important to point out the openness which some participants showed me in a community where one's personal life is respected, and people may project a false state of independence and economic security to appear independent and strong in the eyes of the wider community.

A more limited understanding of the study phenomena would have resulted from the exclusive use of formal methods. Without time dedicated to spending time with participants in their daily lives it is likely I never would have heard about the surroundings or interactions of participants. If I had not seen the patients discussed in the following two chapters as well as their families' interactions in providing care, this knowledge would not have been produced. Being in the room and participating with someone's families also conveys a level of care that transcends boundaries of culture and language. Relying on formal interviews only, would have given me only partial information, which I would have been unable to contextualize.

3.8 Reflexivity

The researcher should consider their effect on the process throughout and then describe it (Malterud, 2001, p. 484). As ethnographers in particular seek to understand the context of their research by participating and living in it, reflexivity has great value. As one takes part in daily life they bring their person and biases with them; taking account of these characteristics is essential if one is to comprehend the development of their research. Regularly asking about the health system and people who are ill early on in my fieldwork may have limited the people and opportunities for data collection I encountered. When I began to recognize this limitation and to consider an approach where I met and conversed with people more freely, I found I was able to gather more robust data.

As a foreigner, my temporary place in the community and the country was often commented on; for example, remarks about the US embassy´s ability to take me away at a moment's notice were often made. Although I was indeed a foreigner, my connections to the community were unique. I had spent time there as a volunteer through a church program the previous year, which was working to challenge the idea of what missionary and development work is, emphasizing learning from the host community. During this recent experience, I had been placed with a local NGO which provides different resources to the community relating to health and nutrition and taught English lessons at a local primary school. It is funded by Christian religious partners in North America, while operating in a largely Muslim community with Muslim staff members. Often, as I got to know individuals in the community, remarks about my connection to this NGO would be brought up later on, whether simply stating that I had been recognized and sometimes with more critical remarks about the organization's allocation of aid.

My previous placement with this organization often entered into conversation as if I might be able to influence what they are doing or know more about the mission it is carrying out. This positioned me as a US citizen who may leave or come back. People in the community were not always in the know about goings on at the NGO and at times were weary of my presence, as its involvement in the past had been more visible. Decisions on my part to investigate health through different conversations early on relied on me simply listening to participants. I had decided early on that my language skill was not developed enough to join in discussions. Overtime I came to influence the conversation more and participate in it, which was especially valuable in the later stages of fieldwork. Conscious efforts to be reflexive over the course of fieldwork and thesis dissemination aided the development of the research and challenged my position as a researcher.

The following findings chapters explore and discuss data formed and analyzed via this methodology. Two chapters presenting case studies of families navigating illness diagnosis and treatment and a final chapter discussing the Universal Health Coverage program represent the understandings and experiences developed during the period of fieldwork. These chapters aim not to share a particular message about the viability of Universal Health Coverage in the context of Senegal, but rather data versed in the lives of participants. The first case study, of Djiby treating his mother, Maimouna, will begin the findings section.

Chapter 4. *Yaa fii suss,* It is all on you – Djiby and his mother, Maimouna.

"Djiby is out with the sheep. He'll be back soon" Awa, Djiby's sister, says to me. It is the early evening and I have just arrived at my friend Djiby's house. The temperature is warm, and pleasant as the sun begins to set and with it goes the heat of the day during this winter afternoon on the Senegalese Sahel. His home is on the outskirts of the town where I have been doing my fieldwork these past couple months. As I look out of Djiby's compound towards the countryside the sunbaked earth and sand covered sparsely by acacias and other brush remain in view. From this land Djiby and the majority of the population must depend on to provide grass and watering holes during the rainy season. Now as the dry season progresses, little to nothing can be found to sustain hungry herds of sheep, goats, and cows. The *sicaar* fence of millet stalks continues to hold up well and wraps around the property containing the two-room house, adjoining shower and toilet, while a faucet, a shelter that serves as the kitchen, and a shelter which under lies a bed. This compound is home to his sister, a couple of brothers, his wife, young daughter, as well as his mother, Maimouna.

4.1 "The Leg"

Djiby ran into me by chance the day before as I was leaving the town health center at noon. It had been a long time since I saw him, and I was happy to hear he was doing well, but I wondered why he was on his way to the hospital. He told me that his mother, Maimouna, was ill and he needed to return to her. She had been admitted there three days before due to a sprain in her leg. This was the third of 5 days that she was hospitalized. Djiby told me that his mother had requested to be taken in, because her leg was not improving and she was unable to walk. With the fare of a *wuteer* she was able to reach the hospital. *Wuteers/Kaleches* are a popular form of transportation in town, where a horse pulls a chariot with room for the driver and two passengers. In my own experience it is not a smooth form of transportation as the chariot is subject to the often jerky movements of the horse in addition to whatever road surface or grade is being traversed. But it is the feasible option, since it is more readily available and cheaper than motor taxis.

The year before, Maimouna was preparing to go to sell at the market early in the morning. It was the day before *Tabaski* (*eid*). This is the biggest festival/holiday of the year in Senegal. Selling is a common job for many women in town. When leaving the house, she fell on the ground and hurt her leg. Upon receiving an x-ray at the hospital it was determined that there was no fracture. Then six months prior to my visit, they decided to return to the hospital, because the point where she had fallen continued to give her pain. At this appointment she was given a brace and some "small" materials and medications were purchased. Djiby made these purchases with the money he had on his person. As the healing had not improved since this last appointment they were now seeking hospital treatment again.

A *marabout* or *serigne* is a healer that occupies an intermediate role between God and people. They can be consulted when treatment by Wolof medicine is sought. Treatments are typically made up of natural substances, like animal products or plants, which are then drunk or poured over oneself. Although they occupy an important role in society and religion, their consultation for the treatment of illness was largely discredited by study participants. Yet I noticed that when treatment itineraries were discussed, marabouts often were present. The consultation of a marabout would depend on what illness and how it manifests according to participants.

Earlier trips to visit a couple of different marabouts were called for by family members after Maimouna's initial hospital stay the previous year. After the marabouts were not able to find a clear causation of her health problems, they returned to the hospital for further follow up, as a sprain in the leg was found to be the problem, according to Djiby. To his dismay he paid a lot of money for the *marabouts'* services with no apparent improvement. He told me that their treatments did not help at all and that they just took his money.

4.2 "One needs company to orient them"

After we connected in the street, I told Djiby I would come visit the hospital later when I was free. That afternoon, I arrived to find a middle-aged woman, seated at the bedside next to a mass of quilts enshrining Maimouna, I greeted them and it became clear that Djiby was out but would return soon. Due to my lack of Pulaar comprehension, the locally spoken language along with Wolof in town, I simply greeted her before Djiby returned. One of the two other beds in the room was occupied by another elderly woman, who also had a companion at her bedside. Djiby explained that the woman seated next to Maimouna is one of his mother's sisters. Aside from the cultural importance of always having someone with her at the hospital, her presence provided him the opportunity to rest after the exhausting first day of getting her there and admitted.

The hospital in town is a primary hospital. Hospitals are in the fourth, highest level of the Senegalese health system, with greater capacity than the health huts, health posts, or health centers that make up the first three levels of the health system. However, this hospital´s primary status positions it below the secondary hospitals in major cities. After passing the welcome building and paying a ticket or discussing with the security guards, one can continue to the main hospital compound. The whole building is open air with a main floor of wards and offices that open into a central garden space. Emergency, obstetric/gynecologic, general surgery, ophthalmology, and pediatric services are available, while social services, the hospital pharmacy, *mutuelle* office, two doctors and administration have offices. Adjacent to each of the offices are chairs typically occupied by someone needing to be seen as well as a couple of family members. Wards typically have two or three beds inside, with a total of 18 beds in 9 rooms available for the population's needs. This is subject to change and another bed may be brought in when the hospital population rises above this.

On our walk home from the hospital that day, Djiby emphasized how tired one becomes when "we do not know the way". In this case "the way" refers to the appropriate places to search for assistance and treatment that make up one's route while a family member or friend is in the hospital. The ill and their families must fit the normal, day-to-day office hours of aid providers at the hospital and NGO into the sudden need where illness presents. The patient must have someone with them to carry out this role, and the role of the companion/care-giver who is with the patient often comes up when conversations touch on serious health events.

In the Senegalese healthcare system, patients must pay for an admission ticket before seeing a health professional. Cases where the patient is elderly or very ill leave this responsibility to the companion. Having cash on hand is essential to pay this ticket as one awaits the writing of tests, prescriptions, and hospitalization. In the case of Maimouna, Djiby assumed this role, going around the town to gather pharmaceuticals from private pharmacies as the public pharmacies at the hospital and health center are quick to run out and possess limited stocks, as well as to gather the appropriate papers to receive a discount on the medicines through the Senegalese government's Universal Health Coverage Program.

4.3 The "house owner" (household head)

As mentioned above, I first learned of Djilby's mother's admission when I ran into Djiby the third day of his mother´s hospitalization, and at this point he had not paid the fees. The doctors had told him that an operation was necessary that would cost 600,000 CFA ($1200) and it would need to be done in Louga, the regional capital which has a secondary hospital. The hospital in town is a primary hospital and could not perform the operation. This amount, of $1200, would include the operation and the respective costs for medications and a hospital stay.

The hospitalization and treatment of Maimouna must be situated in the local social and economic context of the family, specifically that of her eldest son Djiby. As a young man in his late 20s, Djiby is the sole source of income for the family, meaning that his family is relatively poor in the community. His money comes from transporting sheep for sale to weekly large markets in surrounding towns and villages. However, he is in the early stages of this business, and when I visited him he had four sheep in the pen within the compound. He is also the "responsible" in the family, with his father deceased. As he discussed with me, one day his father passed away and the family called on him to assume this challenging role. In most households, responsibility falls on the man of the house or an adult woman, who makes decisions about how expenses of the household are met and provides counsel for decisions of family members. Djiby took on this role as the moment called for him to step up.

In addition to these responsibilities Djiby is also the companion for his mother at the hospital as his younger siblings are not yet mature enough to assist with tasks such as hospital care. This leaves him as his mother's companion at the hospital, setting aside his work for the time being for such tasks. Some family members from the countryside came to visit, and stay at the house, as is commonplace when someone is ill. This put him in a delicate situation, paying more for the daily expenses (due to feeding guests) while not able to earn his usual daily income. These observations gave me insights into the ambiguous role of family and social relations. "Uncertainty is entwined with social relations; in some situations, social relations create uncertainty, while at other times social relations alleviate uncertainty, and often the equilibrium is held in suspense" (Cooper, Pratten, 2014, p 2).

On the 5th day of his mother's hospitalization Djiby decided to bring her home, as it was an uncomfortable space and the hospital had no further treatment to offer, aside from the recommended operation. When we met again on the 5th day, after walking to the hospital together, I remained with his sister, an aunt, and his mother while he prepared and paid the papers for discharge. His mother was still not eating and losing weight. The conditions and location of the hospital room were uncomfortable for her, with "heat and flies" as Djiby explained to me while I accompanied him out of the hospital. He made this decision against the advice of the doctors who obliged him to take responsibility before she would be discharged. The quick signature formalizing Djiby's role as the responsible person for his mother did not change anything, but perhaps cemented the fact he is the only one paying.

4.4 "No money, no treatment"

Money is always discussed as the first thing that you will need when someone is sick and they need to visit the hospital. It is rare that the ill or a single member of a family will have the cash on hand to cover costs of a hospital stay. Many Senegalese families have large networks of family members and social contacts that they can call upon in the case of a significant need, such as an illness. Social capital is unevenly distributed, maintaining and strengthening unequal power relations and social hierarchies (Mladovsky et al., 2010, p. 19). As we continued our walk home from the hospital Djiby told of how he is waiting for a little help from one friend and from a biological brother in the capital, but they have not yet followed through sending money. In Maimouna's case, the bulk of the cost fell on the shoulders of Djiby, her oldest child. However, thanks to the government's program for Universal Health Coverage, Djiby paid 20% of the hospital bill (from the 5 days' stay at the primary hospital) while the state covered the rest.

Djiby keeps his focus ahead on what his mother really needs, an operation. This is an expense that demands someone who can "really help you" as he puts it. Thanks to relatives and friends who contributed small amounts of up to 2,500 cfa (5 USD), 50,000 cfa (100 USD) had been collected to be used for her operation. This did not change anything for Djiby though, as the full amount of 600,000 cfa (1,200 USD) for the operation remained out of reach. "That's not money" he mentioned in his frustration about the insufficient funds he had collected. In general, in town, family is described as the first people to know and the first source of assistance when a member becomes ill. Seeking assistance outside of the family structure is uncommon, and many people told me about how this is actually bad. Talking about one's problems is something that will just bother people and could give you a bad reputation in the town because you cannot manage your own needs. My host father explained to me that every person has their own challenges and it is better to take care of your needs privately and in the family. Djiby told me about how it is difficult to seek assistance and he does not ask for money at this point. Even the day that we visited the NGO and a couple of offices regarding the *CMU* program's coverage, he was uncomfortable. He explicitly stated that it hurts asking others for money and that it is no good. One negative phrase to say about someone in Wolof is that "they do not have secrets" (*Kii amoul sutuura*), meaning that they do not keep their problems to themselves.

People are dependent on others, but must navigate the fine line of not widely disclosing their needs, so that they lose respect in the community.

The social interactions of the family coming to Djiby points to the two sides of such relationships. Their support is important and gives Djiby some rest, but it is also expensive as he must increase his daily allotment for food expenses. I did not notice this tension in my interactions with his family (Djiby never complained about it to me), but it may very well be another form of privacy that Djiby upholds.

As we leave the hospital, throngs of people and animals are visible on the road and sidewalks. It is the day of the "Louma" weekly market where the town is bustling and economic activity is visible. One does not have to visit the market square to see the dramatic change in traffic, including people, animals, and carts, largely from the surrounding villages, that visit town to refill supplies and sell goods. Shopkeepers and merchants alike look forward to this uptick in the otherwise slow-moving county seat. One friend put it to me that the town is 'dry' or *konkon bi dafa woo* except for the market day (meaning, the town's economy). As we walk the way back, it feels like Djiby is greeted by every other person that we meet. Djiby mentioned that a friend of his sold three sheep for him at the animal market near the hospital, a market square that is more specialized from the vegetables and goods. Having owned a shop before getting involved in the sale of sheep, he is familiar to many. When discussing assistance he told me that all of these people believe that he is managing his finances. They assume that he has money because he had a shop.

4.5 "Searching for Support"

Djiby remembered that we needed to visit the pharmacy for his mother's prescriptions. He told me about how earlier at the hospital the prescriptions had been a flash point between him and the doctor. He said that since the doctor knew that Djiby is not a wealthy man, the doctor questioned if he should write an expensive medication for Djiby's mother's prescription. Doctors may avoid writing prescriptions for costly medications, so that the patient is able to afford the treatment. Djiby said that he told him to write it, because treatment is what she came there for. Perhaps the doctor was attempting to limit the financial total of treatment and the economic burden; however Djiby rather took it as a form of judgement that his family members were not receiving the best resources that were available to combat the illness due to his economic position.

Before the pharmacist would allow us to purchase one of the medicines prescribed (the other was out of stock) with the government subsidy, we needed to visit the departmental office and obtain a guarantee from the *CMU*. During this trip to and from the office, Djiby explained to me that “when someone is sick you are just back and forth”. The different offices of the health system and the aid organization present a handful of opportunities for one to receive aid, but the same goes for opportunities to get one’s hopes up. When assistance does not come through or fully cover the prescribed treatment for one reason or another, attaining the treatment may remain as far out of reach as beforehand – but a lot of time would have been spent on searching for support. After a return trip to the pharmacy to know the total prescriptions cost, we find out that the NGO only has an agreement with the other pharmacy in town. After visiting this pharmacy, we find that only one medication can be partially covered with the assistance of the NGO. We return to the NGO to find that they have gone to lunch. Having decided returning home is a better option I accompany Djiby until I reach the home of my host family. We remain in touch and the following week I accompany him to the pharmacy. Having purchased one of the two medications prescribed, and, after indicating that I will cover the second medication, we return and purchase the second drug. During our walk home Djiby explains exactly what the money in his pocket will be used for. He just received it by money transfer from his oldest younger brother for one of the medications and some cement to fix the shower at his house. If he had purchased both medications he would not have been able to repair the house. However, he has been unable to raise money for his mother´s operation, and for now, they must make do with medicines.

Hope for the future is one way that Djiby manages current times. As his second youngest brother continues to study and achieve an education, Djiby hopes that he may be able to help them get ahead. Currently Djiby can just support him as best he can, by paying his registration and board fees while he continues his schooling. Hope in his younger siblings to grow and become independent is something he has seen in his own neighborhood as he points out neighbors whose situations have improved. As Cooper and Pratten argue, “Hope’s realization depends on an ‘other,’ whether that other is fate, chance, God, or another human individual” (2014, p 11). He hopes that he will have some money to help other people and former classmates. He has told me that people come to him for assistance, but he is unable to fulfill their wishes with his current situation. When he has a more stable situation then he will be able to form some of these relationships.

4.6 Discussion

I will now discuss some of the aspects of Djiby's life that came to the fore as he pursued treatment for his mother. These were observed and developed as the large responsibility fell on his shoulders and decisions.

Responsibility

Djiby is obliged to manage his family's needs. Despite being young, the absence of working adult family members places him as the eldest son and in the position to provide and make decisions for the family as is regularly expected of a man in Linguere. This tremendous responsibility is a burden for him, as his working life and social network are not well developed, to the extent which they can come to his aid. These moments weigh on him, and force him to be decisive about the family members' well-being, while determining what will be done to meet individual needs.

Morality

Djiby's pride limited him from visiting others and going around to attempt to collect money, although he did not have the sufficient money or foresee an imminent form of financial support. His sense of pride and independence limited him from visiting others and soliciting charity. Discussion with friends in town pointed to this value of modesty having special significance among poorer Senegalese. People do not want to talk about financial need and in doing so expose their weakness. When someone hears the request of another, it is in their discretion whether or not to contribute. Regardless of their decision, the person in need has already disclosed their personal desires and in so doing loses whatever privacy they may have had.

Religion

In this case people must find ways to continue living and endure the harsh economic conditions that life brings. Religion is a common framework through which life's day-to-day uncertainty is perceived. The presence of Islam is particularly evident in the course of each day. At the end of our conversation Djiby prayed for me and discussed how God brought us together. When referring to daily challenges in making ends meet he describes the difficulty and exhaustion, but also the quiet confidence that God has made things the way that they are. If God intends for him to see peace and love then they will find him. He also sees God's activity when referring to past decisions out of his scope, such as him attending a Qur'anic school rather than primary school. This worldview puts one's relationship with and destiny from God as a frame in which to contain the dependence that one has on others.

Time/Orientation/Route

Knowing where to go and when to go there was extremely important when Djiby needed to access the healthcare system and the services that could assist with healthcare expenses. The social service office located in the hospital is one form of assistance that can pay a percentage of a bill which is present at the hospital, but this does not mean that the population is using it. Many residents in town shared that there are services for assistance available from the NGO or through the collection of alms at the mosque. People make practical decisions about which ventures are worthwhile and helpful through the consultation of neighbors, friends, and family. For example, the hospital's social services manager stated that he is "the most popular person around" among community members as news of significant assistance provided by the service travels in the community. Although, this does not prove that all participants necessarily know or have easy access to these services.

Different participants mentioned the significance of "having someone who can orient you" or of "knowing the way" when you or a family member is sick. This implies that it is not clear which offices or providers to travel to when seeking treatment and financial assistance. Another participant discussed orienting other people. During the final day of hospitalization for Maimouna, I spent the morning on errands with Djiby before returning to the pharmacy the following Monday for medications. A lack of stock of medications meant passing by different pharmacies to determine the drug costs before gathering the appropriate guarantees from the *CMU* and returning again to purchase the drugs. In the case of Maimouna, the *CMU* partnered pharmacy did not possess one of the prescribed medications, leading to a long morning walking between the other pharmacy and the NGO that partners with them. Finally, Djiby delayed buying the medications until the following week as lunchtime and midday prayer were rapidly approaching and he wanted to return to see his mother settled in at home.

No money, no treatment

The *CMU*, *La mutuelle de la ville*, and the hospital social service are the forms of state-sponsored illness support offered. Djiby's mother was able to receive 80% CMU coverage of the hospital stay through Plan Sesame (the CMU pillar covering care for individuals over 60 years of age); however this was not the case for the treatment required outside of the local area. Djiby had no other options for her treatment, aside from mutuelle membership, which he had not enrolled in. Short of full treatment, it rested on Djiby to find the cash to provide the additional care she needed. Issues of state-sponsored social protection and the CMU and *mutuelles* will be returned to in the final chapter

Many people mentioned “no money, no treatment” in town. It was typically invoked when I would first ask a resident about healthcare and illness in town. This was a common mindset in town and was the perception despite the presence of the *CMU*, *La mutuelle de la ville*, and the hospital social service. Djiby’s case exemplifies the reality that such expressions speak to. After explaining the *CMU* to me, one doctor put it that “if you do not have money you will have a real problem getting treatment.” This underlies the point that people are living in a context of scarcity where money is needed to carry on every activity in life, including the healing of the sick.

Support Network

The size and depth of an individual’s support network is especially felt in cases of illness when this group of people come to visit and financially assist the ill. In the case of Maimouna, her network comes to her aid, but the fact that neither she nor her eldest son, Djiby, had connections with “someone who can help well” meant they were not able to pursue an operation for what was diagnosed as a persistent and painful sprain in her leg. In this case of Djiby’s mother, payment of treatment is contingent on Djiby’s family’s network and social capital. The contributions of many were gathered, but perhaps the depth of these connections as well as the economic situations of these individuals led to Djiby not being able to raise the needed cash for the operation. Despite the presence of a UHC program that included his mother, Djiby found that he still needed to gather large amounts of cash to pursue her treatment.

Chapter 5. *Ñiokobok,* We are together: the case of Aissata, aunt of Ramatoulaye

In this chapter, I discuss another case of illness within a family. The case of Aissata demonstrates the extent to which family and social support networks are drawn on in the case of illness. Her family members move to act on a treatment plan when she withdraws from daily life and ceases interacting with other people. Multiple members of the household earn a living, through working as a housekeeper and selling vegetables. Though operating on a meager income, the multiple family members in the household help the household make due. The economies of these members are informal, but more or less regular, while extended family members inhabit the surrounding area.

The white light of the TV screen shone onto each of our faces casting indistinct shadows as the evening news flickered across the screen. The chair in which I was seated had one leg in the doorway, so as to fit next to the large bed where Ramatoulaye, her mother Jojill, and her sister Khady sat, near the edge so as to see the images playing on the small TV screen. The segment was showing footage of and discussing people in villages unable to obtain treatment until their disease had developed to a late stage. Ramatoulaye's sister Khady exclaimed, "You see this? It is what we have!" as one man with massive swelling in his leg was introduced followed by his phone number if anyone could aid paying his treatment and send a money transfer. Ramatoulaye´s home compound is made up of three buildings containing three different households. Sometimes families live in the same compound, but with different social or familial relations. Jojill's brother Khadim and his wife Aissata live in one of the other houses. When I arrived that evening to visit Ramatoulaye, Aissata, who is her aunt and is suffering ill-health, was sitting up on a mat in the compound. During our discussion Ramatoulaye emphasized how Aissata has not been able to do that up until recently, because she has had "stress".

Ramatoulaye is the employed housekeeper of my host family and I have now known her for a couple of years. My curiosity in cooking and spending time observing and asking about meal preparation led to us becoming close friends. Ramatoulaye is 30 years old and despite her father having had one wife, has extended family in town. Our discussions of cooking would often lead into the discussion of daily responsibilities. During an interview two months earlier, her mother mentioned that Aissata was sick and could not get treatment. Aissata is the wife of Ramatoulaye´s mother's brother. She is 52 years and has six children, two whom are away studying at university, while the others live at home for schooling locally. One's mother's brother or *nijaay* is an important connection in Senegalese family arrangements. He is someone who is often present during upbringing and a nurturing male influence. The father is often involved with the responsibility and family commitments of other wives and children. Being the wife of Ramatoulaye's *nijaay*, Aissata is a family member of direct importance.

As I began to ask Ramatoulaye about this situation I came to learn that she was undergoing treatment. She told that earlier in the year, Aissata, would sometimes feel "the stress" some, but these symptoms were not serious until the start of the school year in October. When Ramatoulaye first became unwell, she did not seek treatment and stayed at home until the pain in her head caused great discomfort. During September, her symptoms became more serious, where her head would hurt and she ceased speaking. This resulted in a visit to the town hospital where she was told, in Ramatoulaye's words, that she has *le stress*. Ramatoulaye explained to me that she did not even understand exactly what this illness is, just that people on the TV sometimes recommend exercise training to manage it. Her description of it reflected what I understand as psychological and emotional stress in the Western context. The doctors wanted to determine if the pain in her head had any complications; however the necessary tests could not be carried out with the scanner in town and a visit to a hospital with psychiatric care was recommended. (I was not able to explore the details of her treatment exhaustively, as my proposed research questions concerned the topic of social and economic support for illness, more than the question of diagnosis). Two months after a three day stay in the town hospital, Aissata was taken by her family for psychiatric treatment in the country's capital, Dakar, but the ordered tests were indecisive. After spending a month during October and November with a family member near the hospital for appointments, she returned to town.

On the day of my visit, it has been four months since her initial symptoms. Even after visiting the large hospital in the capitol, as well as a marabout at the recommendation of a brother in Dakar, Aissata´s situation was not noticeably improving. "She got a little better" as Ramatoulaye put it. They went there because Khadim has a brother who lives near the hospital. Many times, people prefer to seek treatment in the capitol because of gossip or personal experience with unintelligible doctors or a lack of medical supplies locally. In this case the family managed to raise a total 700,000 cfa (1,400 USD) necessary for transport and the different steps of the treatment, before Ramatoulaye could travel to the capitol. Despite not having a formal job or belonging to any *mutuelles* or other forms of health insurance, Khadim was able to provide the necessary cash for the expenses of Aissata's three-day hospitalization in town. (It felt too disrespectful to ask Khadim about the payment for the earlier portion of Aissata's treatment). The visits in Dakar on the other hand proved to be a much costlier barrier to clear, as I explain below. Ramatoulaye knew how financing these costlier visits developed, and was clear about the steps taken.

5.1 "Here, everyone in the family stands up"

The analyses and treatments that were advised following the first hospital stay in town were expensive, to the point where Khadim's regular pay from informal manual labor could not cover the 700,000 cfa (1,400 USD) for his wife´s treatment in the capital. Ramatoulaye's family does not have great means. As a vegetable seller and housekeeper, she and her mother do not net enough income to cover any of these treatments either. Bringing in the extended family members who live outside of the compound included other informal workers like tailors, but also formally employed family like one of Ramatoulaye's brothers, a teacher. They had need for everyone to participate, because Khadim is not rich.

Word got around to the other houses of the family in town, and money was pooled together as different family members contributed 10,000, 15,000, or 20,000 cfa (20, 30, or 40 USD). These contributions and 150,000 cfa ($300) from a *naht* (neighborhood money pool) allowed Aissata to travel to the hospital in Dakar. While there, the family requested additional cash for her treatment, leading to money being gathered and sent again. Ramatoulaye talked about the value of these relationships: "When it is time for an event, an illness, or other problems everyone comes and gives the oldest" – meaning that when the word is spread that a family member has a need then the family comes to the oldest sibling with the money that they can spare to assist. The oldest sibling or *taaw* is someone with greater responsibility, who may have the role of teaching siblings or answering questions about life. The Senegalese singer Youssou Ndour chronicles this briefly in his song *Taaw,* stating that "you call them if you are worried" and "you call them when you stop worrying."

These types of money pools are quite common among work colleagues, neighbors, or friends as well as for an upcoming event like a baptism or marriage. The organizer may recruit members or information about the pool may travel by word of mouth. The organizer decides how much the pool is going to contain, the timing of contributions, as well as the duration of the money pool. Members then contribute an amount that participants pay or "set" each week or each month. The contribution is followed a few days later by a regular winner, typically drawn from names in a hat. Participants can find a replacement to pay their share during a given time period, but a late contribution will incur a small penalty which goes to the money pool organizer. This process of placing cash followed by one person taking the collection continues regularly until all members of the money pool have been drawn and given the cash from a collection one time.

Ramatoulaye´s mother, Jojill, and her younger sister accompanied Aissata to the capitol for treatment. Ramatoulaye explained that she also wanted to go to Dakar, but she could not because of her work and her children in the home. Ramatoulaye was primarily caring for Aissata in the house, as Aissata would only accept the food or clothes that she offered. She was also quick to include Aissata in discussions, because "when you are included in activities it helps you feel better." Research has pointed to the ameliorative effects on mental illness which membership in the daily routine of an African family can provide. Thomas and Collogne demonstrated such benefits in treatment regimens using the family and village arrangement in Western Africa (Akyeampong et al., 2013, p.33).

5.2 "You pass there and then pass here. Here you combine everything"

As we sat outside of the bedroom, Ramatoulaye continued discussing Aissata´s illness. She mentioned how much better Aissata is doing now, compared to the time when I visited a couple of months earlier. She said that the marabout was the last place that the family visited for her treatment.

As mentioned earlier, a marabout is an Islamic healer whose skills and treatments cater to the spiritual world. After no decisive diagnosis was obtained at the hospital in Dakar, a visit to a marabout was recommended by the brother in Dakar, who knew of one. This marabout found that a *rab* (type of spirit) was giving Aissata problems. This diagnosis fit with her symptoms, such as that she was not able to do things that she could before and was not speaking. Following the return to town from Dakar, two more marabouts were visited at the recommendation of neighbors, before a visit to the final, effective marabout was recommended.

This marabout was in a village far from town, so one must rent a car specifically for that journey as there is no regular transport there. The family covered the $90 for the car and driver, as well as an advance for the marabout, which was in addition to the price for the determined treatment. Khadim, Aissita's husband, traveled by himself there, as this marabout would conduct the treatment without physically seeing the patient, a regular form of treatment by marabouts. A second visit was made later on per the marabout's recommendation.

Treatment with a marabout is cheaper than that at the hospital, but is still expensive and leads to consideration and access of one's support networks. The marabout was first sought out after the initial stay at the local primary hospital did not improve Aissata's condition. Ramatoulaye pointed out, "This is good, but that is good too, it depends on the illness", referring to the tendency of local people to visit a marabout after inconclusive diagnosis or treatment following consultation with the health system. Although some marabouts are prone to take one's money without providing a visible change in the patient's condition, Ramatoulaye was quick to praise this man's knowledge and ability.

Based on conversations with different people in town, healthcare was often reduced to "having means" or "not having means". In case of the former, it is said that one stays at home passively waiting for God. The experience of Aissata shows that such a simplification is not based in reality. Senegalese people are rather active in the search for treatment and navigating treatment options among Wolof medicine and biomedical treatment in various locations known to the family members. As I visited with Ramatoulaye, she mentioned how Aissata's energy and affect are clearly different from earlier when she was seeking treatment. She pointed this out as I was completing fieldwork, but phone conversations shortly after my departure in January were far more confident in how Aissata now addressed everyday activities such as conversation, cleaning, and washing clothes. In the case of Aissata, treatment from the marabout was the last place that she visited before experiencing some recovery and peace of mind.

5.3 Discussion

The case study of Aissata underlines that one's social relations are what allow someone to be treated. In her case, through the group effort of multiple family members, the cash was gathered to continue her treatment itinerary until her family was satisfied. In the social world of Linguere in Senegal, the family is the typical place obtain assistance with large expenditures, where one is dependent on who is close to ensure this kind of support. This case also demonstrates the pluralistic medical system to which Senegalese people turn for intervention.

Illness

Determining the affliction which Aissata was suffering from took a great amount of time and left family members with inconclusive diagnoses from different practitioners. Symptoms of a psychological nature led family members to consider other forms of treatment, when biomedical care through the health system did not lead to a clear plan for therapy. Trial and error of multiple practitioners in both the biomedical and traditional practice led to credible points that spiritual health was concerned. When biomedical medicine offered no further possibilities, traditional medicine continued to offer possibility. As different well-versed practitioners of traditional medicine offered treatments and followed practices to rectify the spirit and return Aissata to a state of well-being, various practices were undertaken, involving other hidden costs, such as one marabout in Dakar who required a white sheep for the appropriate task. Within the field of traditional medicine, as Ramatoulaye often explained, “there are those who can and those who cannot.” One goes with their experience and recommendations to navigate this unpredictability with more precision.

Costs

Avoiding this unnecessary cost is essential in their daily lives. Jojill pointed to one of the boys in the house who was not feeling well a couple of months earlier. The family purchased paracetamol from the pharmacy and his condition improved. And “just that” returned his functioning. Jojill does not see it as a necessary expense. When she purchases food at the market before she goes home, it is necessary, whereas illness is not a consistent expense. “I use whatever I have from selling vegetables to purchase that day’s ingredients for lunch.” In this case, a cost that is regarded by the family as unnecessary and burdensome will not be prioritized.

Pluralistic Treatment

Indecisive answers from biomedical analyses and medications did not limit Aissata’s treatment. Her family continued searching for treatment from other care providers during and after biomedical methods did not provide any definitive answers. Locally held beliefs about illness and the spiritual led Aissata to receive additional treatment from a marabout, ultimately leading to an improvement in her condition. Government and hospital programs do not give marabouts any recognition as care providers, despite their prominent role in Senegalese treatment itineraries. Treatment itineraries demonstrated the pluralistic nature of health in Senegal.

Greater income and a larger family network allow Aissata's family to accumulate the resources necessary to explore various options in the pluralistic context of treatment, including the hospital and religious healers known as marabouts. Although Aissata's case underlines the importance of marabouts' treatments, it is important to note that the family first tried to get treatment at the hospital. In many of the cases of illness I followed, the national healthcare system fulfills a major part of treatment consideration and action taken. Having social relationships of significance, where one is in touch is a prerequisite to engaging them when health and illness are concerned. These relationships and treatment are book-ended by social relations. Whereas Djiby (in Chapter 4) did not access many of these relations as he did not have them, Aissata's family did. The following ethnographic chapter will explore the Senegalese state's efforts to increase access to this formal system through free initiatives and health insurance coverage.

Network

The means of the family were what allowed Aissata to be treated. The size and proximity of the familial network made it possible to gather the cash required to seek treatment from the necessary care providers. These members were all within the family, which follows suit with the majority of people with whom I had discussions, who stated that the spouse followed by relatives are the first point of contact when someone is ill in the family.

It is important to situate this in a broader context. The most common gifts of money within one's wider social network are presented during baptisms, marriages, and funerals. Visits from family members or close relations typically include cash put forward as a gift and sign of respect to elders or the head of the household present. This may be a sign of respect or recognition of showing one's consideration and pity. Relationships of this nature display active care and participation in another's life. At the same time, the preference to keep financial matters to oneself or within the family was often brought up by participants, and welcoming others into this *biir* or "inside" indicates an established level of trust involving personal matters or *sutura*.

In Aissata's case, despite her husband's lack of wealth, support from numerous relatives in the immediate area allowed her to continue seeking treatment. Despite not belonging to any insurance or assistance programs, the large amounts of cash did not prove to be an insurmountable barrier for Aissata's family. This was the common denominator among the different forms of treatment pursued by the family. Although these relationships could be relied upon in this case, they are contingent on the spread of awareness and the financial availability of the needed persons. Ramatoulaye mentioned that some younger siblings did not see Aissata because “they were in the bush.” Living in the countryside away from their sick family member, these relatives may not have heard about Aissata’s need for treatment or simply not had the cash to spare. One friend emphasized that if you do not have money you will not go to visit/see a sick friend/family member. In the end, you will say you did not know about it because you cannot contribute. Others emphasized that visiting and giving fruit or soap is valuable for the sick.

The local options for social protection accessible through the hospital’s social service, the local *mutuelle*, the CMU, and the local NGO, did not figure into Aissata’s illness – unlike in the case of Djiby´s mother, discussed in chapter 4. When I asked Ramatoulaye why this seemed to be the case, she said that she wants to belong to the *mutuelle*, but still has not gone to sign up. She told me that she has told Aissata we must try to enter the *mutuelle*, but the family still has not. Ramatoulaye’s mother, Jojill, belonged to the *mutuelle* years ago, but let it go, citing it as too expensive and exclusive. Daily costs are numerous and payment for these expenses takes priority over an event that is less likely. Finally, the family’s support came through in the case of Aissata, and there is no reason to expect a different outcome in the case of another family member’s illness.

Chapter 6. Perspectives and Experiences of *Les mutuelles de santé* as part of *Couverture Maladie Universelle*

In this chapter I discuss the formal system of health insurance available to people in Senegal, a scheme known as *Les Mutuelles de Santé.* I focus on the question, how leadership, doctors, pharmacists, and community members understand and perceive the *mutuelle* scheme. It is of particular interest and importance to my study to understand how the largest *mutuelle* in town, affiliated with the state's Universal Health Coverage program (*CMU*), is perceived and used by study participants.

As underlined in the previous chapters, the time I spent with participants and families led me to understand that health insurance was less significant than I had anticipated in meeting the financial cost for families to obtain healthcare. The observed actions and forms of support differed, and instead the family's social network was key in raising money for healthcare costs. However, Senegal´s government policy is to expand financial protection for citizens in contexts of illness and ill health through membership in health insurance schemes (called *mutuelles*). Therefore it is important to understand how my research participants perceived and experienced health insurance schemes.

It is notable that no formal system of *mutuelles* played a role in the treatments of the ill in the previous two ethnographic chapters. However, the experiences of these participants did contribute to my understanding of the position of the *mutuelles* and the (limited) role they play in covering some healthcare costs. Over the course of fieldwork I learned about the various systems of community health insurance (*mutuelles*) present in town and the terms that these programs operate on. Senegal's *CMU* Program has multiple pillars to provide the population with healthcare coverage. Health insurance through a local *mutuelle* is one of these pillars, and indeed is the largest component of this system, while initiatives for free healthcare cater to certain groups of the population, namely those under 5 years of age and those over 60 years of age, in a program known as *Plan Sesame*.

This chapter focuses on data from informal conversations with community members and health staff as well as interviews with health staff. It is based on seven formal interviews with two leaders of the local *mutuelle* scheme, two pharmacists, and three doctors from the local health center and hospital. I visited with the local *mutuelles* manager on five different occasions and the *mutuelle* president on seven occasions. Informal conversations with community members, hospital staff, and NGO staff, as well as observations at the hospital, health center, and in town also contribute to understanding people's views and opinions about the *mutuelle* and the data presented in this chapter. I met with government employees at the headquarters of the Universal Health Coverage program (*D'agence couverture maladie universelle*) in Dakar on two occasions, but I was not able to interview them, due to additional ethical approvals and time conflicts.

I begin by discussing how my informants perceived the government's Universal Health Coverage program (CMU), and its relationship with the system of health insurance (*mutuelles*), which already existed in Senegal before the introduction of CMU, and which the government hopes to build on, to ensure that everyone has access to financial protection for healthcare. I continue the chapter by introducing the different local *mutuelles* and their origins and management, before going on to discuss the challenges faced by the *mutuelles* and their members. The chapter will follow a progression that expands on the following questions:

- What are *mutuelles* and how are they structured and funded?
- What different kinds of *mutuelles* exist and who are the members of these different mutuelles?
- How does the *mutuelle* system relate to the governments UHC program?
- What challenges do *mutuelles* face? (according to informants)

These are then followed by three sections focusing on the various challenges that participants understood and perceived to exist alongside and in opposition to *mutuelles* and the state's CMU program.

6.1 The State and the CMU's implications

As explained in the introduction to this thesis, Senegal is using insurance membership (in *mutuelles*) to provide its citizens with Universal Health Coverage (UHC). As the Senegalese government is focusing primarily on financial protection, it is anticipated that the country will achieve UHC once all citizens are enrolled in mutuelles (*Ministère de la Santé et de l'Action Sociale* 2012).

In this section I discuss how participants viewed the provision of health services by the government together with the efforts of the Universal Health Coverage program (CMU) to offer coverage. In my interviews with members of the scheme leadership, they offered nuanced opinions about the aims and use of the CMU. As my local supervisor suggested at the beginning of fieldwork – the families may discuss many challenges regarding the programs, but scheme leaders' perspective must also be heard. It is from these interactions and observations that my understandings and practices regarding the state's Universal Health Coverage program have been placed and understood.

Conversation with community members and participants yielded shared characteristics. Chief among them was the financial cost of health. Its significance was evident in daily conversations; health care expenses are among the unknown events and costs that may suddenly enter one's life. Free policies and *mutuelle* insurance scheme recruitment occur as healthcare services are generally sought out in moments of a sudden and abnormal nature. This context of expanding state financial intervention in the unforeseeable and expensive event of serious illness informs people's actions and decisions.

Nowadays most *mutuelles* fund themselves through membership fees, either collected monthly or annually. These are collected by the local manager or they are deducted from one's salary before payment. Some *mutuelles* match the contribution made by the employee to meet the required membership fee.

The structure of *mutuelles* can vary with the size of each organization. Some organizations work locally. They exclusively function in one city, while others are reached more widely and work around the country or in multiple communities. *Mutuelles* may have a local representative or manager who processes forms and payments locally before sending them to a national office. Leadership is typically made up of a committee headed by a president who is elected annually. These individuals make decisions about the running of the *mutuelle* and ensure that it carries out its functions. A treasurer, a secretary, and several at-large members are also present on the advisory committee in addition to the manager.

6.2 An Overview of the mutuelles operating in the town of Linguere

Mutuelle name	Type of funding	Includes services at:
La mutuelle de la ville	Private (Budgeted to receive State Subsidies)	Public Health Center, 1 of 2 Private pharmacies
La mutuelle de la zone	Public	Public Hospital, Private Pharmacies
La mutuelle eglise	Private IPM (Scheme with contribution of employer and employee)	Public All Levels, Private Pharmacies
La mutuelle de les professuers	Private	Public Hospital

The communal level, *La mutuelle de la ville,* exists in a landscape of healthcare payment options that many consider to be a fragmented system (Mladovsky 2020). Different programs have been created by the government and citizens to address the financial cost of healthcare. These programs provide cost assistance that can range from a percentage to full coverage of various services and medications. Hospital treatment can be covered for members of user fee exemptions (*Des initiatives de gratuité*), members of an employer's private insurance (*institute prévoyance maladie*, IPMs), and members of private insurances, state-employee insurance, as well as *mutuelles* (community-based health insurance schemes). These different *mutuelles* have been created under different circumstances and with unique membership to provide healthcare coverage, although the origins of this style of insurance lie with formal employment by the state.

Some schemes, such as *La mutuelle de la ville*, are referred to as 'communal level' schemes, because they are at the level of the municipality. Other *mutuelles* like *La mutuelle de la zone*, cover the *department* or county, which is the level of government above the municipality. This *mutuelle* has benefits for treatment at the hospital in town. The function of such health insurance schemes relies on local membership and leadership. The local *La mutuelle de la ville* provides coverage of treatment at the smaller health center in town, while *La mutuelle de la zone* covers treatments at the hospital in town. *La mutuelle de la ville* has the largest membership of any in town – approximately 3,000 beneficiaries and approximately 7,000 members. Each beneficiary with a registration booklet can enroll other household members by adding their photos. *La mutuelle de la ville* is the largest in the Louga region of Senegal.

When persons want to use *La mutuelle de la ville* to utilize financial support for healthcare, they show their membership booklet at the ticket office. They then visit the mutuelle manager in her office during morning business hours (9 am-1 pm), where she provides a letter of guarantee. Upon furnishing the letter of guarantee, the health center consultation fee for the member is 20% of the normal cost. Further services at the health center are billed at 20% of the normal cost, until one visits a different health facility. This typically occurs when one visits the private pharmacy, because medications at the public pharmacy inside of the health center tend to be out of stock. After presenting their prescription at the private pharmacy, a receipt with medication costs is created and members return to the *mutuelle* manager for another letter of guarantee. This letter of guarantee allows the medication to be purchased at 50% of the normal cost with contributions limited to 7,500 cfa (15 USD).

6.3 *La mutuelle de la ville* – intervention and the local private *mutuelle*

La mutuelle de la ville was originally set up through an Abt Associates/USAID project in 2004, and it continues to receive support from USAID for meetings, teaching engagements and other activities. It is a private *mutuelle*, which has been independent of government leadership. This is the local *mutuelle* in town, which caters for the whole population, but especially the poor informally-employed majority. The *DECAM* (*Desentralisation de l'assurance maladie*, decentralisation of health insurance) program of the Senegalese government has sought to network together these various *mutuelles* throughout the country, with subsidization based on the number of enrollees in a scheme. The membership fee is very low, so as to encourage the poorer members of the population to join. Membership is not tied to employment, making it technically accessible to the entire population. A membership fee of 1000 cfa ($2 USD) gives the beneficiary a booklet, which is good for life and does not have an expiration date. Before each member is added to the booklet and enrolled in the scheme two passport photos must be presented per enrollee. The insurance membership costs 7,000 cfa ($14 USD) per member for the year, but the government subsidizes half of the cost for all, leaving 3,500 cfa ($7 USD) to be paid by each beneficiary when they register. Membership booklets can include up to 20 members.

This scheme involves local people, including well educated community members already in positions of community leadership. This large *mutuelle* and its agenda were referred to more often than not as an extension of the government, and not in terms of local oversight.

This is the perception, despite the government's approach of subsidizing *La mutuelle de la ville* without strictly dictating its functioning. The president of *La mutuelle de la ville* pointed out that USAID continues to support the *mutuelle* in the days of the Universal Health Coverage Program and so follows through on its promises. Abt Associates/USAID no longer directly funds the mutuelle, but they continue to fund training workshops for staff. Abt Associates continues to push for equity, quality of care, and financial protection and its website discusses the importance of its projects that promote Universal Health Coverage, especially in Sub-Saharan Africa (Abt Associates Website 2020).

In the town of Linguere, as elsewhere in Senegal, there are *mutuelles* for employees who belong to private companies, *mutuelles* serving members of a particular group formed by employees (such as teachers), *mutuelles* for government employees (such as hospital employees and civil servants), as well as private *mutuelles* created by different organizations, both locally and through the subvention of NGOs and aid initiatives. Other *mutuelles* in the town cover larger portions of health costs. These are typically for better paid jobs that are with larger organizations, which have a local branch as in Linguere.

One *mutuelle* functioning locally was set up by the Evangelical Lutheran Church of America which supports a Senegalese NGO and the Lutheran Church of Senegal. *La mutuelle de l'eglise* functions with contributions from employees and matching contributions from employers. Its office is based in Dakar, where the administrative committee meets every month, and the General Assembly meets annually. The administrative committee consists of 7 people, including the president, secretary, treasurer, and 4 at large members, as well as the manager.

The local teachers' *mutuelle, La mutuelle de les professeurs,* is described differently. Employees pay into it monthly with every salary, so it does not run out of money. The people who "arm it" with their money are the ones who oversee this *mutuelle*, and actively participate in it. The *mutuelle* is private, meaning that it is independent of the political wishes that come with the state's budgets and positions. Members control it and determine how it continues to operate. These decisions can be made by those who are most qualified, independent of their political affiliations. *La mutuelle de les professeurs* covers hospitalization costs and half of other hospital costs.

As explained in Chapter 1, the two arms of the Senegalese government's *CMU* focus on enrolling people in insurance schemes as well as providing free care to specific groups of the population. The latter which requires one present their national identity card. Children under 5 years of age are not obliged to pay for consultation tickets or simple medications, while adults over 60 years of age do not pay for analyses or services aside from medications which remain the patient's responsibility. It is an advantage to belong to a *mutuelle*, even if you are eligible for one of the free initiatives, because it covers some medications.

The state is ambitiously enrolling people in insurance with the purpose of financial protection from illness through the *CMU*. The major policy initiative networking these various *mutuelles* under the name of the *CMU* is *DECAM*. Its goal is that the state will cover half of the one-time annual payment for membership in a voluntary *mutuelle* scheme for every citizen who is not otherwise covered. This effort shows an increased level of participation by the state in citizens' lives, a significant commitment, and investment in a means of providing health coverage. As citizens are provided financial protection it is anticipated that the country will have achieved UHC. This remains an incomplete vision. As one Senegalese friend put it to me, "The government is not a big state, so it is not possible to support everyone's healthcare, so they have begun slowly." This is evident of the early stages that the program is in, and its direction to develop. If these commitments gather strength, a potential scenario where the entire population has full financial protection in the use of state health facilities may develop.

Although the CMU offers a bold policy proposal and implementation, the target audience is skeptical of those advocating universal health coverage. The state has struggled to hold trust in the public eye and is widely criticized by ordinary citizens. Bridging this lack of trust in state institutions and initiatives is sure to be a barrier that determines how a young program unfolds and enables the ill to obtain treatment, found to play a significant role in study participants' understandings of the state and the CMU. Citizens wonder about the direction it will take as they critically observe its development.

State responsibility is a peculiar idea to many participants, because the state has never occupied this sort of role in their lives. The governing administrations were all discredited by multiple participants, brushed off as being more concerned about accumulating capital and advancing their interests than the wellbeing of the population. Other participants held beliefs to the contrary: that the state's CMU does work for people, only that stronger financial commitments are needed. It is in relation to these varying opinions and experiences of the state intervention, that research participants understood the challenges of the health insurance schemes and their membership.

6.4 Challenges

Universal Health Coverage, "*c'est une bonne idée*" (is a good idea), where someone does not have to pay for healthcare. When members of my host family and friends in town discussed the "good idea" that the *Couverture Maladie Universelle* (*CMU*) is, their praise stopped there. Few people positively viewed the CMU, due to frequent medication shortages and tiring journeys to complete necessary paperwork. Some of the challenges that complicate how its perception by community members, health professionals, and scheme staff will now be discussed.

6.4.1 "It's your chance": Uncertainties surrounding health insurance schemes (mutuelles)

"If you have the *mutuelle* you just go and find out if it is operating. When I was married, my husband had one, and when we went to treat my son it was blocked. We paid ourselves. Sometimes you go and it is working, and sometimes not. If you are a part of it and get sick, you just go and find out" (Ramatoulaye Community Member - Chapter 5).

Beginning the uncertain process of medical treatment is precluded by the financial means to pay for services. Various *mutuelles* provide membership as an avenue to reduce the financial cost of treatment. Different actors have come together to procure services to community members in Linguere and many locals have experienced these community development efforts firsthand or through accounts shared by neighbors. It is important to note that the local *La mutuelle de la ville* is not understood by all as a dependable source of financial support. In a context where the financial capital for treatment is not always available, citizens grow weary of new opportunities and informed choices are made in one's best interest. Some may choose to rely on their own personal means in the chance that they become ill, while others may rather "take a chance" with a local *mutuelle*.

"Like myself, many people neglect it. When you go there (i.e. to a government health facility), they may not have the materials you need, but your money is already inside." This remark was shared by Ali, a well-off merchant, referencing his own previous bout of serious sickness from diabetes, who did not consider using a *mutuelle*. In his opinion paying for *mutuelle* membership beforehand will not lead to a guarantee, but rather a financial loss (*perte*). It would amount to participating in an institution that has no use to the participant. For Ali, a more recent withdrawal of financial coverage by *La mutuelle de la ville* for diabetes and hypertension medications reaffirmed his decision not to join. This scenario where "those in the office have your money" shows how the availability of treatment is independent of the payment of membership fees, something mentioned during other informal conversations. In other words, people say that paying membership fees does not guarantee that you get financial coverage of healthcare, even if this is what has been promised. Such distrust and doubt led to and explained people´s tentativeness to enter such programs. This proved to be a common perception, as my conversations with hospital staff also concluded that most patients pay for their treatment in full, forgoing the financial cost assistance offered by a *mutuelle* membership.

When someone is sick "they need to go for treatment immediately", emphasized Ali. Limited hours of mutuelles personnel do not accord with moments of sudden need. Given that the *mutuelle* manager and president work half days, someone needing *mutuelle* staff may be forced to return the following day. However, when I spoke to her, the manager of *La mutuelle de la ville* emphasized how she is available all the time, and that hospital personnel often come and get her to ensure someone's *mutuelle* membership is considered. Her goodwill and effort may go above and beyond the call of duty, but such initiative is not an official part of her position. I observed several people approach the *mutuelle* manager's office, where the security guard would tell patients or family members that the manager is off work, making them choose to continue to the ticket office or turn homewards. Citizens look to these actions by the government relative to previous promises and its undependable reputation. Reaching and successfully obtaining treatment through mutuelle membership thus remains uncertain. The CMU's user fee exemption programs were discussed with similar skepticism, as perceptions among participants were that the ill may seek treatment without receiving the promised policy exemptions. Study participants navigated this context of uncertainty when trying to access services.

Unlike many others, Djiby (introduced in Chapter Four) held a positive opinion of the CMU program. Its financial coverage of his mother's treatment was a significant expense, which was taken off his shoulders. The *Plan Sesame* program (the component of the Universal Health Coverage program, which provides user fee exemptions for citizens over 60 years of age) largely covered the treatment she received at local health facilities. One is automatically included in these free services by possessing a government-issued identity card and fitting the age criteria. Even though these services were not enough, however, to complete Djiby's mother's prescribed treatment. Djiby was not downcast. He had emerged from the crisis without overwhelming financial debt, looking hopefully towards the future.

However, Djiby has not yet joined the *mutuelle*. When I asked about *La mutuelle de la ville*, Djiby replied that he intends to join it, but he plans to enroll his five family members at the same time. According to Djiby, he will enroll when God gives him a chance and he has an income to shoulder the financial burden. He regards it as an important program, but is simply not ready to join its ranks. When he reaches a point of financial security he will join it, he said. Although inexpensive on the individual level, enrollment of multiple family members can put the costs of membership out of reach for the irregularly employed, such as Djiby. Enrollment remains in the not-so distant future as he focuses on accumulating material wealth.

As health professionals and community members stated to me time and again, “treatment requires money.” As another doctor stated, “if you are not holding money you will have a real problem with treatment.” Despite the existence of this universal program, the general population is required to have money when it comes time for medical treatment. This is challenging for the general population, however. As one of my research participants explained, they purchase their food with whatever earnings they have from what they can sell on that day. Such systems, where the coverage of healthcare is based on the existence of cash in one’s hand, is how many understand the Universal Health Coverage of Senegal at this moment. The uncertainty of getting a hold of cash in the moment of illness plays into this situation.

6.4.2 Solidarity and its limitations

> “This is our solidarity. Maybe she is sick and I am healthy. She will use the card for treatment, but I will have paid for my card and praise God that I am healthy.” (*La mutuelle de la ville* manager, referring to a friend and *mutuelle* member standing next to her)

The mutuelle manager clearly cares about what she does, but as she explained to me during an interview, like other voluntary positions in community health, working for the *mutuelle* “is not money that you can live on.”

I reached out to local scheme members and other community members to better understand the challenges and benefits provided by the *mutuelle* and the ideals forming it as understood by its leadership. From these conversations and interviews, I understood that there are also many uncertainties in the mutuelle structure and organization. Although the *mutuelle* president has made it a priority to provide the *mutuelle* manager a small monthly stipend of 20,000 cfa ($40 USD), the other positions she holds do not add up to a livelihood. They do however point to her commitment to the community. Further essentially voluntary community health work as a 'health relay' and *bajjinu gokh* (aunt of the neighborhood), may net a small stipend of a few hundred cfa following different events. The role of these positions is to help the state and nongovernmental organizations communicate with and reach local people, for example, when the heights and weights of children need to be taken in each neighborhood. They also aid in the distribution of different resources from the state, such as Vitamin A and other supplements for fighting undernutrition. These relationships and close ties to the community give the scheme and its membership a special value to the *mutuelle* manager. She pointed out that although her husband is a teacher, making her a member of the national teacher's *mutuelle*, she can still belong to the local *mutuelle*. Her belonging to *La mutuelle de la ville* despite already possessing coverage through her husband's workplace, helps demonstrate her commitment to the program that she is soliciting to the population.

This sense of solidarity is tested however, when staff of the local *mutuelle* are not given the promised compensation for their services. The manager for *La mutuelle de la ville* scheme continues to work and carry out her duties, despite having not received any monthly stipend for the last two years, a contribution which the *CMU* program has supposedly allotted for *mutuelle* managers. When CMU-allotted compensation fails to materialize, it reinforces the sense that national programs are distant and ineffectual. Unlike hospital staff, the *mutuelle* manager is not provided membership in one of the state's *mutuelles*, but rather must take care of *mutuelle* membership on her own accord. Her missing stipend introduces uncertainty and prevents her from relying on the state to carry out its promises. Despite raising such concerns, she regularly professes the sense of solidarity that enrolling brings with it.

In regard to the *mutuelles* scheme, local *mutuelles* were met with more trust. Those that were created by local people living in the town, and relied on money staying in the area. Money in other schemes was perceived to leave the area or "pass through other places". When a mutuelle is private (not government-affiliated), it is the participants who get to make decisions about it and maintain it, by "arming it" with their means and ideas. Locally created organizations with local leadership allow users and members to maintain some form of regulation over the scheme and keep tabs on its operation. This also goes for local 'money pools' (*naht*) which are a popular way to gather a larger sum of money when one needs or when there is an occasion. These sometimes large networks of coworkers, neighbors or the organizer’s contacts are capable of gathering significant amounts of cash. During my research in Senegal, it was evident that demonstrating one’s care or consideration for someone through the exchange of cash has greater meaning to both parties than when one’s financial resources effectively vanish and enter into a government program.

Other community member participants mentioned that the CMU is different from other forms of financial support, because “the government’s money” is involved. If it involves “the government´s money”, citizens have little decision-making power. Generally local people and services receive more trust than those based with the government in Dakar. Community members have little influence over what happens with such funds. The *mutuelle’s* administrative committee and general assembly have the ability to lead it, which is perceived by community members as a good thing, though local concerns may be slighted by national targets.

Sometimes the agenda of CMU leadership is questioned. The priorities of the CMU financing was often at odds with its vision of providing health coverage to its citizens. Policy emphasizes the role of training and administration in the CMU’s implementation timeline (*Ministère de la Santé et de l’Action Sociale*, 2012). Trainings and related activities often occur at the expense of CMU funding to communities. As one hospital employee stated, “The CMU staff have many training workshops.” These occurred at the expense of supporting *mutuelles* affiliated with the CMU. Prior ethnographic research has pointed to the disparity in promotional staff receiving payments relative to those carrying out work on the ground (Wood, 2020). Discrepancies between the pillars of the CMU policy and financed activities, raise questions about the program’s purpose and erode trust.

Mutuelles often need to supplement financing through their own searches. Partners are commonplace, as previously explained. However, *la mutuelle de la ville* is recognized differently, because its patron is the town mayor of Linguere, who is also the current minister of the interior. He secured 4 million cfa (ca 8,000 USD) in funding from the Senegalese MOH to aid the enrollment of community members. Locally, there are no other *mutuelles* supported by someone of such status and wealth. The mayor is known for bringing assistance and programs to his hometown, such as the town’s only garbage truck, a large farm on the outskirts of town, solar-powered streetlights, pavement and sidewalks on major streets, and a new center for the police. He has found financial support to aid the *mutuelle* in recruiting members, where the first 2,000 members each year receive a 2,000 cfa reduction in the membership fee, reducing each beneficiary's yearly cost from 3,500 cfa ($7) to 1,500 cfa ($3). This is a way for him to recognize and pay homage to his community. Locally he is known for caring about his community, and it is sure not to hurt his political support. Many locals approve of his actions, while disapproving of the state's actions. This support of the *mutuelle* is not only seen as a way of remembering his home community, but also his own family, as both the communal level mutuelle *(la mutuelle de la ville*) and the department level mutuelle *(la mutuelle de la zone)* are managed by his relatives.

By standing with the community the town's mayor is positively remembered for helping his community, while maintaining a positive standing with political elites for strengthening efforts towards national policy. His work with the *mutuelle* is sure to be of this nature as well, but must have some political benefits as he uses his influence to raise awareness and support for a national policy.

6.4.3 People are not aware of the *mutuelle's* activities

Research participants generally pointed out that the population is not aware of the *mutuelle's* existence and what uses it has. *La mutuelle de la ville* regularly visits the neighborhoods to share about its functioning to recruit more locals. Djiby remarked that there are often many women at these gatherings, and that he does not attend them. Many community members emphasized how the population simply does not understand the *mutuelle*. Others were of the opinion that as it is around for a longer period of time more people will enroll in the mutuelle program, since it does provide some help in the cost of healthcare. However, other people stressed that the *mutuelle* has gone into the neighborhoods and raised awareness again and again, but the community still does not buy in. This level of awareness seems to be largely connected to the issue of trust and its reputation which has already been put forward. As for the illness treatment trajectories of participants, it is the advice and opinions of one's social contacts that take precedent, leaving people to look ahead and determine solutions.

Doctors I interviewed in Linguere mentioned that the Universal Health Coverage program needs to be widened, so that more of the population can receive treatment. The age of the program was brought up regarding the growing number of members and the strengthening of benefits provided. Doctors interviewed believed that the CMU needs to be prioritized by political will. One local doctor believes the CMU must be widened to include more people and more services, "Health is a right, and inequalities today prevent the poor from being healed."

One cannot forecast what future policy proposals will contain, though these conversations show hopes of a future where larger groups of the population can obtain health insurance membership or access to a further-reaching system that exempts citizens from user fees. Such remarks testify that the CMU is not fully developed. Though the current propositions of the CMU remain ambitious in the context of civil society's outsized influence in health care financing (Tichenor, 2019; Tichenor, 2020). Criticisms notwithstanding, the CMU holds goals of reaching the large majority of the Senegalese population.

6.4.4 "The government's support is slow to come"

The sense of togetherness and solidarity that *mutuelles* are supposed to engender is also strained when the state's budgeted funds do not come through. Such scenarios leave local staff members to evaluate and act with insufficient monies, despite the commitments by the state to subsidize the schemes. As it stands, the scheme is able to carry out its functions, but operates with limited means, since the state's financial support has not been received for the last three years (therefore its operation is solely dependent on membership fees). Despite having the necessary registers, cards, and booklets for enrolling members, participants explained to me that the finances needed for ongoing function of *La mutuelle de la ville* are irregular.

These pitfalls lie in wait as members interact with other points of the healthcare system where the *mutuelle* provides coverage. The pharmacist *Ibrahima Ndiaye* found that government financing predictably becomes less and less dependable as time goes on. He listed off a number of *mutuelles* in the *department* (county) which he has blocked.

As he explained to me,

> "But almost all of the *mutuelles* on earth –the state seriously helps them one time, two times, or three times and it never pays again. And there are many *mutuelles* that I ended our collaboration (cut), which I do not ever work with because I do not see any money anymore. There is the teachers' mutuelle, I blocked it. There is also a second teachers' mutuelle that I have also blocked. The *mutuelle* at the hospital, it has been a while that we have not worked together, because there was a late payment. There are *mutuelles* that suggest we work together but I refuse too. Because they are not reliable." (*Ibrahima Ndiaye*, Pharmacist pseudonym)

These previous experiences inform his unwillingness to continue taking chances on *mutuelles*, because it may hurt the pharmacy's operation. The same even goes for the more reputable *la mutuelle de la ville* based at the hospital. As we continue to examine scenarios where the financial cost of health comes to the foreground, community members shared nuanced opinions about the coverage of hospital bills which *mutuelles* benefits provided. *Dr. Ndiaye's* unwillingness to continue with such a relationship is based on previous interactions with the state and other *mutuelles*. Hospitals receive payments from the state late or simply do not receive them at all, as is the case for the hospital in town, which has not received a payment from the CMU in the last two years. Doctors and key health persons recognized that the state is not quick to pay the hospital back. When the hospital is low on financial resources, it can be challenging for its management to continue providing care. Paychecks from the state to the hospital staff are regularly a couple of months late, and state-supplied orders of medications tend to be unreliable and quickly exhausted.

6.4.5 "You are left to find who you can"

The current dilemma remains that government payments for such programs are not going through. Leadership of the *CMU* made remarks that the scheme is not well developed in Linguere. This state of development means that payments from the *CMU* are few and far between, leaving local leaders to "solve their problems." This was also evident in study participants' personal understandings and perceptions of *La mutuelle de la ville,* where tentativeness and distrust came to take great meaning.

According to *la mutuelle de la ville* president, everything from the state is slow. "Nothing is reliable", *mutuelle* president, *Mamy Ndaw* told me, "When the state does not come through you are left to solve the problems… It is a little difficult… No, it is very difficult!".

The Senegalese government and CMU have made grand statements about the voluntary *mutuelles* schemes, with the target of reaching 90% of Senegalese citizens by 2022 (*Ministère de la Santé et de l'Action Sociale*, 2012). State contributions through the CMU were arranged to begin in 2017, and local hospital and *mutuelle* staff members continued to wait during my fieldwork in 2020. Such action has distanced the state and the people implementing policies. Navigating unpredictable state support has led staff to make internal changes in *la mutuelle de la ville*.

The *mutuelle* leadership has continued to operate the *mutuelle* and negotiate budgetary challenges, unlike other *mutuelles* in the *department*. The *mutuelle* president owes its continued operation to the large number of beneficiaries enrolled. “When there are not many beneficiaries it will not work. It will do nothing. That is why many *mutuelles* are not working.” *La mutuelle de la ville* is currently the only functioning *mutuelle* in the county (*department*). As the government works to streamline these voluntary *mutuelles* schemes, local leaders look to the state for financing with growing apprehension.

My interviews and conversations on the subject of the mutuelles revealed that the ideal structure of *mutuelles*, where the state is the behind-the-scenes manager of the *mutuelle* network, and communities are the owners, is not the reality that most people experience. As the state is tardy or simply unable to respond to matters of financial support, the responsibility to lead such programs shifts to community members. This leaves the process more decentralized as it is up to local boards to decide if and how to close shortcomings of a program largely perceived by participants as national and state-run. It also creates confusion.

> “At first the state did nothing, only ABT/USAID helped the *mutuelle* when it was created in 2004. The CMU was created in 2017, but the state does not do anything for the *mutuelle*. Nothing. Nothing.” (*La mutuelle de la ville* president Mamy Ndaw)

The relationships that the state advocates with communal level *mutuelles* like *la mutuelle de la ville* is undermined when it does not uphold its financial commitment. When promises for “financing sustainability and improvement” by the state do not follow through, cynicism and skepticism grow. (*Ministère de la Santé et de l’Action Sociale*, 2012) This position of the state regarding the *CMU* program contrasts with that of donors and outside organizations which directly support the *mutuelles*. These sorts of partnerships are the reason for the existence of certain *mutuelles*, like *la mutuelle de la ville*. Others have been formed by community members independently, or following the creation of the *CMU*. Despite the CMU’s recent creation and greater commitment to community *mutuelles*, Abt Associates & USAID were regarded more positively than the state, namely for being consistent.

Ideals of solidarity give structure to the Senegalese state’s plan for Universal Health Coverage. This section explored different *mutuelles* (CBHI) operating in the town of Linguere, Senegal. As Universal Health Coverage is rolled out, the challenges of scheme leaders, pharmacists, and hospital administration have been brought forward to lend a critical perspective to the broad claims that a universal program is for everyone. In the socioeconomic context of a small Senegalese city where resources are scarce, lingering distrust of state policies and rumors of unreliable guarantees challenge local *mutuelles* leaders with member enrollment. Local leaders solve budgetary challenges, making due with existing members and paid fees. They search for confidence among a skeptical local population and the unreliable, distant state. Some key points from this data will now be discussed.

6.5 Discussion

The interviews, focus group discussions, and conversations I had with various actors and participants about the role of *mutuelles* and the challenges they face suggest that until the state can dependably commit to making regular payments to mutuelles, it is unlikely that these voluntary state-supported schemes will experience much growth in membership. People are slow to enroll with such schemes because they do not expect to receive any benefit in the very cases of illness these schemes are intended to benefit. People do not want to use their (scarce) money on a program if they perceive this program as a bad investment. When discussing the *CMU*, people often shared experiences of friends or neighbors going to seek treatment, hoping to get coverage from the *CMU* or a *mutuelle*, only to be forced to pay for treatment. Stories of negative experiences travel farther when it comes to shared experiences and the general critique of the state by local people.

Time involved

The amount of time that is spent obtaining the proper administrative approvals to get financial coverage is another common point people made when discussing mutuelles and the CMU. "They make you tired" is how multiple community members described it to me. Being forced to pass through different offices and wait for different approvals before the sick person can obtain treatment is not convenient– it is an added burden to an already burdensome situation. One participant emphasized how treatment has to be sought right away when it's needed and waiting is not an option. Even friends who do not know much about healthcare pointed to these extra steps when accessing treatment. Such steps create additional challenges in the lives of community members.

Distrust in the state

At the same time many become cynical of the Senegalese state, as they see a different set of rules apply for those at the top of the socioeconomic scale and for those with political connections. An example of this happened shortly before I arrived in Senegal to organize my fieldwork, when a scandal involving the president's brother and his oil dealings with British Petroleum were streaming news feeds. When discussing the role of the government in healthcare, community members pointed to this scandal as evidence of nepotism, or they pointed out the high costs of accessing healthcare, electricity and water for ordinary citizens, while political leaders and the political elite fly for expensive healthcare treatment in foreign countries. During the first month of fieldwork, a contract between a Turkish firm and the government was in the news because bidding had not been properly vetted. Such frequent reports underline ordinary people´s concerns that politicians -and the government they represent- are more interested in lining their pockets than looking after the citizenry. The impression people have with the government is that it is inconsistent and cannot be depended on in daily life.

As people look towards treatment and medical care the state is rarely regarded as being reliable. Its offices in Dakar and its universal programs seem distant when citizens cannot utilize their benefits on the local level. The *CMU* program is "globalized," and has a high national profile – often being invoked by politicians as evidence of the government´s efforts - but the provision of the needed funds and the resultant care materialize locally only irregularly.

Efforts taken by the state to provide Universal Health Coverage to its citizenry have been put into place by the Senegalese government through its *CMU* program. In the socioeconomic context of Senegal, where citizens do not trust the state, these funds are not regarded by local people as dependable. As people navigate these programs and the financial cost of illness, it is local socially-close networks of support through family members, and the subjectivity of social relationships which are experienced as more reliable, since they are tried and tested in cases of serious illness.

The state cannot be relied upon

This issue of trust is a challenge however, as the state is considered by many to be unreliable. Reliability is a key factor in any transaction. Organizations such as *mutuelle* schemes, which depend upon paying members and infrequent streams of cash from the state struggle as the population remains skeptical of the state's gradual response to such services under institutional rules. By contrast, in many people´s experience, one's close social network on the other hand never turns someone away. In the case that someone does not have anything to spare, most of the time he or she will strive to contribute in some fashion, even if this does not go towards the financial cost of treatment. For example, through visits in the hospital and offering toiletries or food. This gesture is up to each individual, and by having a social network there are bound to be persons who can put cash together.

Citizens have learned not to depend on the state in meeting their basic needs. I have explained that the state is a major force in the lives of participants. However, according to participants, its inability to follow through on promises to its citizens time and again leave a population often looking elsewhere to continue functioning in daily life. The unreliability of state support for healthcare needs, and the lack of trust many people had in *mutuelles*, means that social networks, and the economic support they can provide in situations of illness, are extremely important.

Concluding Remarks.

Senegal's administration is embracing promises to provide its citizens with Universal Health Coverage, the West African country's national strategies are attracting attention on the world stage. *Mutuelle* community based health insurance membership and user fee exemptions are the prominent features of *Couverture Maladie Universelle*, which is the national UHC program. As policy implementation takes place, insurance schemes are expanded and membership fees are paid. The social and economic aspects of health typically get overlooked when aggregate statistics are presented, such as outcomes or coverage. This study has aimed to explore the social side of support in illness and treatment. The research process has been guided by the research questions previously described in chapter 2, and by the rural Senegalese town of Linguere, which served as the fieldwork site over a 5-month period. The duration of time in the field created opportunities to observe and interpret the actions and rationales of individuals and families navigating treatment landscapes and the social ties which envelop them.

The CMU Universal Healthcare Coverage program aims to furnish healthcare coverage to the informal majority of Senegal's population. *Mutuelle* voluntary health insurance schemes and user fee exemptions form the backbone of this approach, which anticipates enrollment of citizens not included in insurance schemes of state employees and other formally employed persons. Informally and underemployed individuals risk financial catastrophe in the case of ill health and healthcare expenditures. The state holds that informally employed and underemployed individuals can enroll and take on healthcare through use of *mutuelles* (*Ministère de la Santé et de l'Action Sociale*, 2012).

Daily life rarely includes state-sponsored programs in Senegal, where the relationship of citizens and the state is oftentimes undependable and at times tenuous. The literature has pointed to infrequent state payments to *mutuelles* and *mutuelle* coverage of a limited package of services that does not significantly change the financial cost of seeking treatment (Mladovsky et al. 2014). Families regularly make out-of-pocket payments to achieve healthcare. Discussions with hospital financial employees underlined that the majority of Senegalese being treated at the hospital pay for services in cash. This indicates that families are not enrolling into *mutuelles* in a number that will bring a sea change in Senegalese health financing. Ethnographic chapters have attended to the methods of health financing that Senegalese families participate, and to the significance of social networks in cases of ill health.

As outlined in Chapters 4 and 5, which presented case studies of illness and how it is dealt with in two families. Local forms of support are engrained in the culture, and express a foundation of solidarity. Social relationships are accompanied by the regular exchange of money, and such activity is significant in times of need. Participants shared that visiting other contacts to discuss borrowing money is another method of paying for needs, such as the financial cost of illness. Family or friends may seek out someone who is sick or in need, but borrowing and asking for money (*nyaan xaalis*) is restricted to persons with whom one is close, such as a trusted friend or family member. It remains that the preference stated by participants was not to ask others for help, but to meet one's needs independently, so as to be discreet and not cause distress. The social nature and significance of these relationships is put simply in the Wolof expression *nit ni ay garabam*, or 'people are people's medicine'. Joining a program like a *mutuelle* or applying for a bank loan are less frequent methods of obtaining financial resources, and limit one's opportunities to strengthen relationships with other people.

Chapter 4 illustrated the case study of Djiby, where state coverage allowed his mother Maimouna to begin treatment locally. This experience demonstrated that state sponsored programs can reach the population with some regularity, and provide access to care. However, Djiby's role of 'the responsible' placed the burdens of and responsibility for the family on him. This included time-intensive tasks early on in her hospital stay, where it was necessary for him to make journeys and office visits to obtain the appropriate forms and approvals for the CMU to cover his mother's care. One other community member referred to the office employees for the CMU with some apprehension, "they make you tired" (*danu lay sonnal*). When a follow-up treatment was needed, CMU coverage ceased to be available to complete Maimouna's treatment, requiring that Djiby gather the 600,000 CFA (1,200 USD) to pay for her operation. This limit to the program's provision occurred during a state of economic insecurity following Djiby's change in employment, though his limited social network ultimately meant that this sum remained out of his reach. Each of these steps is ridden with uncertainty, and point to how he is living in a state of contingency (see Whyte & Siu 2015), dependent on different happenings, circumstances, and institutions. Without other alternatives for gathering the money needed, Maimouna would be supported at home in the presence of her family.

The size and dependability of one's social network greatly influences the economic costs incurred in cases of illness. Maintaining access to such networks is built on reciprocal exchanges. Not everyone has a large or supportive social network. Chapter 4 pointed to Djiby's social isolation, as a young man responsible for his extended family, without anything to share with others (i.e. he does not have access to extra money). It seemed difficult for him to ask others to help him in his moments of need. He is also self-described as shy (*kersa*). While having pride in meeting one's needs, independence is an important value which helps him to maintain respect in the neighborhood and community, even when short of significant financial means. In the case that one does not have a large social network of family members or friends (as is the case for Djiby), individuals are left to sort out their challenges alone. These decisions to maintain one's respect and one's secrets (*sutuura*) greatly limited the treatment that could be sought, but they also allowed Djiby a certain respect and sense of self-worth. Other cases where the family was close and large (As was the case for Aissata of Chapter 5) or wealthy did not implicate the same concerns of pride and independence.

Chapter 5 described the effort of Aissata's family network to arrange the necessary capital to ensure that she received treatment, until her status was acceptable in the eyes of the family's 'therapy management group' (Janes, 1973). Her niece, Ramatoulaye, recounted discussions and decisions of family members as they determined the treatment trajectory upon which Aissata would embark. Previews of treatment cost, the proximity to family members, the convincing nature with which practitioners diagnosed and treated her (evidenced in her condition), and the advice and experience of neighbors and other family members, were exhaustively assessed and selected. Aissata's family members leaned into doubt and hope as they pursued treatment from traditional practitioners repeatedly when doctors did not offer a definitive biomedical diagnosis. The financial participation of Aissata's husband Khadim's social network ensured that treatment could continue as the 'therapy management group' deemed necessary, while Khadim waited upon those in his social circle who could contribute. Other more general, local forms of financing also contributed towards accessing treatment.

Money pools such as *nahts* are a way for people to strengthen relationships with one another and create opportunities. These institutions are dependent on trust between members as well as with the organizer, who holds the cash and oversees the collection and distribution of collections. These money pools are created with some regularity, and one can join at a moment's notice - as Ramatoulaye (Chapter 5) described, "When you set up a *naht* you just walk around the neighborhood asking who is interested and plan it." The frequency of these meetings is high, meaning that one can participate in multiple *nahts* at the same time if so desired. With money pool buy-ins varying widely, participants can find a contribution that they find affordable and worthwhile. Situating these different forms of health financing in the activity and struggle of life, led me to use a lens of uncertainty (Cooper & Pratten 2015). Uncertainty is present at every turn in the incident of illness.

Treatment plans relied completely on the cash collected by the family, and in neither case study was any form of *mutuelles* utilized. The perception of cost was challenging for family members. As Aissata's treatment demonstrated, purchase of health insurance is not a required expense for survival. The costs of food and living expenses are not subject to the same unpredictability as healthcare costs. Insurance memberships are limited to the state health system, leaving out traditional healers, as observed in Aissata's case. She was under the care of traditional practitioners who did not have any relation to or membership in a *mutuelle*, such as *La mutuelle de la ville*.

Chapter 6 concerned the role of the state and *mutuelles* as regarded by stakeholders, with special attention to local *mutuelle* leadership. The unpredictable nature of the CMU exasperated local scheme staff and eroded their trust. Without promised financing *mutuelle* staff operated with a 'subjunctive' regard to the state, perplexed, but self-reliant in their ongoing work. *La mutuelle de la ville* continued to operate through membership fees as they awaited the state's promised payments. Generally, state support was not perceived as dependable among community members. Only a select few of the many community members I met in Linguere belonged to *La mutuelle de la ville*. A sense of mistrust existed around the reliability of insurance networks and their connection to the state, despite a functioning local scheme. The perception that community members may join and not receive coverage when seeking care rivaled the ideal of solidarity lauded by *La mutuelle de la ville* scheme staff. I also regularly met community members who were not even aware of its efforts. Such interactions suggest that efforts to raise awareness should be given greater priority by *La mutuelle de la ville*.

Though distant to the population, the state does find ways to support the demand side of the healthcare system. These ethnographic chapters have shown how the claims and targets of policy are not experienced uniformly by members of the community. A contextualized understanding has helped to expand on forms of support where socially close family members and neighbors are the ones who come through with the money in cases of serious illness and ill-health. Despite a social closeness of frequent interactions that families depend on, these moments and processes are riddled with uncertainty as each social relation is dependent on the current “subjunctive mood” (Cooper & Pratten, 2015). This refers to when individuals lean into such moments tentatively, with a real sense of doubt tinged with hope that the actions of others will come through (Merriam Webster 2020). The time period before and during which treatment takes place provides an opportunity for one’s family and network to be contacted and respond, but such moments tend to be happenstance, and dependent on the viability of these members’ personal economies. The presented case studies and the data from which they were formed describe the interpersonal nature of spending and financial matters, specifically as it pertains to healthcare. Such research cannot provide simple answers to questions of program efficacy and functioning, but by contextualizing cases of serious illness we can see the support of one’s social circle is most often primary, while the state takes a secondary role.

The prospect of accessing treatment in Senegal has been detailed in the accounts of ethnographic chapters and case studies. Contingency (see Whyte & Siu, 2015) emphasizes how treatment can depend on people, happenings, circumstances, and institutions. Data has strongly indicated that the treatment sought and the financial means to pursue appropriate treatment are hugely dependent on social relations and infrequent state support of *mutuelles* and user fee exemptions. As Ramatoulaye (Chapter 5) pointed out to me, “people are people’s medicine” (*nit ni ay garabam*), because in situations of illness you and your family must be interacting with others. When the state plays a limited role on the ground, contingencies and social conditions are especially apparent. The empirical data points to how the presence of one’s social network is how treatment is obtained and completed. Furthermore the data points to the erratic follow through of state health financing, and suggests that if the state is to make good on promises of universal health coverage by implementing *mutuelles*, allotted subsidies and current budget priorities must be first addressed.

Future studies may investigate the developing UHC landscape in Senegal as *mutuelles* are advocated and grown by the state to function as a healthcare financing mechanism for the population. Exploration of these programs and of user fee exemptions will be valuable in a context of unfolding claims and policies by the state. UHC efforts are receiving different levels of focus and resources as pilot studies and donors are engaged in different communities (Doff, 2020). Plans to implement a mobile phone application and accounts for payment of insurance premiums are being considered. As user fee exemptions become increasingly burdensome for the Senegalese Ministry of Health budget, other financing mechanisms are being explored, such as the tax base (Doff, 2020). Such predictions demand serious questions about the means by which UHC programs, what UHC is, and what messages are being conveyed to citizens.

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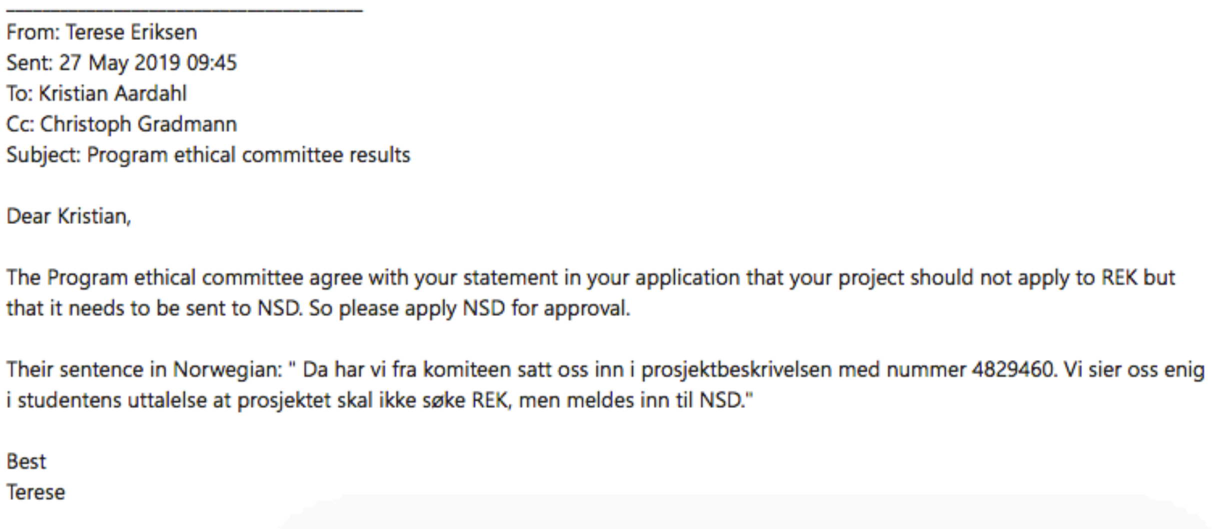
Appendix 1. Letter from the Internal Ethics Committee



From: Terese Eriksen
Sent: 27 May 2019 09:45
To: Kristian Aardahl
Cc: Christoph Gradmann
Subject: Program ethical committee results

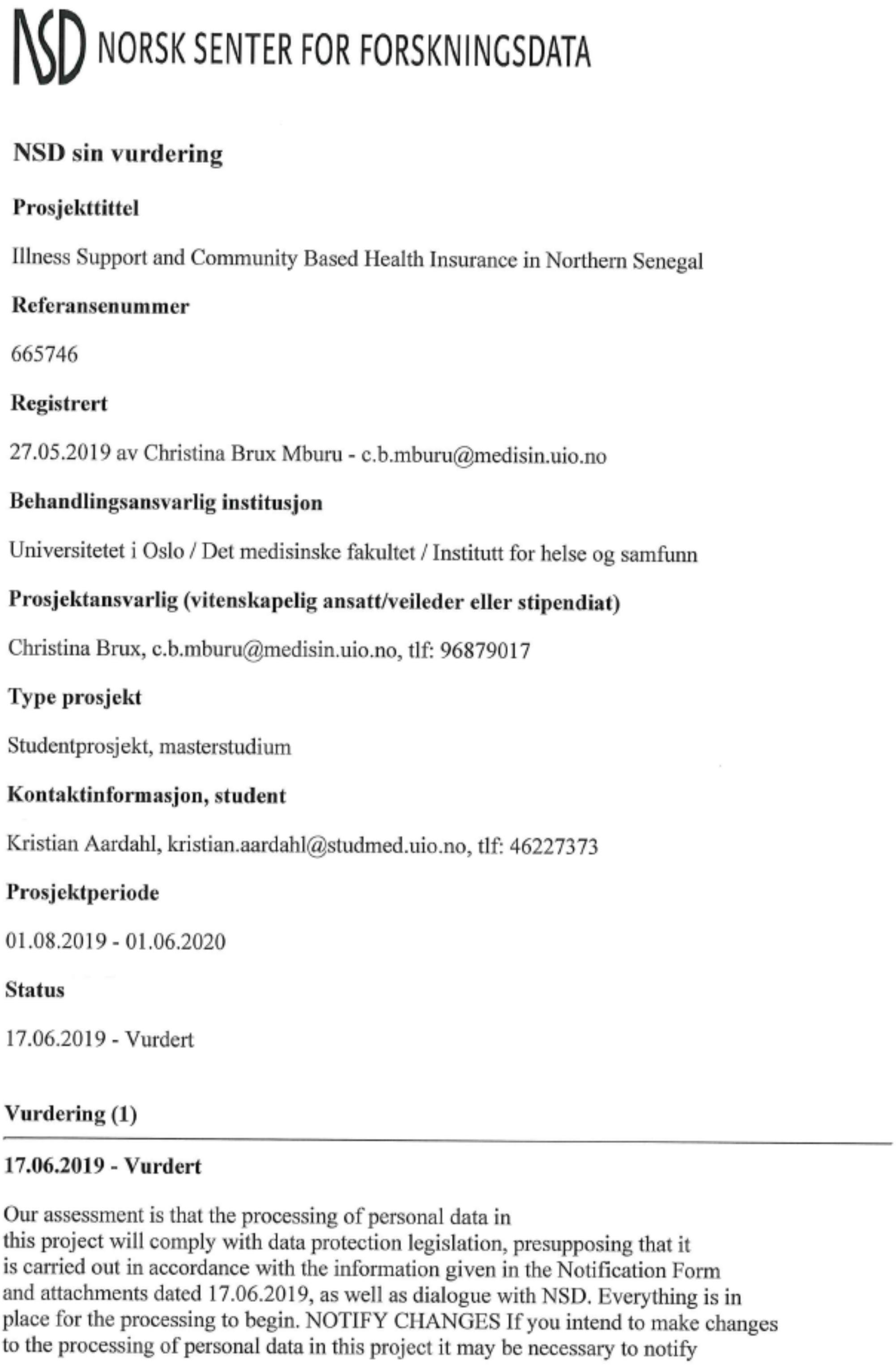
Dear Kristian,

The Program ethical committee agree with your statement in your application that your project should not apply to REK but that it needs to be sent to NSD. So please apply NSD for approval.

Their sentence in Norwegian: " Da har vi fra komiteen satt oss inn i prosjektbeskrivelsen med nummer 4829460. Vi sier oss enig i studentens uttalelse at prosjektet skal ikke søke REK, men meldes inn til NSD."

Best
Terese

Appendix 2. NSD Notification Form & Assessment



NSD NORSK SENTER FOR FORSKNINGSDATA

NSD sin vurdering

Prosjekttittel

Illness Support and Community Based Health Insurance in Northern Senegal

Referansenummer

665746

Registrert

27.05.2019 av Christina Brux Mburu - c.b.mburu@medisin.uio.no

Behandlingsansvarlig institusjon

Universitetet i Oslo / Det medisinske fakultet / Institutt for helse og samfunn

Prosjektansvarlig (vitenskapelig ansatt/veileder eller stipendiat)

Christina Brux, c.b.mburu@medisin.uio.no, tlf: 96879017

Type prosjekt

Studentprosjekt, masterstudium

Kontaktinformasjon, student

Kristian Aardahl, kristian.aardahl@studmed.uio.no, tlf: 46227373

Prosjektperiode

01.08.2019 - 01.06.2020

Status

17.06.2019 - Vurdert

Vurdering (1)

17.06.2019 - Vurdert

Our assessment is that the processing of personal data in this project will comply with data protection legislation, presupposing that it is carried out in accordance with the information given in the Notification Form and attachments dated 17.06.2019, as well as dialogue with NSD. Everything is in place for the processing to begin. NOTIFY CHANGES If you intend to make changes to the processing of personal data in this project it may be necessary to notify

NSD. This is done by updating the Notification Form. On our website we explain which changes must be notified. Wait until you receive an answer from us before you carry out the changes. TYPE OF DATA AND DURATION The project will be processing special categories of personal data about ethnic origin and health, and general categories of personal data, until 01.06.2020. LEGAL BASIS The project will gain consent from data subjects to process their personal data. We find that consent will meet the necessary requirements under art. 4 (11) and 7, in that it will be a freely given, specific, informed and unambiguous statement or action, which will be documented and can be withdrawn. The legal basis for processing special categories of personal data is therefore explicit consent given by the data subject, cf. the General Data Protection Regulation art. 6.1 a), cf. art. 9.2 a), cf. the Personal Data Act § 10, cf. § 9 (2). PRINCIPLES RELATING TO PROCESSING PERSONAL DATA NSD finds that the planned processing of personal data will be in accordance with the principles under the General Data Protection Regulation regarding: - lawfulness, fairness and transparency (art. 5.1 a), in that data subjects will receive sufficient information about the processing and will give their consent - purpose limitation (art. 5.1 b), in that personal data will be collected for specified, explicit and legitimate purposes, and will not be processed for new, incompatible purposes - data minimisation (art. 5.1 c), in that only personal data which are adequate, relevant and necessary for the purpose of the project will be processed - storage limitation (art. 5.1 e), in that personal data will not be stored for longer than is necessary to fulfil the project's purpose THE RIGHTS OF DATA SUBJECTS Data subjects will have the following rights in this project: transparency (art. 12), information (art. 13), access (art. 15), rectification (art. 16), erasure (art. 17), restriction of processing (art. 18), notification (art. 19), data portability (art. 20). These rights apply so long as the data subject can be identified in the collected data. NSD finds that the information that will be given to data subjects about the processing of their personal data will meet the legal requirements for form and content, cf. art. 12.1 and art. 13. We remind you that if a data subject contacts you about their rights, the data controller has a duty to reply within a month. FOLLOW YOUR INSTITUTION'S GUIDELINES NSD presupposes that the project will meet the requirements of accuracy (art. 5.1 d), integrity and confidentiality (art. 5.1 f) and security (art. 32) when processing personal data. An interpreter is a data processor for the project. NSD presupposes that the processing of personal data by a data processor meets the requirements under the General Data Protection Regulation arts. 28 and 29. To ensure that these requirements are met you must follow your institution's internal guidelines and/or consult with your institution (i.e. the institution responsible for the project). FOLLOW-UP OF THE PROJECT NSD will follow up the progress of the project at the planned end date in order to determine whether the processing of personal data has been concluded. Good luck with the project! Contact person at NSD: Karin Lillevold Data Protection Services for Research: +47 55 58 21 17 (press 1)

NSD NORSK SENTER FOR FORSKNINGSDATA

Notification Form 665746

Last updated

17.06.2019

Which personal data will be processed?

- Name (also with signature/written consent)
- Address or telephone number
- Email address, IP address or other online identifier
- Sound recordings of people
- Background data that can identify a person

Type of data

You have indicated that you will be processing background data that can identify individual persons, describe which

Age, family composition, employment, educational background,
residence, gender

Will you be processing special categories of personal data or personal data relating to criminal convictions and offences?

- Racial or ethnic origin
- Health data

Project information

Project title

Illness
Support and Community Based Health Insurance in Northern Senegal

Explain why the processing of personal data is necessary

Names
and contact information will be collected for practical purposes of contacting research participants during the fieldwork period. Background information will be collected to the extent that this is necessary for the study objective, and

to explore the various factors in which health care and health insurance are implicated. Directly and indirectly identifiable personal data will be collected only to the extent that it is relevant and necessary for the study. Under the list of 'special categories' in the 'type of data' section, we have indicated that data about health, and about racial and ethnic origin, will be collected. Information about health is necessary, given that this is a study about health care, the health care decisions made during episodes of ill health, and treatment trajectories. Information about racial and ethnic origin is only necessary to the extent that this is, in the Senegalese context, potentially a factor in which the health care options and decisions of the study participants are implicated. If this is not the case, this data will not be collected. If this is the case, this data will be collected only to the extent that it is of direct relevance to the study objectives.

External funding

Type of project

Student project, Master's thesis

Contact information, student

Kristian Aardahl, kristian.aardahl@studmed.uio.no, tlf: 46227373

Data controller

Data controller (institution responsible for the project)

Universitetet i Oslo / Det medisinske fakultet / Institutt for helse og samfunn

Project leader (academic employee/supervisor or PhD candidate)

Christina Brux, c.b.mburu@medisin.uio.no, tlf: 96879017

Will the responsibility of the data controller be shared with other institutions (joint data controllers)?

No

Sample 1

Describe the sample

Community members / families in the local
community

Recruitment or selection of the sample

Approximately 10-15 participants from the local community will participate in this study. If possible, approximately five participants will be selected as key informants and/or followed more closely during the fieldwork duration - either persons in positions of specialized knowledge about the community or health system, in the case of key informants, and/or persons who are open to on-going research participation as they navigate various health events and care seeking decisions. Snowballing will be used to recruit research participants, starting with contacts that the student researcher already has in town, as well as purposive sampling techniques, if possible, to select information-rich cases and achieve maximal diversity in the study sample. Recruiting participants of diverse backgrounds (with respect to gender, age, family composition and familial role, employment and education, for example), will elicit multiple perspectives and aid in creating the richest possible data set. Sampling will conclude when saturation is reached and little or no new information is collected in the last interview. There will be no strict inclusion or exclusion criteria other than being a community member over 18 years of age. When recruiting via snowball sampling, the researcher will not receive contact or other personal information relating to anyone who has not consented to this or contacted the researcher themselves.

Age

18 - 110

Will you include adults (18 years and over) who do not have the capacity to consent?

No

Personal data relating to sample 1

- Name (also with signature/written consent)
- Address or telephone number
- Email address, IP address or other online identifier
- Sound recordings of people
- Background data that can identify a person
- Racial or ethnic origin
- Health data

How will you collect data relating to sample 1?

Personal interview

Legal basis for processing general categories of personal data

Consent (art. 6 nr. 1 a)

Legal basis for processing special categories of personal data

Explicit consent (art. 9 nr. 2 a)

Explain your choice of legal basis

Participant observation

Legal basis for processing general categories of personal data

Consent (art. 6 nr. 1 a)

Legal basis for processing special categories of personal data

Explicit consent (art. 9 nr. 2 a)

Explain your choice of legal basis

Group interview

Legal basis for processing general categories of personal data

Consent (art. 6 nr. 1 a)

Legal basis for processing special categories of personal data

Explicit consent (art. 9 nr. 2 a)

Explain your choice of legal basis

Information for sample 1

Will you inform the sample about the processing of their personal data?

Yes

How?

Written information (on paper or electronically)

Sample 2

Describe the sample

Health
Care Providers

Recruitment or selection of the sample

The student
researcher will reach out to local hospitals and health care establishments, either personally or via mutual contacts. The researcher will receive contact information of other parties through mutual contacts only in the case that these other parties have consented to this and given permission for their contact information to be shared with the researcher, or contacted the researcher themselves.

Age

18 - 110

Will you include adults (18 years and over) who do not have the capacity to consent?

No

Personal data relating to sample 2

- Name (also with signature/written consent)
- Address or telephone number
- Email address, IP address or other online identifier
- Sound recordings of people
- Background data that can identify a person
- Racial or ethnic origin
- Health data

How will you collect data relating to sample 2?

Personal interview

Legal basis for processing general categories of personal data

Consent (art. 6 nr. 1 a)

Legal basis for processing special categories of personal data

Explicit consent (art. 9 nr. 2 a)

Explain your choice of legal basis

Group interview

Legal basis for processing general categories of personal data

Consent (art. 6 nr. 1 a)

Legal basis for processing special categories of personal data

Explicit consent (art. 9 nr. 2 a)

Explain your choice of legal basis

Information for sample 2

Will you inform the sample about the processing of their personal data?

Yes

How?

Written information (on paper or electronically)

Third Persons

Will you be processing data relating to third persons?

No

Documentation

How will consent be documented?

- Manually (on paper)
- Orally

Describe how oral consent will be documented

Written consent will be obtained in all possible cases.
However, in the case of illiterate research participants who are unable to sign their names, or in the case of persons who are not comfortable documenting their signature in writing, oral consent will be an option. In these cases, the provision of oral consent will be audio recorded by the researcher.

How can consent be withdrawn?

Participants can contact the researcher and can withdraw their consent either orally or in writing. They can do so at any time, without providing any reason, and without any consequences.

How can data subjects get access to their personal data or have their personal data corrected or deleted?

Research participants can access their personal data by contacting the researcher, in which case they can review their individual interview transcripts and obtain a copy, if desired. They can report any errors or request any corrections directly with the researcher, and these wishes will be respected. They can request that their personal data is deleted by notifying the researcher, either verbally or in writing - without providing any reason and without any consequences. This will be the case until the data set is fully anonymized.

Total number of data subjects in the project

1-99

Approvals

Will you obtain any of the following approvals or permits for the project?

- Other approval

Other approval

Internal Quality Management Committee at the University of
Oslo's Master's Program in International Community Health

Processing

Where will the personal data be processed?

- Computer belonging to the data controller
- External service or network (data processor)

Who will be processing/have access to the collected personal data?

- Student (student project)
- Data processor

Which data processor will be processing/have access to the collected personal data?

A local
interpreter will be utilized during the field work period. This interpreter will be present during the data collection encounters and will have access to the audio recordings only to the extent that they assist with transcription, when together with the researcher. The interpreter will not have their own copies of the audio data, transcriptions, or any other data material. The interpreter will sign a confidentiality agreement.

Will the collected personal data be transferred/made available to a third country or international organisation outside the EU/EEA?

No

Information Security

Will directly identifiable data be stored separately from the rest of the collected data (e.g. in a scrambling key)?

Yes

Which technical and practical measures will be used to secure the personal data?

- Personal data will be anonymised as soon as no longer needed
- Restricted access
- Other security measures

Indicate which measures

The University of Oslo's secure data storage services, TSD, will be utilized to the greatest feasible extent. While in Senegal, the researcher will attempt to use TSD. In the case that it is not feasible while in Senegal, due to unstable network, then data will be stored and processed on the University of Oslo's M-drive, which is a username and password secured server. This will be accessed through a private computer belonging to the researcher, which is also username and password protected. Upon return to Norway, all data will then be transferred and processed via TSD. This will all be clarified with the University of Oslo, and internal procedures will be followed.

Duration of processing

Project period

01.08.2019 - 01.06.2020

Will personal data be stored after the end of the project?

No, the collected data will be stored in anonymous form

Which anonymization measures will be taken?

- The identification key will be deleted
- Personally identifiable information will be removed, re-written or categorized
- Any sound or video recordings will be deleted

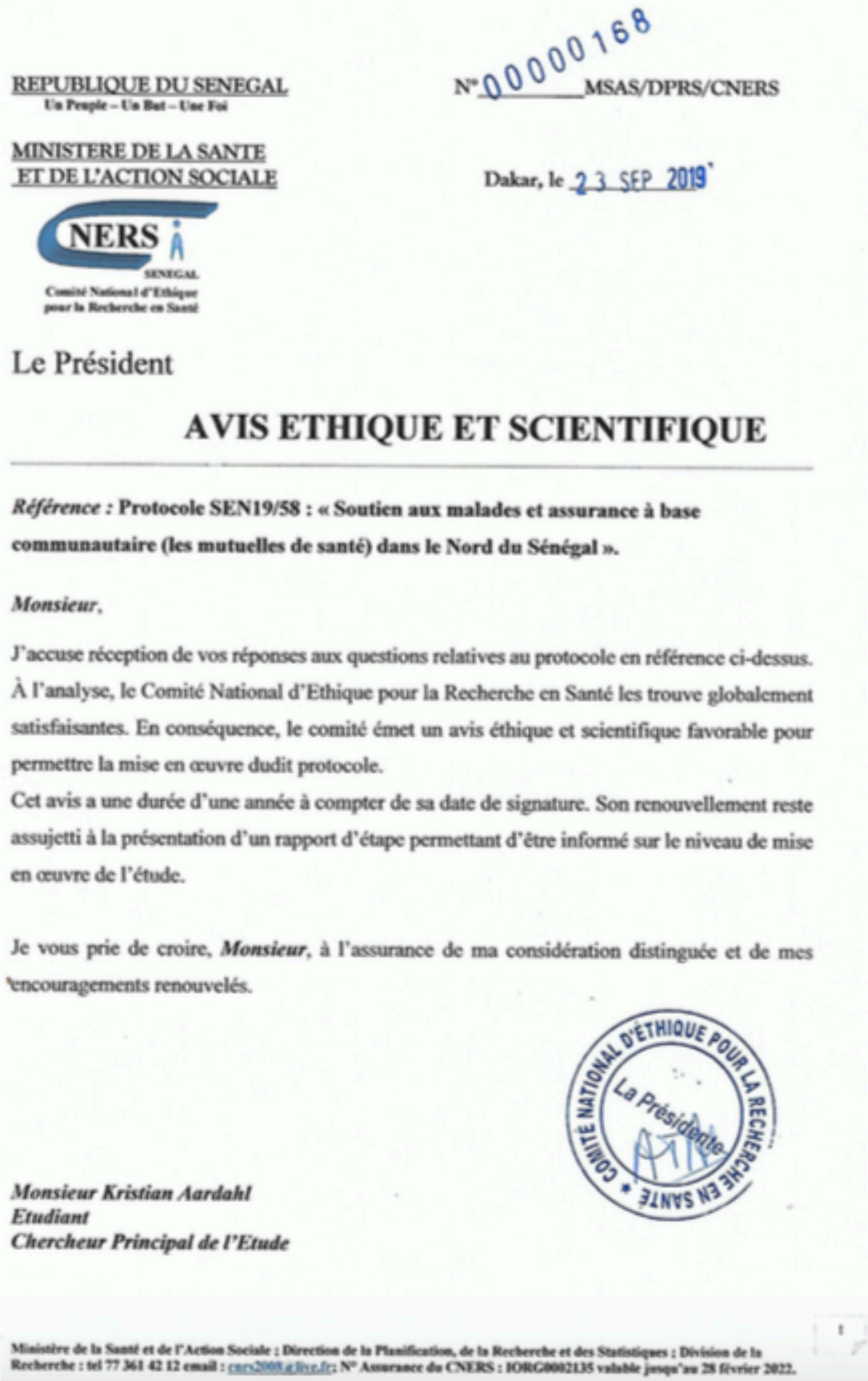
Will the data subjects be identifiable (directly or indirectly) in the thesis/publications from the project?

No

Additional information

As indicated, personal data will not be collected about third parties. As this project will explore illness support and health care trajectories, including decision-making processes, support and care seeking within the family, informed consent will be obtained from all family members. No personal data will be collected about children, family members who do not wish to participate, or any other third parties who have not or who are not able to provide consent.

Appendix 3. Senegalese Ministry of Health



REPUBLIQUE DU SENEGAL
Un Peuple – Un But – Une Foi

MINISTERE DE LA SANTE
ET DE L'ACTION SOCIALE

CNERS
SENEGAL
Comité National d'Ethique
pour la Recherche en Santé

N° 00000168 MSAS/DPRS/CNERS

Dakar, le 23 SEP 2019

Le Président

AVIS ETHIQUE ET SCIENTIFIQUE

***Référence :* Protocole SEN19/58 : « Soutien aux malades et assurance à base communautaire (les mutuelles de santé) dans le Nord du Sénégal ».**

***Monsieur*,**

J'accuse réception de vos réponses aux questions relatives au protocole en référence ci-dessus. À l'analyse, le Comité National d'Ethique pour la Recherche en Santé les trouve globalement satisfaisantes. En conséquence, le comité émet un avis éthique et scientifique favorable pour permettre la mise en œuvre dudit protocole.

Cet avis a une durée d'une année à compter de sa date de signature. Son renouvellement reste assujetti à la présentation d'un rapport d'étape permettant d'être informé sur le niveau de mise en œuvre de l'étude.

Je vous prie de croire, ***Monsieur***, à l'assurance de ma considération distinguée et de mes encouragements renouvelés.

La Présidente

Monsieur Kristian Aardahl
Etudiant
Chercheur Principal de l'Etude

Ministère de la Santé et de l'Action Sociale : Direction de la Planification, de la Recherche et des Statistiques : Division de la Recherche : tel 77 361 42 12 email : cnrs2008@live.fr; N° Assurance du CNERS : IORG0002135 valable jusqu'au 28 février 2022.

1

REPUBLIQUE DU SENEGAL
Un Peuple-Un But-Une Foi
Ministère de la Santé
et de l'Action sociale
DIRECTION DE LA PLANIFICATION
DE LA RECHERCHE ET DES STATISTIQUES
Le Directeur

N° 00001129 MSAS/DPRS/DR ✓

Dakar, le 27 SEPT 2019

AUTORISATION ADMINISTRATIVE

Protocole SEN19/58: « Soutien aux malades et assurance à base communautaire (les mutuelles de santé) dans le Nord du Sénégal »

Référence : Avis éthique et scientifique N° **00168**/MSAS/DPRS/CNERS en date du 23 septembre 2019

Monsieur,

Sur la base de l'avis éthique et scientifique du Comité National d'Ethique pour la Recherche en Santé visé en référence, je vous accorde une autorisation administrative d'une année, à partir de la date de signature pour permettre la mise en œuvre de votre étude.

Je vous prie de croire, ***Monsieur,*** à l'assurance de ma parfaite considération et de mes encouragements renouvelés.

Directeur
P.I

A
Monsieur Kristian Aardahl
Etudiant
Chercheur Principal de l'Etude

Direction de la Planification, de la Recherche et des Statistiques (DPRS) – Ministère de la Santé et de l'Action sociale
Rue Aimé Césaire - Fann Résidence – DAKAR – SENEGAL
Tél. : (221) 869-42-42 – 869-42-74 – BP 4024

Appendix 4. Interview Guides

Interview Guide:

Group 1) Community members

Greeting/Introduction

Background Information

- Are you married?
- How many children do you have? What ages?
- Where do you live?
- Do you contribute to household expenses? If so how?
- Can you describe your household?
- What are your roles in the household?
- What work do you have?
- What do you spend your money on?

Could you take me through the last health decision made for the family?

- Who was sick?
- What happened to the person?
- Who usually takes care of the sick? Who took care of the patient in this case?
- How was the patient supported?
- How did you react to the illness? Were any actions taken and if so when?
- Who made the decisions?
- What do you believe was the most important part of this decision being made?

Method of Financing

- How much did the family spend on seeking diagnosis and/or treatment?
- Who contributed financially and how much?
- How was it decided who would contribute?
- What are other sources of money the household can use when someone is sick?
- How does someone participate in these? Who can participate?
- Have you participated in these before? Do you know people who have participated in these before?
- Are any of these forms of financing popular?
- Are you helped by other forms of support, e.g. religious group/women´s group/any other mutual support groups?

Les Mutuelles Insurance Scheme

- What do you know about Les Mutuelles de Sante?
- Have you considered joining the insurance scheme?

- Are you a member (or the household head?) (Since when? What does he/she/the household/you pay every month or every year for this? How do you pay it?
  What is your relationship with the scheme leadership here?
- Do you know present or past members of the scheme?
- Is the scheme useful for you and members of the community?
- Do you think you get services for what you pay for?

This is the end of the discussion. Do you have any questions or comments?

Group 2) Healthcare Providers

Greetings/Introduction

Background Information

- Are you married?
- How many children do you have?
- Where do you work? How long have you worked there?
- What are your work obligations?
- Who do you meet in your work?
- When do you see the ill and their family members?
- What is important to discuss with them?
- Who takes care of the ill in the community? Who does in the family?
- What challenges do you face in your work?

Illness decisions

- What options do people have when they are sick? Yourself?
- What are important factors in making decisions about intervention? For your family?
- Who makes decisions in the family when a family member is sick?
- Who supports the sick? How are they supported?
- How do people obtain money for treatment?
- What forms of payment do people use?

Les Mutuelles

- Do many patients use Les Mutuelles?
- Who uses it? Do you?
- How do patients use it here?
- How are claims processed here?
- Why do people use Les Mutuelles?
- What health services does Les Mutuelles cover? (list them) Does it cover some health services for some members and not for others, or does every member get the same services?
- Does Les Mutuelles cover chronic disease (e.g. diabetes, cancer, others…)? How and which treatments and diagnostic tests…?
- In your opinion, are there expectations for Les Mutuelles? Do you have expectations for the scheme?

This is the end of the discussion. Do you have any questions or comments?

FGD/Group Interview Guide

Group 1) Community Members:

Greeting/Introduction

Group discussion of the Les Mutuelles Insurance Scheme and treatment trajectories followed when family members fall ill. Potential topics to be discussed:

- Knowledge about Les Mutuelles de Sante and experiences with it or opinions of it.

- Is the scheme useful for you and members of the community?

- What are typical responses within this community when a family member falls ill?

- Who usually makes decisions about health care?

- To what extent and in what ways do financial considerations affect these decisions?

Appendix 5. Information & Informed Consent Forms

Information Form – Community Members

Research Project Title: Illness Support and Community Based Health Insurance in Northern Senegal

Request for participation in a research project

This is an information sheet about participation in a research project involving forms of social and economic support in cases of illness. In this letter, we will give you information about the purpose of the project and what your participation will involve.

Purpose of the project

Countries around the world are working towards Universal Health Coverage. Senegal is using different health insurance schemes to meet this goal. I would like to hear what actions you and your family take when family members are sick. I would also like to learn about what ways the ill in your family and community are supported. I believe that you can help improve the support people receive during illness by sharing your experiences and opinions with me. I am interviewing family members and healthcare providers in Linguère to gather information for my master's thesis.

Who is responsible for the research project?

The Institute of Health and Society at the University of Oslo is the institution responsible for the project. I (Kristian Aardahl) am a master's student at this institution, and I will be carrying out the project as the basis of my master's thesis.

Why are you being asked to participate?

I am conducting research observations and interviewing people affected by illness either in the family or community. I think you have interesting experiences and opinions to share about this. I am talking to friends and acquaintances first. I will also include other people as I meet them. There will be approximately 15 people total participating.

What does participation involve for you?

I will visit and talk with you during one or more interviews and a focus group discussion. You can choose to participate in only one interview or only one focus group discussion if you prefer. If you are open to it, I would also like to spend time with you for observational purposes, in an effort to better understand health care decision-making processes, responses to health events within families, illness support and health care seeking, and in the interest of increasing my understanding of your everyday life and local community.

- The focus group discussion will include 5-8 members. One will contain community members and another will contain healthcare providers. The discussion will include me and a translator. We will start the discussion by asking about participants' forms of support in their family or community during illness. We will also discuss Les Mutuelles and who uses the insurance program, as well as other types of economic support in the event of illness. I will not ask you to share any personal beliefs or experiences you are not comfortable with. The discussion will take place in a setting that yourself and the other participants are comfortable. No one besides the translator and me will be present. The discussion will be audio recorded. Your confidentiality will be maintained. Only the translator and I will have access to the recording. It will be stored on a password protected computer inside of a locked cupboard. No one will be named on the tape.

• The interviews will take place at a location of your choosing and last approximately one hour. A translator and I will be present. The interview will take place at a location you choose. I will make sure that you are comfortable before the interview begins. If there is anything you would not like to answer, you can let me know and we will continue with a different question. The interview will be tape-recorded and stored on tape. Your information will be kept confidential on the tape, and the tape will be stored on a password-protected computer in a locked cupboard. The translator and I will be the only people with access to the tape.

I will ask you about illness events in your family or community and any action taken. I would also like to know about the forms of support your family uses when a member is ill. I will also ask you about Les Mutuelles insurance scheme and what you think of it.

Participation is voluntary

Participation in the project is voluntary. If you chose to participate, you can withdraw your consent at any time without giving a reason. All information about you will then be made anonymous. There will be no negative consequences for you if you choose not to participate or later decide to withdraw. Your responses will have no impact on the healthcare that you receive.

Compensation

There is no compensation for participation in this study.

Your personal privacy – how we will store and use your personal data

We will only use your personal data for the purpose specified in this information letter. We will process your personal data confidentially and in accordance with data protection legislation (the General Data Protection Regulation and Personal Data Act).

•The translator will have access to data for translation and transcription purposes only, and the translator will be bound by a confidentiality agreement. Otherwise, only I, as the researcher, will have access to your personal data.

• Following the interviews and focus group discussions, audio recordings will be uploaded to a secure server and the audio file will be deleted from the recording device. Upon transcription of the audio file, all identifying data will be removed. Your name and contact details will be replaced with a pseudonym, and the list of names, contact details and respective pseudonyms will be stored separately from the rest of the collected data.

•I will store the data on the University of Oslo's M-Drive, which is an access-restricted, username and password protected domain through the University of Oslo network, which I will access through a computer that is username and password protected, and that I store in a locked cupboard. I will review your responses with you after the interview to be sure I am correctly representing your responses. I will not share information about you with anyone besides the translator. I will keep the information from our conversations private.

It is of necessity that you and the other discussion participants maintain confidentiality.

I will analyze your responses next spring, when I return to my university. Your name will not be used in publications and an alias location will be used. Combinations of indirectly identifiable information, such as gender, age, occupation and family make-up will also not be published, to ensure that you are not identifiable in the published findings. During analysis, all data will be stored on TSD, the University of Oslo's secure data service.

What will happen to your personal data at the end of the research project?

The project is scheduled to end June 2020, when I complete my master's thesis. All data will be anonymized and all non-anonymous data will be deleted and/or destroyed at this time.

Your rights

So long as you can be identified in the collected data, you have the right to:

- access the personal data that is being processed about you

- request that your personal data is deleted

- request that incorrect personal data about you is corrected/rectified

- receive a copy of your personal data (data portability), and

- send a complaint to the Data Protection Officer or The Norwegian Data Protection Authority regarding the processing of your personal data

What gives us the right to process your personal data?

We will process your personal data based on your consent.

Based on an agreement with The University of Oslo, Institute of Health and Society, NSD – The Norwegian Centre for Research Data AS has assessed that the processing of personal data in this project is in accordance with data protection legislation. By agreeing to participate in this study you do not waive any of your rights or release the researchers, the sponsor, or the institution where this research project takes place from their civil and professional liability.

Where can I find out more?

If you have questions about the project, or want to exercise your rights, contact:

- The University of Oslo, Institute of Health and Society via Kristian Aardahl, kristian.aardahl@studmed.uio.no, Christina Brux, c.b.mburu@medisin.uio.no, and Ruth Prince, r.j.prince@medisin.uio.no. (xxx) I will provide my local phone number I have throughout fieldwork.

- The University of Oslo's Data Protection Officer, by email: personvernombud@uio.no

- NSD – The Norwegian Centre for Research Data AS, by email: (personverntjenester@nsd.no) or by telephone: +47 55 58 21 17.

Thank you very much for your participation in this research study.

Yours sincerely,

Student : Kristian Aardahl
Institution:
Institutional Address
Post Box:
Telephone: (local telephone number to be added)

Project Leader: Christina Brux

Insitution: University of Oslo, Institute of Health and Society

Institutional Address:
Frederik Holsts hus, Ullevål universitetssykehus, Universitetet i Oslo
Kirkeveien 166
Oslo, Norge 0450

Institutional Email: c.b.mburu@medisin.uio.no

Le comité d'éthique de la recherche du xxx a approuvé ce projet de recherche et en assure le suivi. De plus, il approuvera au préalable toute révision et toute modification apportée au formulaire d'information et de consentement et au protocole de recherche. Pour toute question relative à vos droits et recours en tant que participant à un projet de recherche, vous pouvez contacter :
Mr Samba Cor Sarr
Coordonnateur du Comité National d'Ethique pour la Recherche en Santé au N° suivant :
+221 33 869 43 13
Adresse email : cnrs2008@live.fr

Consent form

Research Project Title: Illness Support and Community Based Health Insurance in Northern Senegal

I have received and understood information about the project, Illness Support and Community Based Health Insurance in Northern Senegal, and have been given the opportunity to ask questions and receive answers to my satisfaction. I give consent:

- to participate in one or more interviews
- to participate in a focus group discussion
- to participate in observational data collection
- for my personal data to be processed outside the EU

I give consent for my personal data to be processed until the end date of the project, approx. June 1st 2020. I can withdraw at any time without prejudice of any kind. I certify that I have been given the time to make my decision. A signed copy of this information and consent form must be given to me.

Thank you very much for your participation in this research study.

« Je déclare avoir lu et compris le présent projet, la nature et l'ampleur de ma participation, ainsi que les risques et les inconvénients auxquels je m'expose tels que présentés dans le présent formulaire d'information qui m'a été remis. J'ai eu l'occasion de poser toutes les questions concernant les différents aspects de l'étude et de recevoir des réponses à ma satisfaction.

Je, soussigné(e), accepte volontairement de participer à cette étude. Je peux me retirer en tout temps sans préjudice d'aucune sorte. Je certifie qu'on m'a laissé le temps voulu pour prendre ma decision.

Une copie signée de ce formulaire d'information et de consentement doit m'être remise.

__________________________ ______________________

Nom du participant Signature

Signé à__________________ le , ____________ 20__________

Le comité d'éthique de la recherche du xxx a approuvé ce projet de recherche et en assure le suivi. De plus, il approuvera au préalable toute révision et toute modification apportée au formulaire d'information et de consentement et au protocole de recherche. Pour toute question relative à vos droits et recours en tant que participant à un projet de recherche, vous pouvez contacter :

Mr Samba Cor Sarr
Coordonnateur du Comité National d'Ethique pour la Recherche en Santé au N° suivant :
+221 33 869 43 13
Adresse email : cnrs2008@live.fr

Information Form – Healthcare Providers

Research Project Title: Illness Support and Community Based Health Insurance in Northern Senegal

Request for participation in a research project

This is an information sheet about participation in a research project involving forms of social and economic support in cases of illness. In this letter, we will give you information about the purpose of the project and what your participation will involve.

Purpose of the project

Countries around the world are working towards Universal Health Coverage. Senegal is using different health insurance schemes to meet this goal. I would like to hear what actions families take when family members are sick. I would also like to learn about what ways the ill in families and the local community are supported. I believe that you can help improve the support people receive during illness by sharing your experiences and opinions with me. I am interviewing family members and healthcare providers in Linguère to gather information for my master's thesis.

Who is responsible for the research project?

The Institute of Health and Society at the University of Oslo is the institution responsible for the project. I (Kristian Aardahl) am a master's student at this institution, and I will be carrying out the project as the basis of my master's thesis. The University of Oslo Institute of Health and Society is providing partial funding for this study.

Why are you being asked to participate?

I am interviewing people affected by illness either in the family or community, as well as health care providers. I think you have interesting experiences and opinions to share about this. I am talking to friends and acquaintances first. I will also include other people as I meet them. There will be approximately 15 people total participating.

What does participation involve for you?

I will visit and talk with you during one or more interviews and a focus group discussion. You can limit your participation to one interview or just one focus group discussion if you prefer.

- The focus group discussion will include 5-8 members. One will contain community members and another will contain healthcare providers. The discussion will include me and a translator. We will start the discussion by asking about participants' forms of support in their family or community during illness. We will also discuss Les Mutuelles and who uses the insurance program, as well as other types of economic support in the event of illness. I will not ask you to share any personal beliefs or experiences you are not comfortable with.

The discussion will take place in a setting that yourself and the other participants are comfortable. No one besides the translator and me will be present. The discussion will be audio recorded. Your confidentiality will be maintained. Only the translator and I will have access to the recording. It will be stored on a password protected computer inside of a locked cupboard. No one will be named on the tape.

- The interviews will take place at a location of your choosing and last approximately one hour. A translator and I will be present. The interview will take place at a location you choose. I will make sure that you are comfortable before the interview begins. If there is anything you would not like to answer, you can let me know and we will continue with a different question. The interview will be tape-recorded and stored on tape. Your information will be kept confidential on the tape, and the tape will be stored on a password-protected computer in a locked cupboard. The translator and I will be the only people with access to the tape.

I will ask you about illness events in your family or community and any action taken. I would also like to know about the forms of support families use when a member is ill. I will also ask you about Les Mutuelles insurance scheme and what you think of it.

Participation is voluntary

Participation in the project is voluntary. If you chose to participate, you can withdraw your consent at any time without giving a reason. All information about you will then be made anonymous. There will be no negative consequences for you if you choose not to participate or later decide to withdraw. Your responses will have no impact on the healthcare that you receive or your future employment.

Your personal privacy – how we will store and use your personal data

We will only use your personal data for the purpose specified in this information letter. We will process your personal data confidentially and in accordance with data protection legislation (the General Data Protection Regulation and Personal Data Act).

- The translator will have access to data for translation and transcription purposes only, and the translator will be bound by a confidentiality agreement. Otherwise, only I, as the researcher, will have access to your personal data.

- Following the interviews and focus group discussions, audio recordings will be uploaded to a secure server and the audio file will be deleted from the recording device. Upon transcription of the audio file, all identifying data will be removed. Your name and contact details will be replaced with a pseudonym, and the list of names, contact details and respective pseudonyms will be stored separately from the rest of the collected data.

- I will store the data on the University of Oslo’s M-Drive, which is an access-restricted, username and password protected domain through the University of Oslo network, which I will access through a computer that is username and password protected, and that I store in a locked cupboard. I will review your responses with you after the interview to be sure I am correctly representing your responses. I will not share information about you with anyone besides the translator. I will keep the information from our conversations private.

It is of necessity that you and the other discussion participants maintain confidentiality.

I will analyze your responses next spring, when I return to my university. Your name will not be used in publications and an alias location will be used. Combinations of indirectly identifiable information, such as gender, age, occupation and family make-up will also not be published, to ensure that you are not identifiable in the published findings.

What will happen to your personal data at the end of the research project?

The project is scheduled to end June 2020, when I complete my master's thesis. All data will be anonymized and all non-anonymous data will be deleted and/or destroyed at this time.

Your rights

So long as you can be identified in the collected data, you have the right to:

- access the personal data that is being processed about you

- request that your personal data is deleted

- request that incorrect personal data about you is corrected/rectified

- receive a copy of your personal data (data portability), and

- send a complaint to the Data Protection Officer or The Norwegian Data Protection Authority regarding the processing of your personal data

What gives us the right to process your personal data?

We will process your personal data based on your consent.

Based on an agreement with The University of Oslo, Institute of Health and Society, NSD – The Norwegian Centre for Research Data AS has assessed that the processing of personal data in this project is in accordance with data protection legislation. By agreeing to participate in this study you do not waive any of your rights or release the researchers, the sponsor, or the institution where this research project takes place from their civil and professional liability.

Where can I find out more?

If you have questions about the project, or want to exercise your rights, contact:

- The University of Oslo, Institute of Health and Society via Kristian Aardahl, kristian.aardahl@studmed.uio.no, Christina Brux, c.b.mburu@medisin.uio.no, and Ruth Prince, r.j.prince@medisin.uio.no. (xxx) I will provide the local phone number I have throughout fieldwork.

- The University of Oslo's Data Protection Officer, by email: personvernombud@uio.no

- NSD – The Norwegian Centre for Research Data AS, by email: (personverntjenester@nsd.no) or by telephone: +47 55 58 21 17.

Yours sincerely,

Project Leader	Student
Christina Brux	Kristian Aardahl

Consent form

Research Project Title: Illness Support and Community Based Health Insurance in Northern Senegal

I have received and understood information about the project, Illness Support and Community Based Health Insurance in Northern Senegal, and have been given the opportunity to ask questions. I give consent:

- to participate in one or more interviews
- to participate in a focus group discussion
- for my personal data to be processed outside the EU

I give consent for my personal data to be processed until the end date of the project, approx. June 1st 2020

(Signed by participant, date)