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# The process and practice of diagnosis: innovations in diagnostics for Lassa fever in Sierra Leone

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**Ann Wilkinson**

Thesis submitted for the Degree of Doctor of Philosophy  
January 2013

SPRU  
University of Sussex

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UNIVERSITY OF SUSSEX

Ann Wilkinson

Thesis submitted for the Degree of Doctor of Philosophy in Science and Technology Policy  
Research

**The process and practice of diagnosis: innovations in diagnostics for Lassa fever in  
Sierra Leone**

**Summary**

This thesis is about the process and practice of diagnosis and the implications of new diagnostic technologies in low resource settings. As a setting and a disease which has seen significant investment in diagnostics, Lassa fever in Sierra Leone has been selected as a case study to examine these themes. In this thesis, 'new diagnostic technologies' refers to laboratory-based diagnostics which are fast, reliable, accurate and can be used in low income settings. The starting point of this thesis is a narrative surrounding such technologies which suggests that they will revolutionise low income healthcare settings by allowing accurate scientific diagnosis in places where it was not possible before. Various perspectives on diagnosis are examined and some limitations are identified in relation to their accounts of diagnostic process, context, practice and technology. To explore the case, aspects of science and technology studies, the sociology of scientific knowledge and medical anthropology are combined. A multi-sited ethnography of Lassa fever diagnosis was conducted in three settings: a rural village, a laboratory and the wards of a hospital. Documents were reviewed and interviews conducted with key actors and ex-Lassa fever patients. Analysis focused on framings (partial and subjective interpretations), narratives (persuasive storylines which make use of particular framings) and practice in relation to Lassa fever and the development of technology for its diagnosis. Assumptions about the disease, diagnostics and the process of diagnosis are identified and the conclusion considers how they compare with practice in each setting. This thesis argues that diagnosis is a complex negotiated process and that new diagnostics represent only one aspect of that process. Thus, they are not a 'silver bullet' to transform low resource healthcare contexts. In particular, 'improved' diagnostics do not always have the expected impacts, sometimes even introducing complexity and uncertainty. In challenging narratives about diagnostics, this thesis provides an alternative, practice-based, approach to thinking about diagnostics and innovations in health systems; this approach acknowledges the importance, and complexity, of the diverse contexts which shape innovations and technology use.

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# Contents

<b>SUMMARY.....</b>	<b>3</b>
<b>ACKNOWLEDGEMENTS.....</b>	<b>4</b>
<b>CONTENTS.....</b>	<b>6</b>
<b>LIST OF FIGURES .....</b>	<b>9</b>
<b>LIST OF TABLES .....</b>	<b>9</b>
<b>ABBREVIATIONS AND ACRONYMS .....</b>	<b>10</b>
<b>1 INTRODUCTION .....</b>	<b>12</b>
1.1 WHY DIAGNOSTICS? .....	14
1.2 WHY LASSA FEVER IN SIERRA LEONE? .....	16
1.3 OUTLINE OF CHAPTERS.....	19
<b>2 UNDERSTANDING DIAGNOSIS, DIAGNOSTICS AND DISEASE .....</b>	<b>22</b>
2.1 FRAMINGS AND NARRATIVES .....	23
2.1.1 A 'scientization' of diagnosis?.....	25
2.2 THEORIES OF DIAGNOSIS.....	28
2.2.1 Sociology of diagnosis and contesting disease.....	29
2.2.2 Process of diagnosis: assemblages and enactments .....	31
2.2.3 Negotiating plural health systems .....	35
2.2.4 Diagnostic technology .....	38
2.2.5 Challenging uncertainty narratives.....	40
2.3 THE DIAGNOSTIC SYSTEM: A MANGLE OF PRACTICE? .....	46
2.4 CONCLUSION .....	51
<b>3 RESEARCH METHODS .....</b>	<b>52</b>
3.1 MULTI-SITED ETHNOGRAPHY .....	54
3.2 RESEARCH PROCESS .....	58
3.2.1 Literature review.....	58
3.2.2 Fieldwork.....	58
3.2.3 Defining the system: selecting the case and sites.....	61
3.2.4 Laboratory.....	64
3.2.5 Clinic.....	67
3.2.6 Community.....	71
3.2.7 The wider system .....	78
3.2.8 Data processing .....	80
3.3 ETHICS .....	82
3.4 CONCLUSION .....	85

<b>4</b>	<b>SYSTEM CONTEXT: NARRATIVES OF EMERGENCE AND RESPONSE .....</b>	<b>86</b>
4.1	DISEASE DYNAMICS .....	87
4.2	NARRATIVES OF LASSA FEVER .....	92
4.2.1	<i>An emerging global threat .....</i>	<i>93</i>
4.2.2	<i>An endemic disease caused by risky local practices .....</i>	<i>95</i>
4.2.3	<i>A neglected zoonotic disease ready for a scientific solution .....</i>	<i>99</i>
4.2.4	<i>The Lassa fever diagnostic system: an official version .....</i>	<i>102</i>
4.3	ALTERNATIVE PERSPECTIVES ON LASSA FEVER .....	106
4.3.1	<i>Long-term dynamics of Lassa fever .....</i>	<i>106</i>
4.3.2	<i>Lassa fever in practice .....</i>	<i>107</i>
4.4	HEALTH CARE DYNAMICS IN SIERRA LEONE .....	109
4.5	SITES IN THE DIAGNOSTIC SYSTEM .....	111
4.5.1	<i>Community .....</i>	<i>111</i>
4.5.2	<i>Laboratory .....</i>	<i>115</i>
4.5.3	<i>Clinic .....</i>	<i>117</i>
4.6	CONCLUSION .....	119
<b>5</b>	<b>'WE ARE JUST LEARNING THAT NAME': DIAGNOSIS IN COMMUNITY SETTINGS .....</b>	<b>121</b>
5.1	SOCIAL LIFE AND LIVELIHOODS .....	121
5.2	IMPRESSIONS OF 'LASSA' .....	125
5.3	LASSA WITHIN TOKENGA'S THERAPEUTIC LANDSCAPE .....	128
5.3.1	<i>Mende hale and Pu hale .....</i>	<i>129</i>
5.3.2	<i>How hale works: regimes of medicine use .....</i>	<i>130</i>
5.3.3	<i>Differential access to medicine and knowledge .....</i>	<i>133</i>
5.3.4	<i>Kinds of disease .....</i>	<i>139</i>
5.3.5	<i>Payment methods .....</i>	<i>143</i>
5.4	HOW LASSA EMERGES .....	146
5.4.1	<i>The process of diagnosis .....</i>	<i>147</i>
5.4.2	<i>"We are just learning that name" .....</i>	<i>153</i>
5.4.3	<i>Uncertainty after diagnosis .....</i>	<i>158</i>
5.5	CONCLUSIONS .....	160
<b>6</b>	<b>'AN EMERGING PARADIGM': DIAGNOSIS IN THE LABORATORY .....</b>	<b>162</b>
6.1	LABORITIZATION .....	163
6.2	NARRATIVES OF LASSA FEVER DIAGNOSIS AT WORK IN LABORITIZATION .....	165
6.2.1	<i>The global threat becomes a research and commercial opportunity .....</i>	<i>165</i>
6.2.2	<i>High quality diagnostics to unravel the "Dogma" .....</i>	<i>168</i>
6.3	DEVELOPING DIAGNOSTIC AND LABORATORY AUTHORITY .....	171
6.4	THE EMERGENCE OF A NEW DIAGNOSTIC PARADIGM IN PRACTICE .....	176
6.4.1	<i>Ingredients .....</i>	<i>177</i>
6.4.2	<i>Technique .....</i>	<i>180</i>
6.4.3	<i>(Re)Interpretation .....</i>	<i>183</i>
6.5	THE VALUE OF A TEST: LIMITS TO LABORITIZATION? .....	188
6.6	CONCLUSION .....	191



<b>7</b>	<b>'CLASSIC LASSA': DIAGNOSIS IN A CLINICAL SETTING .....</b>	<b>193</b>
7.1	FORMAL CLINICAL DIAGNOSIS OF LASSA FEVER .....	195
7.2	DIAGNOSING LASSA FEVER IN PRACTICE .....	199
7.2.1	<i>Diagnostic pathways</i> .....	200
7.2.2	<i>Classic Lassa?</i> .....	208
7.2.3	<i>Laboratory results in clinical practice</i> .....	215
7.2.4	<i>Diagnostic interactions and decision making in clinical settings</i> .....	220
7.3	CONCLUSION .....	223
<b>8</b>	<b>CONCLUSION.....</b>	<b>225</b>
8.1	A MANGLE OF PRACTICE: THE DIAGNOSTIC SYSTEM.....	227
8.1.1	<i>Framings within the mangle of practice</i> .....	231
8.1.2	<i>Implications of the mangle</i> .....	234
8.2	CHALLENGING NARRATIVES .....	235
8.3	CONCLUSIONS AND FUTURE RESEARCH.....	243
<b>9</b>	<b>REFERENCES.....</b>	<b>246</b>
	<b>APPENDIX 1: INTERVIEW DETAILS .....</b>	<b>268</b>

## List of Figures

Figure 1 Dimensions of incertitude .....	44
Figure 2 Map of Sierra Leone, with research site locations marked .....	60
Figure 3 Ethnic and linguistic regions in Sierra Leone .....	72
Figure 4 Satellite image of Panguma, Dodo Town and village research site .....	73
Figure 5 Pictures of Lassa fever symptoms .....	89
Figure 6 Risk map of Lassa Fever .....	91
Figure 7 Lassa fever health promotion poster .....	96
Figure 8 Cat eating a captured rodent, probably not <i>M. natalensis</i> .....	98
Figure 9 The hospital at Panguma.....	100
Figure 10 The Lassa laboratory at KGH .....	106
Figure 11 The water supply and houses in Tokenga.....	114
Figure 12 Houses and kitchens in Tokenga.....	115
Figure 13 The entrance to the Lassa ward.....	118
Figure 14 Women threshing communal 'town rice' .....	122
Figure 15 Cleared and burnt upland farm, with farm hut.....	124
Figure 16 A man climbing a palm tree to collect kernels for oil .....	156
Figure 17 Rodent trap, with mock 'rat' .....	157
Figure 18 A used ELISA plate .....	174
Figure 19 Comparison of 'Traditional' and 'Recombinant' IgM ELISA.....	175
Figure 20 Visual representation of ELISA (IgM) protocol from the laboratory wall .....	175
Figure 21 A member of the outreach team using the centrifuge in the field .....	180
Figure 22 Laboratory technician examining results, showing bar charts .....	185
Figure 23 A satellite listing financial supporters .....	195
Figure 24 Lassa fever case definition form.....	197
Figure 25 Sign at the Lassa ward's entrance.....	198
Figure 26 Lassa ward entrance, with faded red 'Do not Cross' line on the floor .....	198

## List of Tables

Table 1 Interview summary.....	81
Table 2 Case definitions for VHF and Lassa fever used in the IDSR .....	104

## Abbreviations and Acronyms

<b>AFRICOM</b>	United States Africa Command
<b>ANDI</b>	African Network for Drugs and Diagnostics Innovation
<b>APC</b>	All People's Congress (political party, Sierra Leone)
<b>AG</b>	Antigen
<b>BSL</b>	Biosafety Level
<b>CDC</b>	Centers for Disease Control and Prevention (United States)
<b>CHO</b>	Community Health Officer
<b>CHC</b>	Community Health Centres
<b>CHP</b>	Community Health Posts
<b>DDDAC</b>	Dynamic Drivers of Disease in Africa Consortium
<b>DDT</b>	Dichloro-Diphenyl-Trichloroethane
<b>DOD</b>	Department of Defense (United States)
<b>EID</b>	Emerging Infectious Diseases
<b>ELISA</b>	Enzyme Linked Immunosorbent Assay
<b>FIND</b>	Foundation for Innovative Diagnostics
<b>FHCI</b>	Free Health Care Initiative
<b>GAR</b>	WHO's Global Alert and Response programme
<b>GoSL</b>	The Government of Sierra Leone
<b>HIV</b>	Human immunodeficiency virus
<b>IDSR</b>	Integrated Disease Surveillance and Response
<b>IgG</b>	Immunoglobulin G
<b>IgM</b>	Immunoglobulin M
<b>IHRs</b>	International Health Regulations
<b>KGH</b>	Kenema Government Hospital
<b>LASV</b>	Lassa Virus
<b>LF</b>	Lassa Fever
<b>MCHPs</b>	Maternal and Child Health Posts
<b>MDGs</b>	Millennium Development Goals
<b>MOHS</b>	Sierra Leone Ministry of Health and Sanitation
<b>MRU</b>	Mano River Union
<b>MRU-LFM</b>	Mano River Union Lassa Fever Network
<b>MSF</b>	Médecins Sans Frontières

<b>NGO</b>	Non-Governmental Organisations
<b>NIAID</b>	National Institutes of Allergy and Infectious Diseases (United States)
<b>NIH</b>	United States National Institutes of Health
<b>NTD</b>	Neglected Tropical Disease
<b>OFDA</b>	United States' Office of Foreign Disaster Assistance
<b>PCR</b>	Polymerase Chain Reaction
<b>PHUs</b>	Peripheral Health Units
<b>POC</b>	Point-of-Care
<b>PPE</b>	Personal Protective Equipment
<b>RUF</b>	Revolutionary United Front
<b>R&amp;D</b>	Research and Development
<b>RDT</b>	Rapid Diagnostic Test
<b>SLA</b>	Sierra Leone Army
<b>SLPP</b>	Sierra Leone People's Party (political party, Sierra Leone)
<b>SOP</b>	Standard Operating Procedure
<b>STI</b>	Science Technology and Innovation
<b>STS</b>	Science and Technology Studies
<b>TB</b>	Tuberculosis
<b>TBA</b>	Traditional Birth Attendant
<b>TDR</b>	WHO's Special Programme for Research and Training in Tropical Diseases
<b>UN</b>	United Nations
<b>UNDP</b>	United Nations Development Programme
<b>UNECA</b>	United Nations Economic Commission for Africa
<b>US</b>	United States
<b>USAMRIID</b>	U.S. Army Medical Research Institute of Infectious Diseases
<b>VHF</b>	Viral Haemorrhagic Fever
<b>WHO</b>	World Health Organisation

# 1 Introduction

A story doing the rounds after the then Sierra Leonean president, Ernest Bai Koroma, visited the Kenema Government Hospital (KGH) in 2010 claimed that, as he was being shown the hospital's general laboratory, he noted a closed door and asked what was behind it. The reply: "the Lassa Lab". On hearing this, the president indicated to his aides that they should make a swift exit. He was apparently eager to get away from anything to do with Lassa fever, a notoriously gruesome, and often fatal, viral haemorrhagic fever that is one of Sierra Leone's peculiar claims to fame. Another story relates to a second unenviable reason for notoriety: the decade long civil war which made the country famous for child soldiers, so-called 'blood diamonds' and amputations.<sup>1</sup> During the war, when some of the Lassa fever research and treatment activities were still carried out at Nixon Memorial Hospital in Segbwema - a town in Sierra Leone's Eastern region where the conflict took a heavy toll - the rebels had sacked the hospital but had left all buildings associated with Lassa fever untouched. These building were avoided, it was said, because the rebels were afraid of the disease. I had trouble verifying both these tales and consequently I am not sure they are true. Their retelling, however, is representative of the symbolic power Lassa fever commands in Sierra Leone - and further afield - much of which is the subject of this thesis. Concern about the threat of infection from the virus, which includes its potential use as an agent of bioterrorism, means that a dedicated laboratory has been set up to research and diagnose it and an isolation ward is used to treat it at KGH.

The 'Lassa lab' and the 'Lassa ward' are important settings in this thesis as they are the places where cases of Lassa fever should be confirmed and dealt with. But the pathway a patient takes in being diagnosed with Lassa fever, a process which is at the centre of the upcoming chapters, is not usually straightforward. A 'typical' story is hard to decipher but Adama's

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<sup>1</sup> The civil war lasted between 1991 and 2002. In 1991, after 23 years of rule by the All People's Congress (APC) party, the Revolutionary United Front (RUF) began an armed struggle from near the Liberian border. A coup from within the Sierra Leonean Army (SLA) followed in 1992. A decade of further coups, new governments and broken peace agreements ensued. The RUF was assisted by Charles Taylor, the ex-president of Liberia. Taylor and a number of senior RUF commanders were convicted of war crimes by the Special Court for Sierra Leone in 2012. See Richards (1996) for an account of the conditions leading up to the war.

account is illustrative<sup>2</sup>: in June 2009, at six months pregnant and living only a few streets from KGH, Adama began to experience a mild fever. She tried paracetamol from a pharmacy but when symptoms persisted she tried a nearby unofficial health clinic. After that, still suffering from fever, she tried a Chinese doctor whom she knew. Between these two informal providers of healthcare she was given antibiotics and drips, paying in total about 70,000 Leones (approximately £12.60 at 2009 exchange rates<sup>3</sup>). Thinking it was malaria she continued to take medicines bought from traders and pharmacists. Ultimately, about ten days after the onset of her illness, she went with her husband to KGH. By that point her eyes were red, a classic sign of Lassa fever. The doctor ordered a laboratory test for Lassa fever straight away; it was positive. She was admitted straight to the isolation ward and put on Ribavirin, the only known treatment for Lassa fever. Adama survived, but her baby died. After four days on the ward Adama suffered a miscarriage, she told me in Krio<sup>4</sup>: “*mi belleh poil*” (my belly spoilt).

As a pregnant woman Adama was lucky to survive. Among those infected with Lassa fever, pregnant women are particularly high risk and it is common for both the woman and their foetus to die (Price et al., 1988). Adama and her husband explained their choice of healthcare as being to do with the severity of symptoms: it was not expense that made them go to informal providers, in fact they paid about as much as they would have for admission and similar treatment at the government hospital, it was because hospitals were only for “*serious sick*s”. They had thought Adama “only” had malaria. Adama’s journey to the Lassa ward took a roundabout route despite KGH’s proximity to her home but, once there, she was swiftly diagnosed with Lassa fever. Her story provides a glimpse into a landscape of multiple health providers and some specific ideas about categorising disease within that landscape. Yet while Adama’s journey was delayed, it was relatively easy compared to that of others whose stories I heard. As I will describe, for many people a journey to hospital involves not only greater distances but higher human and financial costs too. Furthermore, simply getting to a formal

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<sup>2</sup> Interview ‘Lassa history 7’, Kenema, 10/04/2010. Chapter three explains how interviews are referenced in this thesis. Appendix 1 contains details of each interview, including interviewee categories, places and any relevant pseudonyms.

<sup>3</sup> I have used a 2009 exchange rate here as that is when Adama fell ill. Elsewhere I use a 2010 exchange rate (1 Leone to 0.00018 GBP) as that is when I did most of my fieldwork. To put this money into context, in 2007 the average annual income (GDP per capita) in Sierra Leone was \$679 USD and between 2000-2007 76% of the population were living on less than \$2USD a day (UNDP, 2009).

<sup>4</sup> Krio is an English-based creole. Originally spoken by descendants of freed American and West Indian slaves who settled in the Freetown peninsular area, it is now widely spoken throughout Sierra Leone. In this thesis I use English, Krio and Mende (an indigenous language spoken in Eastern Sierra Leone. As Krio and English can be similar any Krio terms and phrases will be italicised in the text to distinguish them. Mende words will be in bold.

health provider does not ensure that a swift diagnosis of Lassa fever, or anything else, will follow. Nor is a laboratory test result necessarily a closed case. Diagnostic pathways, as in the various routes and turns which a patient takes, are varied even within the hospital grounds.

This thesis is about diagnostic technology and diagnostic processes in low resource and complex health care systems. It is about how both disease and diagnosis are framed, meaning how they are defined, interpreted and represented (Jasanoff, 2005, Schon and Rein, 1994), and how that relates to diagnostic practices. A number of factors shaped this research. First, my interest was sparked by growing excitement about developments in biotechnology which have the potential to “revolutionise” (MacArthur, 2009 p23) the management of disease by making laboratory approaches<sup>5</sup> to diagnosis available in resource poor settings where previously it could not be imagined. Second, I had become aware of efforts to improve diagnostics for Lassa fever in Sierra Leone which presented a suitable case study. As developments in diagnostics for Lassa fever unfold it is timely to examine how they are being achieved, and to ask whether narratives of revolution like those above are justified. Accordingly, the question driving this research is: how are developments in laboratory-based diagnostic technologies incorporated into the process and practice of Lassa fever diagnosis in Sierra Leone?

To understand diagnostic process and practice, I combine the sociology of diagnosis with aspects of medical anthropology and selected works in science and technology studies. I use literature on framing and narratives to challenge some of the assumptions about diagnostic technology and their revolutionary potential: how are Lassa fever and diagnosis framed in these narratives? On what basis are improvements in diagnostics made? What are the implications for people living and working in resource poor settings such as those in Eastern Sierra Leone where Lassa is prevalent?

## **1.1 Why diagnostics?**

In 2002 a panel of scientific experts considered the ‘Top ten biotechnologies for improving health in developing countries’ and concluded that “Modified molecular technologies for affordable, simple diagnosis of infectious diseases” was the area of biotechnology which would bring the most improvement in the next five to ten years (Daar et al., 2002 p230). They

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<sup>5</sup> For example diagnosis based on analysis of immune responses or genetic information

noted how many existing diagnostic technologies were not suitable for use in limited resource settings but that innovations in molecular testing systems meant that reliable diagnostics could increasingly be provided in contexts with minimal infrastructure.

Laboratories have been described as the ‘Achilles heel’ of health services (Berkelman et al., 2006). For a long time overshadowed by efforts to produce drugs and vaccines (MacArthur, 2009), currently laboratory and diagnostic services in sub-Saharan Africa suffer from inadequate funding and a range of related capacity and infrastructure problems: staff and skill shortages, poor training, a limited range of tests on offer, lack of consumables and equipment to do them (e.g. reagents<sup>6</sup>, refrigerators), limited support services (e.g. for the transport of samples), lack of basic facilities (i.e. clean water, electricity) and lack of regulation, standards and protocols (Bates and Maitland, 2006, Peeling and Mabey, 2010, Petti et al., 2006).

The potential benefit of appropriate diagnostics has now been extensively outlined (Global Health Diagnostics Forum, 2006, Mabey et al., 2004, Peeling and Nwaka, 2011). ‘Lab on chip’ point-of-care (POC) and rapid diagnostics tests (RDT) is a field of rapid development but commentators also predict a ‘coming of age’ of laboratory medicine in Africa (Bates and Maitland, 2006). Laboratory services and systems are increasingly high up on the policy agenda. In 2008 the World Health Organization (WHO) convened a conference in Mozambique to focus on laboratory challenges (Olmsted et al., 2010). Integrated laboratory systems are argued to underpin health system strengthening (Nkengasong et al., 2010) and to be key to meeting health targets such as those in the MDGs (Birx et al., 2009).

Diagnosis now finds itself the target of international attention and investment. The Foundation for Innovative Diagnostics (FIND) was set up in 2003 with sponsorship by the Bill and Melinda Gates Foundation to support innovation in diagnostics<sup>7</sup> (FIND, 2012). From 2004 to 2006 the Bill and Melinda Gates Foundation also convened<sup>8</sup> the Global Diagnostics Forum to assess the impact of new diagnostics (Burgess et al., 2006). The African Network for Drugs and Diagnostics Innovation (ANDI) was launched in 2008 to encourage African-led innovation

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<sup>6</sup> A reagent is a substance used in diagnostic procedures which tests for a reaction

<sup>7</sup> Focus was initially on diagnostic solutions for tuberculosis, malaria and African Trypanosomiasis, it has since expanded.

<sup>8</sup> Along with the Rand Corporation



in those areas<sup>9</sup> (ANDI, 2010). Developments in genomic and molecular research mean that diagnostics have become increasingly attractive to the biotechnology industry (Poste, 2001), although for diseases which afflict developing countries the perceived lack of market can still be a barrier to investment (Mabey et al., 2004). It has also been claimed that an increasing concern for biodefense within some governments has raised investment which will converge with research and development for diagnostics more generally (Mabey et al., 2004, Peeling and Mabey, 2010).

In this thesis I examine how increased interest and investment in diagnostics translates into research, practice and impact. The final point above about biodefense is especially relevant because Lassa virus has been classified as a 'Category A' priority pathogen by the US National Institutes of Allergy and Infectious Diseases (NIAID) on account of its potential threat to public health and security (NIAID, 2012). Moreover, it has been designated a potential bioterrorist weapon by the Centers for Disease Control and Prevention (CDC) (CDC, 2012a). So, in this case, to what extent do biodefense and infectious disease control agendas converge?

The experts in the 'Top Ten biotechnologies' study confidently conclude "Infectious disease can be controlled by molecular diagnostics (rated first) and recombinant vaccines (second)" (Daar et al., 2002, p230). In questioning whether such technologically optimistic assertions and the 'narratives of revolution' noted above are valid, this thesis considers what they might overlook. Pang and Peeling (2007) note that when developing diagnostic tests for developing country settings context needs to be taken into account. Yet consideration of 'context' has been limited. Moreover as the next chapter shall demonstrate, what evidence there is suggests that 'improved' diagnostics do not always have the impact they are expected to have (Chandler et al., 2008a, Chandler et al., 2012, Polage et al., 2006). What these studies show is that 'new' diagnostics do not act on a blank slate; rather, they come to interact with older established processes calling claims of 'revolution' into question.

## **1.2 Why Lassa fever in Sierra Leone?**

Sierra Leone is one of the world's poorest countries. In 2009, at the start of this research, it was ranked 180 out of 182 in the Human Development Index (UNDP, 2009) having moved from the bottom in 2007 (UNDP, 2007). The Ministry of Health and Sanitation (MOHS)

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<sup>9</sup> ANDI has been supported by the WHO's Special Programme for Research and Training in Tropical Diseases (TDR) and the United Nations Economic Commission for Africa (UNECA)

struggles with underinvestment, a high disease burden and a health system weakened during the civil war (MOHS, 2009, SSL and ICF Macro, 2009). Basic infrastructure, such as roads and electricity, is severely limited even in the capital Freetown let alone more rural areas. Such conditions make the kind of high-tech diagnostics available in richer countries, which need reliable electricity and expensive equipment, a challenge. As such, Sierra Leone is precisely the kind of country where improved diagnostics are expected to have the most impact.

Looking at Sierra Leone's long list of health problems, Lassa fever stands out. Lassa fever was first identified in Nigeria in 1969 (Frame et al., 1970). In the following few years, large outbreaks were recorded in Sierra Leone (Monath et al., 1974) and decades later Lassa fever still continues to afflict communities there. As a rodent-borne virus it cross-cuts issues of land use, stigma and poverty. A much cited paper has estimated there to be between 100,000-300,000 infections a year across West Africa with as many as 5,000 deaths (McCormick et al., 1987b). Others put that figure higher with as many as 3 million new infections a year and 67,000 deaths (Richmond and Baglole, 2003). Although it is not Sierra Leone's biggest killer<sup>10</sup> a number of factors make it a worthy case study.

First, as the above figures make clear, there is considerable uncertainty about prevalence which has implications for diagnosis and framing. Diagnosis presents a number of problems. In some instances symptoms appears to be so mild that they can go unreported (Khan et al., 2008, McCormick et al., 1987a). Or as Adama's story above makes clear, when symptoms are evident they are mostly non-specific, such as fever, which means infection can be mistaken for other common diseases. The combination of non-specific symptoms followed by rapid decline into severe disease and frequently death means that reliable fast diagnostics are of great value.

Second, the dangers associated with Lassa virus mean it is subject to the highest biosafety regulations: it is a Biosafety level 4 (BSL-4) pathogen. As such, producing laboratory diagnostics for Lassa fever is both expensive and difficult, meaning they have been largely unavailable in Sierra Leone (Khan et al., 2008). Investment for a disease which primarily

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<sup>10</sup> Data for cause-specific mortality rates are not reliable but diseases estimated to cause the greatest mortality and morbidity in Sierra Leone are malaria, malnutrition, pneumonia, anaemia, tuberculosis, diarrheal diseases and respiratory infections, with HIV/AIDS also being a potential problem (MOHS, 2009, SSL and ICF Macro, 2009)

affects poor populations in West Africa had not been forthcoming. Until recently that is, as Lassa fever is now the focus of international collaboration to improve diagnostics and surveillance (Khan et al., 2008). These efforts grew out of mounting concern with regional and international disease outbreaks and, in an important example of framing, the Lassa virus' classification as a potential bioterrorist agent. The result is the 'Lassa lab', an island of relatively high investment and technology in an extremely resource poor region in Eastern Sierra Leone. Such contextual issues make Lassa fever diagnosis in Sierra Leone an interesting, if extreme, case through which to explore the opportunities and challenges presented by innovations in diagnostics.

A third reason for studying Lassa fever is that the work to enhance diagnostics intersects in a fundamental way with diverse framings of the virus. Lassa fever is primarily associated with Sierra Leone, Liberia, Guinea and Nigeria where it is routinely and historically reported. However, estimates of disease burden and geographical spread across West Africa are increasingly contested. As the figures quoted earlier make clear there is huge variation in estimates. In the time since I began this research Lassa fever has been detected in areas where it was not previously thought to occur (Sogoba et al., 2012). Recently an article in *Nature* asked if the observed expansion represented real changes in prevalence or just improved diagnosis (Gire et al., 2012). Another article comments "It is possible that the illness may be one of the infections responsible for mysterious deaths in many parts of Nigeria and other African countries (Ogbu et al., 2007 p4). Clearly there are some fundamental questions about how to frame Lassa fever: is the disease old or emerging? Is it stable or on the move? Is it endemic to all of West Africa or just Sierra Leone, Guinea, Liberia and Nigeria? As this thesis will show, such framing debates are not simply distant scientific musings, they are central to the practice and process of diagnosis. Furthermore, with developments in diagnostics and epidemiology, many of the most well-established principles relating to Lassa fever are being challenged.

A fourth and final reason for studying Lassa fever is that there has been no extensive qualitative research into the disease. Thus, there is an urgent need to illuminate the perspectives of those who live and work with Lassa fever on a daily basis, including healthcare workers. How do inhabitants of a large and potentially increasing area of West Africa understand Lassa fever, or fever more generally? How do they interpret and deal with

the risks that accompany Lassa fever? The narratives of revolution might be justified in the long term, but in the short term new biotechnologies need to be put in context.

### **1.3 Outline of chapters**

In the following chapter, I begin by outlining the importance of framings and narratives in this thesis. Central to this research is the notion that there can be multiple positioned and partial views of Lassa fever and of diagnosis, and that combinations of these get pieced together into distinct policy narratives which emphasise particular dynamics, responses and outcomes. After that I explore the literature on diagnosis. There have been recent attempts to carve out a 'sociology of diagnosis' which aim to address a perceived neglect of the issue (Jutel, 2009). Despite some compelling observations, I suggest that there are some oversights which limit this literature's capacity to answer my research questions. In order to understand the significance and use of new diagnostic technology I highlight that process, technology, practice and context have been overlooked. I turn to aspects of science and technology studies, the sociology of scientific knowledge and medical anthropology to fill these gaps. A conceptual framework is described where the diagnosis of Lassa fever is conceptualised as a system; and the processes and practice within that system are characterised according to Andrew Pickering's 'mangle of practice' (Pickering, 1995).

In chapter three, I set out the non-positivist methodological underpinnings of my research strategy. Arguing that in-depth qualitative data collection is needed to assess diagnostic practice across a variety of settings involved in diagnosis, I explain why and how I conducted a multi-sited ethnographic study of the diagnostic system. Using a combination of observations and interviews, supplemented by documentary and literature reviews, I collected data in three sites: a remote rural village, the 'Lassa lab' and the wards at Kenema Government Hospital. Data collection is described for each site.

Chapter four provides some more detail on Lassa fever and healthcare in Sierra Leone. It describes three narratives which emphasise different aspects of Lassa fever's emergence and control: Lassa as a global threat, as an endemic disease contained in West Africa and as a neglected disease in need of a scientific fix. After that, I set out the official version of the diagnostic system, as described in formal surveillance documents. I then suggest two areas of research which focus on aspects of Lassa fever which are less well represented in these

narratives and surveillance policy documents. These are the longer term dynamics of Lassa fever and Lassa fever in practice. In order to see how new diagnostic technologies fit into existing diagnostic processes, and how that differs from policy descriptions of these processes, this thesis seeks to contribute to the latter area of research.

In the first of my ethnographic chapters, chapter five, I describe the therapeutic practices and landscape of a rural community in Eastern Sierra Leone. As well as identifying the health and healing providers used by villagers, I explore the categories, techniques, tools and patterns with which people navigate the 'therapeutic landscape' (Leach et al., 2008). Perspectives on, and experience with, Lassa fever are woven in to this. I find that, in this village, Lassa fever has a 'big name' but in practice it blends into existing understandings and approaches to illness, particularly fevers.

The focus of chapter six is practices within the 'Lassa Lab'. I show how narratives identified in chapter four are adapted by researchers and technicians and then drive activity in the laboratory. The global threat becomes a commercial research opportunity while the lack of research highlighted in the neglected disease narrative leaves gaps in knowledge which the researchers argue need to be addressed, starting with improved diagnostics. I use Karin Knorr Cetina's term 'laboritization' (Knorr Cetina, 1999, p26) to characterise the reconfiguration of natural orders which takes place in the laboratory. Claims to superiority (compared with old tests) are made on the basis of innovations, or manipulations, in the ingredients, technique and interpretation of the diagnostic test. I describe each of these, and then suggest that there are some limits to the laboritization processes.

The last of the empirical chapters, chapter seven, takes the wards of Kenema Government Hospital as its subject. A contrast is drawn between the view of Lassa fever and diagnostic pathways described in case management and surveillance forms and the messier reality of diagnosis in this setting. There, under significantly constrained conditions, the diagnosis of Lassa fever is an uncertain, non-linear and variable affair. The laboratory test results form part of this landscape but they intersect with some well-established practical and experience-based categories of the disease, and appropriate ways to deal with it in the circumstances. The diagnostic profile of Lassa fever in this context proves to be more multi-dimensional than the

reductionist definitions of 'positive' 'negative' or 'indeterminate' which are made in the laboratory.

With chapter eight, I conclude this thesis by drawing together key observations from the three settings and relating them to the 'mangle of practice'. The implications of this perspective on diagnosis are discussed. It is apparent that the process of diagnosis cannot be said to be pre-determined by an underlying cause and it is not straightforward even when there is an identifiable virus. Diagnostic pathways are not singular, even when there are clear treatment protocols set out. Diagnosis is the result of many hands, tools and negotiations and as such, it is unpredictable. On the narratives of technological optimism, there is evidence to suggest that a revolution will not take place based on technology alone. Indeed, I suggest that 'improved' diagnostics can introduce uncertainty and complexity. Ultimately, efforts to improve diagnosis, or disease control more generally, need to be broadened and should consider the diverse social settings of their application. Lastly, the extent of the 'convergence' of interests in delivering health interventions and biodefense is questioned as a way of delivering wide-ranging benefits in global health.

## 2 Understanding diagnosis, diagnostics and disease

As the expansion of diagnostic capacity gathers excitement it is timely to explore diagnosis and its practice. By unpicking various aspects of diagnosis I establish a conceptual basis from which to view the implications of new technologies. I review a loose but increasingly self-defined collection of studies which fall under the umbrella of 'sociology of diagnosis'. To this I add concepts from medical anthropology and science and technology studies (STS), taking a particular interest in politics of knowledge and 'science as practice' arguments.

Before discussing diagnosis, I introduce the concepts of *framing* and *narratives*. By framing, I mean an awareness of partial and differential interpretations of the world (Jasanoff, 2005, Schon and Rein, 1994). By narratives I mean the piecing together of certain framings into persuasive stories (Roe, 1994, Wald, 2008), which then find traction in particular institutions or communities. I deal with framing and narratives first because they run throughout what follows. This can be illustrated by simply asking, what is diagnosis? In some accounts diagnosis is presented as a scientific endeavour: the 'modern scientific physician' applies 'modern statistical theory' in the pursuit of a 'scientific diagnosis' (Miettinen, 2001). In contrast, others emphasise the importance of tacit knowledge (Braude, 2009, Henry, 2006) and pattern recognition in the 'art of diagnosis' (Eddy and Clanton, 1982). The art or science question *frames* diagnosis differently. It is portrayed either as a flash of intuitive brilliance on the part of a clinician or the methodical application of scientific logic. Elsewhere it is reasoned that diagnosis, like most clinical decision making, requires a blend of both interpretive and methodical elements (Malterud, 2001).

In what should be considered my own framing of diagnosis, I argue that diagnosis is a complex and negotiated process. In fact, it entails many processes all playing out within what I call the 'diagnostic system'. This system is full of multiplicity, assorted assemblages of people and things, diverse classifications and enactments of disease used by different actors at different times which frame disease in various, sometimes conflicting, ways. I use Andrew Pickering's (1995) concept of a 'mangle of practice' to characterise the diagnostic system. The mangle suggests something which is twisted, contested, hard to disentangle and above all, not straightforward. As a metaphor it conveys the complexity of the diagnostic system without rendering it systematic.

This chapter consists of three main sections. In section - I discuss the significance of framings and narratives and their place in this thesis. Section 2.2 provides the core literature on diagnosis. The insights and oversights identified here provide the basis for my characterisation of the diagnostic system as a mangle of practice. Finally in section 2.3, I review the principles of Pickering's mangle and discuss the implication of applying it to diagnosis. In the course of reviewing this literature the research question which I introduced in chapter one is supplemented by three sub-questions, shown below.

How are developments in laboratory-based diagnostic technologies incorporated into the process and practice of Lassa fever diagnosis in Sierra Leone?

- How is the diagnosis of Lassa fever framed and how do these framings relate to diverse narratives about the disease's significance and control?
- How is Lassa fever diagnosed in practice and how do different framings and practices intersect with each other?
- How do new diagnostics influence the uncertainty surrounding diagnosis?

## 2.1 Framings and Narratives

Noting that perspectives can be situated and partial is not new (for example, see Haraway, 1988). The diversity of explanatory cultural models and worldviews has long been noted in anthropology (Evans-Pritchard, 1976) especially in relation to explanations of disease, illness and healing (Janzen, 1978, Kleinman, 1980, Young, 1982). My reason for putting framing at the centre of my analysis is that it represents a way of examining the extent and impact of these different perspectives. Broadly, framing is used to describe an 'assumptional basis' through which issues are viewed, described and acted upon (Rein and Schön, 1996, p88). Framing analysis has been applied to disease in different ways: as a 'recognition' process by which a society comes to understand a disease *over* time (Aronowitz, 2008, Rosenberg, 1989, Rosenberg, 1992); and in the approach that I use here, by looking at how disease is understood and represented by different actors *within* society (Edstrom, 2010, Leach et al., 2010b). This second use of framing builds on the tradition of applying framing to policy debates (Jasanoff, 2005, Schon and Rein, 1994). Although I follow this latter approach, Charles Rosenberg's work is also relevant as I will set out shortly.



The second framing approach treats disease as a complex system whose emergence, re-emergence or stasis is due to interlinked, non-linear, context specific social, technological and environmental processes (Leach et al., 2010b). Framing in this context is used to draw attention to the diverse ways in which the system's dynamics can be interpreted. It means paying attention to "the many ways in which system boundaries, dynamics, functions and outcomes are open to multiple, particular, contextual, positioned and subjective assumptions, methods, forms of interpretation, values and goals" (Leach et al., 2010b, p371). Different actors value and make use of different forms of knowledge in their framings of systems. A particular actor's response to disease is dependent on their framing of it and responses can then feedback in to shape the framed dynamics. This is particularly true when framings are institutionalised. In this way framings are more than just interpretations, they are also implicated in system dynamics. Epidemics provide a good example of framing. Epidemics can be understood as short shocks caused by recent triggers or as the result of longer term stresses and changes (Leach and Dry, 2010). A premise of this research is that both Lassa fever and its diagnosis involve interlocking social, technical, cultural, political, economic, ecological and biological dynamics which can be framed differently.

Framings can become particularly influential when they become part of narratives. Narratives adopt particular framings to make a coherent story and to suggest and justify actions (Roe, 1994, Wald, 2008). They are mobilised by particular people, institutions, networks or communities and are often embedded in institutional and political governance processes (Leach et al., 2010b). Narratives define response pathways and given their institutionalisation, they implicate politics at various levels. Some are more dominant than others. These more dominant narratives can conceal alternatives, thus marginalising groups who may experience the world through contrasting frames or narratives (Leach and Dry, 2010).

Ann Kelly and Uli Beisel (2011) demonstrate the importance of framing and narratives in their discussion of the various biological, socio-political and behavioural 'guises' of Malaria. They argue that the articulation of malaria as a grand challenge, backed up by stunningly high worldwide mortality statistics, obscures its multiplicity and paints it as a singular 'Enemy Number One'. Over the years this enemy has been targeted for eradication many times. Mass spraying of Dichloro-Diphenyl-Trichloroethane (DDT) has given way to the power of public-

private partnerships to generate bold innovations for better detection, treatment and other silver bullets. The authors suggest that current policy formulations of malaria “struggle(s) to come to grips with the malaria found in urban plots and tyre tracks” (p73). They highlight a “back alleys” malaria (p71), “a product of relations” (p84) whose management is an everyday affair of co-existence between man and mosquito. The complexity of the practice of disease and health interventions is highlighted in the authors’ alternative framing of malaria.

In this thesis I identify framings and narratives associated with diagnosis and with Lassa fever. Some are familiar in international health policy discourses while others are rooted in practices and everyday concerns in Sierra Leone. Framings and discourses about Lassa fever which are articulated on the global stage, by international organisations such as the WHO or Northern governments, emphasise the risk of infection to Northern populations. In contrast, for people living and working with Lassa fever in Sierra Leone, it is an endemic disease which is both feared and normalised and as such, it occupies a quite different position in the health landscape. As I will show, framings and narratives on both levels have influenced approaches to disease control and diagnosis.

### **2.1.1 A ‘scientization’ of diagnosis?**

This introduction to framing and narratives allows me to introduce a key theme in this thesis: namely, that heightened expectations surrounding diagnostics are related to particular framings of the process of diagnosis, healthcare systems and disease. The most visible contemporary narrative about diagnostics in low-resource healthcare settings is of technological optimism and implicit determinism: new diagnostics have made accurate scientific diagnosis possible in settings where previously it was not possible which, in turn, has generated an expectation the rational provision of healthcare will follow. The speculation is that this new generation of diagnostics will replace the misdiagnosis, ignorance and uncertainty which previously characterised medical care in these settings.

As discussed in chapter one, expectations of molecular diagnostics are rooted in their potential to be rapid and mobile, as well as to achieve high levels of accuracy. As such they appear to be continuing a documented trend from symptom-based medicine to specific disease-based medicine, enabled by technology (Jutel, 2011c, Rosenberg, 2002). There is an underlying ‘scientization’ narrative at work wherein symptom based diagnoses have been

referred to as “pre-scientific” (Blaxter, 1978, p10). The capacity of science to reach new levels of specificity (Cambrosio and Keating, 1995) creates the potential for new levels of specificity in diagnosis: antibodies and virus proteins can be targeted making disease identification more scientific. This narrative is not new; indeed diagnosis has previously been framed as a moving from an art to a science (Zung, 1973). Yet the application of this narrative to low income settings is new. Is this narrative of an increasingly scientific process at play for Lassa fever in Sierra Leone? What about the implicit framings of disease and of health care systems that they entail, for example that disease and ‘underlying causes’ are out there waiting to be detected by the ‘right’ or ‘most accurate’ diagnostics? Or that ignorance is being replaced by science? In chapter four I will show how these narratives have been applied to Lassa fever.

To answer these questions, biomedicine must be understood as a particular framing of disease. Similarly to Michel Foucault’s (1973) work on the ‘gaze’ of clinical medicine, Rosenberg (see 1989, 1992, 2002) reveals the terms on which modern medical framings of disease have emerged. He charts the advent of biomedicine by showing how increasingly specific conceptualisations of disease replaced the fluid, transient and individualised manifestations of symptom-based ‘humoral’ medicine. It was these developments, he argues, which propelled diagnosis to occupy such an influential place in modern medical practice. Diseases began to be identified by unique characteristics and treated in a specialised manner. New tools played a part as “instruments of precision” (Rosenberg, 2002, p243) boosted the “specificity revolution” (Rosenberg, 2002 p240). By the 21<sup>st</sup> century, disease was defined more by accounts produced by those precision instruments than the narrative of the patient; and disease was imagined as an entity independent of the patient. ‘Ideal-typical’ (Rosenberg, 2002, p243) models of both diseases and bodies were developed. These models had characteristic mechanisms which could be objectively captured by technological investigations. A technology-enabled rise of diagnosis has also been noted by others who point out that it replaced prognosis as a central element of modern medical practice (Christakis, 1997). The underlying assumption, Rosenberg points out, is that stable and specific disease entities were the cause of illness. These ‘specific disease entities’ have since become a critical cog in medical practice and are the basis for healthcare systems, hospital administration and a range of associated bureaucratic institutions as well as a considerable amount of moral and social order. All of these developments also feedback to, and strengthen, the disease entities. In this sense they could be said to be ‘co-produced’ (Jasanoff, 2004).

Rosenberg himself describes the traction that ‘specific disease entities’ have in society as the ‘tyranny of diagnosis’.

Rosenberg points out a number of problems with the specific disease diagnostic model. Despite being effective and seemingly value free organisers of treatment and healthcare systems, it is unclear how to fit particular cases to the ‘ideal’ model (or framing), particularly when those cases are atypical. Much of this thesis provides empirical observations of precisely this problem. In practice, a number of disease framings are often used. A specific and mechanistic framing of disease tends to overlook the multi-dimensionality of disease, as do the bureaucratic institutions which are co-produced by those framings. Rosenberg reminds us that the mechanistic framing of disease is very good at dealing with aspects of disease pertaining to the immediate physiological causal mechanisms of a complaint but is less good at dealing with multi-causality and longer-term causal mechanisms. Diagnostic categories and the medical institutions co-produced by them only deal with a small segment of disease in society. Rosenberg gives the example of a homeless person who becomes visible when an ailment flares up but returns to invisibility once treated saying it is “almost as though the disease, not its victim, justifies treatment” (Rosenberg, 2002 p255). Rosenberg’s analysis takes a similar direction to that of Paul Farmer, who has emphasised how inequality, as a driver of infectious disease, is often overlooked (Farmer, 1999). Both I think would emphasise that the act of diagnosis is always political and blinkered. I do not mean political in the sense that there are controversies over whether the disease being diagnosed is real or not (a topic explored in section 2.2.1), but rather that it moderates which aspects of disease (and patients) are seen and which are ignored.

Rosenberg’s work is extremely insightful. His account of the dominant biomedical framing of disease and its blind-spots is powerful. I have one concern relating to the ‘tyranny of diagnosis’ which he says pervades most aspects of life. On closer inspection how far does such tyranny prevail? In both high and low resource health care contexts other conceptualisations of wellbeing and disease (and the body) have long been noted (Janzen, 1978, Kleinman, 1980, Scheper-Hughes and Lock, 1987). There are limits, and resistances, to the reach of biomedicine (Williams and Calnan, 1996). Rosenberg himself acknowledges that the biomedical model is reductionist, but might the extent of contemporary agreement about this form of disease classification have been overstated? In Sierra Leone (constrained) biomedical health services compete with (well established) traditional healing practitioners. As a result

biomedical authority is not guaranteed. It follows that the disease-specific bureaucracies that Rosenberg describes may not be as omnipresent as in the well-resourced US/European insurance and welfare based healthcare systems which he describes.

Applying Rosenberg's ideas to a setting like Sierra Leone raises questions about the assumed trajectory of technological development and accompanying societal co-production. In his descriptions of the biomedical model and the way its influence extends into aspects of societal organisation he highlights the assumptions upon which expectations about new diagnostics are founded. He describes an idealised biomedical healthcare system model which is now being proposed for low resource settings like Sierra Leone with the expectation that they will follow the same trajectory as Europe and America. Health and surveillance systems based on 'specific disease entities' are the gold standard and are viewed as universally applicable. But will the same social processes identified as having occurred historically in Europe and America also occur in Sierra Leone? By this I mean the medical, bureaucratic, social and moral order which Rosenberg describes as created, or made possible, by 'specific' framings of disease. It is these processes which are presumed will accompany rolled out diagnostics in low resource contexts. It would be reasonable to expect that the 'tyranny of diagnosis' may be less pervasive; and also, that the direction of technological and social change may be different.

## **2.2 Theories of diagnosis**

In the years since I started this doctorate in autumn 2008 it seems that the calls for a 'sociology of diagnosis' (Brown, 1995, Jutel, 2009) have been heard. Diagnosis has gone from being overlooked (Blaxter, 1978, Jutel, 2009) to emerging as a sub-discipline in the space of a few years. A special edition of *Social Science and Medicine* was devoted to diagnosis (see Jutel and Nettleton, 2011); and at least three books have been published on the topic: "Ethnographies of Diagnostic Work" (Büscher et al., 2010) was followed by the "Sociology of Diagnosis" (McGann and Hutson, 2011) and "Putting a Name to it: Diagnosis in Contemporary Society" (Jutel, 2011c). Although diagnosis was afforded considerable importance in much early medical sociology and anthropology it was often not the explicit focus of study. For instance diagnosis was important in Eliot Freidson's (1970) work as a means of separating medical professionals (who could diagnose) from lay people (who could not diagnose); a distinction which he used to highlight the issue of medical authority and professional dominance. Similarly, for Talcott Parsons (1951) a diagnosis gave whoever was granted one a

sanctioned exemption from normal participation in society. Thus for Parsons, diagnosis was interesting because it performed a function in social systems. Consequently, diagnosis has been referred to as an “absent presence” in the sociology of health and illness<sup>11</sup> (Jutel and Nettleton, 2011 p793). However recent efforts, spearheaded by Annemarie Jutel, have succeeded in bringing many of the relevant but disparate studies together, as well as generating a new body of focused research on the subject as I discuss in the following sections.

### **2.2.1 Sociology of diagnosis and contesting disease**

The overarching concern in much of this literature, judging by both old and new reviews of diagnosis (Brown, 1990, Brown, 1995, Brown et al., 2011, Jutel, 2009, Jutel, 2011a, Jutel, 2011b, Jutel and Nettleton, 2011, McGann and Hutson, 2011), has been to show how diagnostic categories, or ‘disease labels’, are as much social, moral and normative constructions as they are objective health conditions. The ‘sociology of diagnosis’ rejects the neutrality of diagnostic categories and the notion of scientifically identifying an ‘underlying cause’ and instead emphasises the social context of diagnosis. Scholars have examined how definitions of medical conditions shift over time or differ between people or cultures; some famous examples being homosexuality (Conrad and Angell, 2004), gulf war syndrome (Brown et al., 2001) and obesity (Jutel, 2006). Steeped in the sociological themes of social construction, medicalization, social control, identity and power, this growing body of work has shown the variety of ways disease labels can be used, for example: to legitimise or delegitimise patient’s illness experiences (Scott, 1990); to access or deny treatment and other resources, such as pensions (Trundle, 2011); to extend medical authority by repackaging previously non-medical feelings or experiences as medical ones (Jutel, 2010); to create, or authenticate, diseases and open up markets for pharmaceutical products (Barker, 2011, Ebeling, 2011, Jutel, 2010); to control, marginalise and stigmatise by turning deviance or abnormality into medical pathology (Conrad, 1980); or more positively, to empower patients, create positive identities, challenge authority and demand equity (Brown et al., 2004). In general, pharmaceutical companies, medical or psychiatric clinicians and their professional associations, large corporations and governments are frequently seen as playing the sinister roles of denying, refusing and inventing while patients and lay populations take on more positive roles such as campaigning, suffering, questioning or resisting. With such strong moral

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<sup>11</sup> The contribution of medical anthropology on the subject of diagnosis is relevant and I discuss this in section 2.2.3.

foundations diagnostic categories are increasing conceptualised as ‘discursive resources’ (Willig, 2011); instead of having fixed meanings they are the vehicles through which tensions and contestations are revealed and enacted.

Even though a key insight from these studies of diagnosis is that diseases can be deeply contested, there is a sense in which the sub-discipline gives up on the argument half-way in. Many of the examples in this literature are of particular kinds of contested conditions, often concerning mental health. This has led to criticism that it has been overly focused on diseases where ‘a biopathological mechanism is either unproven or unprovable’ (see also Aronowitz, 2008, Rosenberg, 1992, pXV). I would add that overall the ‘sociology of diagnosis’ literature is concerned with a strikingly Western collection of diseases and struggles. Such details appear to have contributed to an over-representation of psychiatric and psychological disorders in the diagnosis literature. Indeed some of the newer reviews replicate this: in the recently published volume ‘Sociology of Diagnosis’ (McGann and Hutson, 2011) every single empirical chapter is about some aspect of mental health, for example Gender Identity Disorder, Attention Deficit Disorder, Addiction and Asperger’s, almost all of which are concerned with disease categories found in the American Psychiatric Association’s controversial Diagnostic and Statistical Manual (DSM). For a book claiming to be about diagnosis in general this is somewhat surprising.

The oversight is important because it seems to suggest that when diseases have identifiable pathogens, such as viruses, then diagnosis is easy. This obscures the complexity of diagnosis and disease, and it means that much of the existing sociological literature is of questionable power for understanding Lassa fever diagnosis. With an identifiable virus and acute symptoms, Lassa fever is not a conventionally contested or Western disease. The Lassa virus can be isolated and so it can be laboratory confirmed, supposedly, in no uncertain terms. In addition to the literature on framing disease described earlier, a considerable body of scholarship says that infectious diseases are as equally contested as many mental health disorders. For example, work on HIV where there are well documented struggles over its characterisation and links with AIDS (see Epstein, 1996). Paula Treichler (1999) has pointed to the layers of social and symbolic meaning involved in HIV/AIDS biomedicine and science, for example in the assumptions about homosexual men’s behaviour and risk factors for infection. Controversies have been intense around the causal link between the HIV virus and

AIDS (Fassin and Schneider, 2003) and its treatment (Cassidy and Leach, 2009), highlighting the interplay between power, politics and viruses. There were problems with the diagnostic profile of AIDS: thus the collection of opportunistic infections recognised as ‘AIDS defining illnesses’ was skewed towards problems observed in men, homosexuals and intravenous drug users and not those common in women more generally (Treichler, 1999). Melissa Parker and Ian Harper (2006) have pointed out the limitations of applying a ‘factorial’ model of disease which makes an implicit separation between science and culture. They argue that public health and biomedicine must also be subject to critical reflection. To avoid applying a factorial model of disease to diagnosis, a close up look at the intricacies of diagnostic practice is called for, whether the ‘disease’ is a virus or a mental health problem. Thus the next section will review literature on diagnostic processes and practices.

### **2.2.2 Process of diagnosis: assemblages and enactments**

It has been a long time since Mildred Blaxter made the point that diagnosis is both a category and a process (Blaxter, 1978) but arguably the process of diagnosis has been overlooked until more recently. As the previous section demonstrated the dominant themes in the social literature on diagnosis have been diagnostic categories and labels. The need to address this imbalance and pay greater attention to diagnosis in action has been noted recently (Anspach, 2011).

It would be inaccurate to say that no studies take process or technology into account; the work of Annemarie Mol and Bernard Elsmann (1996) and Blaxter (1978) are early examples and there are more appearing. Emerging themes have been experiences of cancer diagnosis (Olson, 2011, Schaepe, 2011, Willig, 2011), the impact of genomic based technologies on medical practice (Bourret et al., 2011, Hedgecoe, 2002) and the politics of risk, identity or reproduction that new predictive technologies bring (Rapp, 1999, Salter et al., 2011). These are important sociological themes but my questions are, in some senses, more practical: how do new technologies actually get used in healthcare systems? What difference do they make to diagnostic processes and pathways? These questions are important because recent work on innovations in diagnostics show that the expected changes do not always materialise. Healthcare workers often ignore the results of malaria rapid diagnostic tests (RDTs) because they attend to other care-giving concerns and are guided by broader conceptualisations of malaria than the evidence of parasites (Chandler et al., 2008a, Chandler et al., 2008b, Chandler



et al., 2012). Newly available laboratory services remain underutilised too (Barat et al., 1999). These last few studies draw attention to the importance of understanding the broad practices and processes which surround the use of diagnostics.

How has the process of diagnosis been described? In the 'scientific' view (Miettinen, 2001) of diagnosis with which I opened the chapter, the process is linear: a clinician accumulates evidence about symptoms and systematically assesses (by rationally applying probability theory no less) the likelihood that those symptoms are caused by each of a differential set of diseases.<sup>12</sup> Another linear view of diagnosis is that it is a process of organisation from disorder to order. Michael Balint talked of "unorganized" and "organized" states of illness pre and post diagnosis respectively (Balint, 2000 p18). Significantly, in his account it is the doctor who has the expertise to bring order to the situation. In contrast, studies which describe diagnostic activity in detail present rather different accounts. Both the 'science' of medicine and the linearity of the process are challenged by authors who bring a 'science as practice' (Pickering, 1992) perspective to diagnosis. A brief detour into this aspect of the science and technology literature (STS) is helpful here as it sets out the principles upon which the studies of medical practice and diagnosis which I am about to discuss are based.

Building on studies which have emphasised the human and social shaping of scientific knowledge, the 'science as practice' perspective (Knorr Cetina, 1999, Latour and Woolgar, 1979, Pickering, 1992) emphasised the fundamental role played by practice in 'intervening' in its research objects (Hacking, 1983) and 'constituting' (Berg, 1996) its findings. For example, for Alberto Cambrosio and Peter Keating (1995) there is no a priori separation between a fact and the technique which discovered that fact. The standardisation of apparatus and techniques to make knowledge and facts stable is a considerable project: "The apparent universality of science is tribute to the power of a collective rendered stable by the pre-circulation of stable objects" (O'Connell, 1993 p165). Knowledge (scientific or otherwise) is shared through shared artefacts and practices (See Knorr Cetina, 1999, Latour and Woolgar, 1979, Pickering, 1992, Star and Griesemer, 1989). Societies, then, are patterned by distinct knowledge communities which operate within knowledge production contexts and through 'machineries of knowing' (Knorr Cetina, 1999). These can be very specialist or more general. A concept I use in chapter six, to describe diagnosis in the laboratory, is Knorr Cetina's notion

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<sup>12</sup> Often a number of possible diseases may be causing the observed symptoms. Differential diagnosis is the systematic exclusion of each possible disease until a positive diagnosis can be reached.

of ‘laboritization’ (Knorr Cetina, 1999, p26). She uses ‘laboritization’ to describe the transformations which objects undergo in a laboratory’s ‘machinery of knowing’. This highlights how the laboratory’s production of knowledge relies on its manipulation of natural orders and social orders *as a result of particular practices*. A theme explored in this thesis is the limits to laboritization.

Diagnosis should be viewed as an exercise in (re)producing disease related knowledge but there are diverse ways of doing this within the diagnostic system, hence the limits to laboritization. The diagnosis of Lassa fever spans a number of knowledge production contexts each with various techniques, routines, and instrumentation. Whether the production context is a network of scientists publishing in peer-reviewed journals or a village that is hours from the nearest hospital, they will apply different practices and framings to the subject of Lassa fever.

Ethnographic studies of diagnostic practice show that the process of diagnosis is not a singular linear process, but many non-linear ones, shaped by divergent interpretations, evaluations, and competing priorities (Büscher et al., 2010). To start with, the distinction between diagnosis and treatment, often assumed to be a fundamental feature of medical order, is fuzzier than it is often said to be. Detecting and treating disease are not necessarily distinct processes (Mol and Elsmann, 1996) and treatment sometimes precedes diagnosis (Starbuck, 2006). In fact, treatment often takes the place of diagnosis, a pattern particularly noted in low resource settings (D’Acremont et al., 2009). In her ethnographic account neonatal care Jessica Mesman questions the received wisdom that diagnosis revolves around identifying an underlying cause and suggests diagnostic work is broader; and more particularly that it is a collaborative practice of moving forward, reading and processing the conduct of others and weighing up opportunities (Mesman, 2010). As such, diagnosis can be conceptualised as many interactive and overlapping processes, consisting of a wider set of priorities than just identifying the root cause of a particular patient’s problem.

Scholars have pointed out that biomedicine is not a ‘seamless web’ and its practitioners do not present a unified professional front. Instead, there are differences and tensions at biomedicine’s core. Disease labels have a fluidity and multiplicity of meaning which vary across different stages in healthcare and between the many people involved in medical work

(Berg and Mol, 1998, Büscher et al., 2010). Clinical medicine encompasses different ways of seeing and interacting with patients or parts of them (Mol and Berg, 1998, p32). Mol coined the phrase 'the body multiple' (Mol, 2002) to make an ontological argument that different versions of the body and disease are made in medical practice. Multiple bodies and diseases are 'assembled' and 'enacted' by a range of people using different techniques: but the 'body multiple' is both singular and many. Mol and Elsmann's (1996) description of diagnosing diseased leg vessels illustrates the heterogeneity:

*"it draws together vessels, surgeons, research designs, hospital organisation, patients, apparatus, general practitioners, dye, buttons, interview questions, catheters, gel, blood, and many other elements. All of them interrelated. Yet each irreducible to the other" (p628).*

It is perhaps more fitting to talk of the *processes* of diagnosis. As Mol points out, these enactments are sometimes in opposition. Mol's lens has been applied to the diagnosis of chest pain (Gardner et al., 2011) where it highlighted the negotiating techniques used by doctors to draw together or discount conflicting enactments into a coherent whole; doctors would question the reliability of tests and promote particular causes of symptoms over others.

If diagnostic processes are made up of enactments of disease assemblages of people and technologies then they are also, by definition, embedded in classification systems. Classification systems are usually assumed to be made up of complete and mutually exclusive categories, with consistent organising principles. In contrast, Geoffrey Bowker and Susan Leigh Star (2000) argue that most modern day classification systems do not fit those specifications. Bowker and Star studied the International Classification of Diseases (ICD) and found it to be contradictory, messy, ill-defined and applied in many different ways, not always as intended. Bowker and Star highlight the importance of hidden practices in the upkeep and application of such a messy classification system. Within well established and formal structures there are informal and ad-hoc classificatory practices and 'rules of thumb' which work around or patch over inconsistency. This speaks to my notion of the diagnostic system. I conceptualise the system, and the process of diagnosis, as involving village healers as well as laboratory technicians. Therefore the diagnostic system is a combination of socio-technical elements, assemblages, enactments, and formal and informal classifications, all of which frame disease differently. The classification work within it is disjointed and not necessarily systemic. It is for these reasons, outlined fully in section 2.3, that I am drawn to the mangle of practice to characterise the system and the emergence of diagnoses within it.

Given this thesis' focus on new diagnostics, I wish to highlight one further insight from Bowker and Star: classifications systems divide up the world, and in doing so, they promote some aspects of the world above others. Bowker and Star note that when classification tools change, different aspects of the world become more or less visible. These shifts can be subtle or obvious and unsettling. The question becomes how do new and old diagnostic technologies shift the established patterns and practices of classification? What aspects of Lassa fever come more or less into focus? So far I have mostly discussed biomedicine and hospital settings. Now, I will outline some diagnostic practices and processes which become important once a broader perspective on diagnosis is taken

### **2.2.3 Negotiating plural health systems**

The negotiation of disease framings and of particular diagnostic pathways begins, usually, at the onset of symptoms. Lay interpretations of symptoms are an important first step. Some symptoms, like those caused by autism, are unusual and so the need for specialist help is quickly noted (Daley, 2004). However, many illnesses begin with routine and ordinary symptoms and so cause little initial alarm. Such is the case for fevers (Kamat, 2006) where there are strong lay traditions of treating high temperatures and flu or cold like sicknesses. For a disease such as Lassa fever, which has non-specific symptoms but where early diagnosis is imperative, it is important to identify when, how, and by whose judgement symptoms of fever are perceived to shift to something out of the ordinary. Equally, the range of responses to such a shift should be established. Even once that shift has occurred, pathways to diagnosis and treatment are not straightforward; indeed Salome Bukachi et al. (2009) have illustrated the back and forth between providers and treatments, and the resulting delays, for patients in Kenya and Uganda for another hard to diagnose disease, African trypanosomiasis (or sleeping sickness).

The interactions between multiple framings of disease, and their enactments in diverse healing practices, are central to the diagnostic process. Importantly, different framings do not always lead to different responses. Barry and Bonnie Hewlett have shown that despite radically different explanatory models for understanding an Ebola epidemic, the Ugandan Acholi's response was broadly consistent with that of the visiting infection control personnel (Hewlett and Amola, 2003, Hewlett and Hewlett, 2008). Though it is sometimes assumed local

cultural practices exacerbate infection, the Acholi communities' protocol (which is rooted in beliefs about bad spirits) for dealing with serious outbreaks matched the biomedical recommendations. However, the authors warn that insensitive implementation of infection control, such as the use of opaque screens for isolation or burials without notice in body bags, fuelled long-held local ideas about Euro-American harvesting of African body parts. There were reports of resistance from local communities as a result. Ebola serves as an example that alternative understandings of disease are relevant to disease control and should not be ignored or assumed to be counter-productive to biomedical efforts. The importance and validity of local perspective has been increasingly acknowledged in Ebola outbreak control (Hewlett and Hewlett, 2008, Leach, 2008) and has been part of responses (Lamunu et al., 2004). Despite differences to Lassa fever, the example of Ebola is especially relevant as at times they can both be subject to similar 'outbreak' panic, albeit to a lesser extent for Lassa fever. Equally, they both require isolation and are hard to diagnose. Yet, understanding of local knowledge and practices related to Lassa fever is currently limited. In exploring processes of diagnosis in Sierra Leone this thesis will go some way in addressing this limitation.

Contrasting, interlocking and complimentary health systems have been the focus of much medical anthropology. The variation in approaches to therapy has been labelled medical pluralism, although this term has been used in a number of ways (Johannessen, 2006, Reynolds Whyte, 1982): it can describe one medical system with many medical traditions within it; or it can describe a situation where multiple medical systems co-exist; it can mean that a society has an orthodox 'closed' system but that therapeutic alternatives also thrive; or, alternatively, it can mean an 'open' system which incorporates many new traditions. The form of pluralism has also been attributed to the scale and scope of the medical system (Baer et al., 2003). John Janzen (1981) and Susan Reynolds Whyte (1982) have emphasised the open and multiple nature of African medical systems and for this thesis, I favour these accounts. In such systems, patients may make use of apparently contrasting medical traditions even at the same time. Janzen points out that the shifting between medical domains is not random but that the plurality is based on multiple causation beliefs (e.g. natural, lack of respect, greed, environmental, misfortune, magic, and sorcery) which are not mutually exclusive. Distinctions are made between treating symptoms and treating causes, and there are hierarchies of medicines for different causes (Reynolds Whyte, 1982). Both authors maintain that these

plural systems are not closed; the incorporation of pharmaceuticals, famously injections, alongside existing alternatives in African medical systems is cited as an example of this.

The argument is also made that Western medicine does not monopolise because Western medicine does not have all the answers. There are diseases which biomedicine fails to cure and established healers are able to operate on its 'outer parameters' (Janzen, 1981). Also, as I noted previously, the limited government provision of biomedical care means alternative approaches to therapy will always be attractive (MacCormack, 1984), particularly when providers are sensitive and more flexible about payments (Reynolds Whyte, 1992). Indeed, more important than the compatibility of underlying beliefs about sickness – or new medical traditions and devices - are the social relations which are involved in causing, diagnosing, managing and healing sickness (Janzen, 1978, Young, 1982). In relation to the mass treatment of neglected parasitic diseases, Parker et al. (2008) note that while local understandings of bilharzia may overlap with biomedical ones they, and the interventions to combat them, are experienced as part of wider local social and political discourses. Fear and resistance to treatment is shown to be a manifestation of inappropriate delivery and health promotion which does not consider the local contexts, as opposed to simple non-compliance on account of ignorance.

Recent work on health systems in developing country contexts have argued that pervasive dichotomies such as those between 'public' and 'private', 'formal' and 'informal', or 'traditional' and 'biomedical' are artificial (Cross and MacGregor, 2010, Leach et al., 2008, Standing and Bloom, 2002). Instead plural medical systems should be conceptualised as hybrid. In Guinea, Melissa Leach et al. (2008) found that categories such as 'traditional' and 'biomedical' are less relevant when you look at what people actually do. Archaic and artificial boundaries are inadequate. Therapeutic practices are related not only to diverse framings of disease and treatments but also to wider social, historical, political and economic factors, including the health service and policy environment. Leach et al. use the notion of a 'therapeutic landscape' to describe the practical, social and historical considerations in complex health systems. I too will employ this concept to explore health and Lassa fever diagnosis at the community level because the landscape of therapeutic options shapes the process of diagnosis fundamentally.

Diagnostic processes and pathways are rooted in various approaches to therapy and their social context; biomedical expertise is not the only relevant knowledge, alternative understandings and experiences of disease are important throughout healthcare and they do not always give way to 'expert' knowledge even when a patient decides to consult those experts. The use and availability of technology also shapes the process of diagnosis. Technology is central to my research question and its importance has been implied throughout the previous pages; it is the focus of the following section.

#### **2.2.4 Diagnostic technology**

Technological change has fundamentally altered medical practice. New technologies have brought about new ways of seeing, investigating and diagnosing the body (Anspach, 2011, Blaxter, 1978, Rosenberg, 2002). Not only have clinical activities been transformed, but arguably the clinicians themselves have been re-shaped as they have been required to possess different kinds of dexterities in order to optimise their new implements (Anspach, 2011, Knorr Cetina, 1999). Technology has a complex relationship with medicine and society; the literature covered in this section suggests that the answer to my main research question about how new diagnostic technology will be incorporated into the process of diagnosis will be multi-dimensional. I suggest that studies of diagnosis have not paid adequate attention to technology, what it is, how it is shaped and used, and so lack insight into some of the key processes which I seek to understand. Here I turn to some key strands of the innovation literature in order to shed light on these processes.

Scholars of technology and innovation have emphasised the social construction of technology (Bijker, 1995, Pinch and Bijker, 1984). Technologies shape and are shaped by social dynamics, such as divisions of labour, hierarchies, configurations of power and knowledge (Blume, 1992). In terms of laboratory diagnostics any developments need to be put in context; as Andrew Cunningham and Perry Williams (1992) have stressed the pre-eminence of laboratory medicine should not be taken for granted, as self-evident progress. It will be a story of group struggle, they say. The characteristics of particular technologies are not the result of pure 'technological determinism' nor 'social essentialism', instead they should be viewed as the result of negotiated practice between the two (Timmermans and Berg, 2003). The practice of technology is multi-dimensional: Michael Hopkins (2004, p9-10) synthesises the work of a number of authors to arrive at a deconstruction of technology as comprising of

*artefact, technique, and regime* (see also Hopkins, 2006). The ‘artefact’ is the tangible, visible element of technology; its material manifestation. ‘Technique’ encompasses routines, skills and habits; it is embodied in people and describes, broadly, the *mode* of human action used to operationalise an artefact (i.e. take a photo with a camera), or group of artefacts (process a film). Techniques have a degree of flexibility, different routines can produce the same effect, and the same routine can be performed with varying degrees of skill (Hopkins, 2004, p15-16). Artefacts are not essential components of technology, techniques can be technologies in themselves (e.g. classification of diseases); thus technology can exist independently of material form. The ‘regime’ includes rules, systems, organisational networks; it is the wider context which structures the deployment of techniques and artefacts. As regime is a concept taken from evolutionary theories of technical change (Dosi, 1982, Nelson and Winter, 1982) it brings with it an emphasis on cognitive processes of innovation as subject to bounded rationality and path-dependency.

Technology then, is neither simply technical nor simply social; in important ways it is a combination of the two. Wiebe Bijker (1995) has referred to technology as a ‘sociotechnical ensemble’ to highlight the bricolage quality of socio-technical interactions which constitute a technology. Likewise, regimes can be characterised as ‘socio-technical’ (Berkhout et al., 2004, Geels, 2004). The science, technology and innovation (STI) literature emphasises that technology should always be understood in the context of broader social dynamics – including interests, networks, history, path-dependency, and material, political and embodied interactions. Importing technology also means importing techniques, systems and regimes, there are likely to be incumbent technologies, embedded in entrenched socio-technical systems and regimes. In Sierra Leone it would be naive to assume that because laboratory diagnostics were not ‘up to scratch’ that there are not alternative technologies and practices related to diagnosis and disease. The interactions between existing and new diagnostics are likely to be significant and complex.

Finally, the ‘biotech revolution’ has been problematised by Paul Nightingale and Ben Martin (2004) and Hopkins et al. (2007). Predictions about the biotech revolution and its relationship to the scope and pace of technical change have been called into question. These papers stress that the path of technical change in the drug innovation process, and the impact of developments in biotechnology on that path, is one of slow, typical and incremental steps



rather than of ‘revolution’. This present research focuses on the broader innovation processes for diagnostics, looking at innovations in practice once new products are developed. It looks at their use and impact once they enter clinical practice. Hopkins et al.’s paper provides some insights: the fact that innovations do not always bring the expected benefit is not simply the arguments that ‘context matters’ or that some issues are not resolved by the new technology as in ‘silver bullet’ analogies (although both are equally true) but innovation surrounding new technologies often make matters more complicated. In terms of possible implications for health care systems like those in Sierra Leone it is important that this research captures broader implications of new technology.

### 2.2.5 Challenging uncertainty narratives

Implicit in the preceding discussion are challenges to an assumed relationship between uncertainty and diagnosis. I have noted how diagnosis is frequently seen as reducing uncertainty but, as I have also suggested, in some situations this is misguided. For example Cornelius Schubert says that instruments determine and resolve the cause of diagnostic uncertainty (Schubert, 2011). Underlying these ideas about uncertainty is the idea that technology makes diagnosis more precise and scientific. Indeed diagnostics are becoming increasingly mechanistic (as opposed to symptom based) as they achieve ‘exquisite specificity’ at the molecular level (Cambrosio and Keating, 1995). With such advances in science the implication is often that levels of uncertainty are reduced.

In the technical literature on diagnostics a test’s performance is judged and reported by ‘sensitivity’ and ‘specificity’ calculations. As well as a diagnostic test’s suitability for low resource settings the dominant theme in discussions about improvements to diagnostics are these two calculations. ‘Sensitivity’ is the proportion of *true positives* that are correctly identified by the test and ‘specificity’ is the proportion of *true negatives* that are correctly identified by the test (Altman and Bland, 1994a). A perfect test would be 100% sensitive and 100% specific: such a test would never miss a person with the disease and would always exclude people without it. A test which was 100% sensitive and 0% specific would never miss a true positive but it would take every person to be positive regardless of whether they had disease or not (false positive). A test which was 0% sensitive and 100% specific would always show people without disease to be negative (true negative) but it would also report everyone

else as negative (false negative), even if they had disease. As the 'perfect test' is (usually) unattainable, clearly there needs to be some middle ground between the last two scenarios.

A degree of error and uncertainty is tolerated and set against the potential for other benefits: the Global Health Diagnostics Forum modelled the impact (lives saved, harm done by misdiagnosis and treatment) of a range of sensitivity and specificity values for tests which could be used in settings with different levels of infrastructure (Giroi et al., 2006, Urdea et al., 2006). The distinction between high, middle and low infrastructure was related to how accessible the test would be; for malaria for example, it was determined that a more accurate test which needed more infrastructure, such as Polymerase Chain Reaction (PCR) or microscopy, would save less lives than a less accurate one which was able to reach more people, such as the 'lab on chip' rapid diagnostic tests (Rafael et al., 2006). These calculations of uncertainty and access are central to the development and provision of diagnostics. The Global Health Diagnostics Forum used this analysis to support their call for improved diagnostics in a number of key diseases. As chapter six will describe, claims made about improvements in sensitivity and specificity play an important role in justifying the superiority of the new diagnostics for Lassa fever.

However, as the following chapters will demonstrate, sensitivity and specificity only portray some aspects of the uncertainties, doubts and limitations to knowledge which pervade diagnosis and diagnostics. They represent an incomplete picture of the incertitude involved. On paper, sensitivity and specificity are straightforward and calculable. They represent the risk of classification error: is this a true positive or a false positive? Error has become the dominant understanding of uncertainty in diagnostics and indeed in laboratories in general (Plebani, 2006). Yet, there are deeper ambiguities. Who and what defines the 'gold standard'? How should these values be interpreted for individual cases? As I explain below, applying the sensitivity and specificity calculations which are reported for a diagnostic test to a given result for a particular patient is conceptually difficult in practice (Miettinen, 2001); worse still, it is spurious to do so for a test which was 'validated' in one population but is used on another where prevalence rates are not known (Akobeng, 2007) as is often the case.

Sensitivity and specificity are characteristics of the test, they do not tell the person using them how likely they are to give a correct result for the patient and disease at hand (Altman and

Bland, 1994b). For this the test results need to be put into context. From a statistical point of view this means calculating the proportion of correct and incorrect diagnoses which are made by a test.<sup>13</sup> To do this you need to know the prevalence of the disease in the population on which you are using the test. As prevalence changes so do the probabilities of a test's positive or negative result being true or false: "The predictive values of a test in clinical practice depend critically on the prevalence of the abnormality in the patients being tested; this may well differ from the prevalence in a published study assessing the usefulness of the test." (Altman and Bland, 1994b). As we shall see with Lassa fever there are not even any published studies on this aspect of diagnosis to refer to. Even when sensitivity and specificity are high the implications of the test in two different populations can be dramatically different<sup>14</sup>. The test is of a fundamentally different value in different populations. And to know the value of a test you must first know the prevalence of the disease in the population. This is exactly what is not known in Sierra Leone. As chapter four will describe, there is much debate and a lot of uncertainty about the prevalence of Lassa fever in Sierra Leone and West Africa.

But uncertainty extends further than the validity of probabilities. Paradoxically, a few studies even suggest that enhanced diagnostics can increase uncertainty and ambiguity (Miller et al., 2005, Rosenstein, 2002) particularly where they disrupt existing classification regimes. The clinical implications of new methods of genetic testing, for example, have included increased ambiguity as differences open up between systems of classification: a person could have a genetic mutation but no symptoms, or they could have symptoms but no mutation. The issue is not of uncertainty about whether the test was right or not, rather that there is underlying ambiguity about the disease. How should it be defined? What does it do to the patient? How can it be passed on? New ways of diagnosing disease can present enormous difficulty because of the ambiguity over interpretation when there are conflicts with old ways of defining it. Caught in the middle of such doubts about classification are the patients. Where classification

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<sup>13</sup> These values are the positive predictive value (PPV) and the negative predictive value (NPV). The PPV is the proportion of patients with the positive test who are correctly diagnosed. The NPV is the proportion of patients with negative test results who are correctly diagnosed.

<sup>14</sup> An example given by Ben Goldacre (2006) is helpful. Take a test which is 99.99% specific and 99.99% sensitive. In every 10,000 people tested the test will give, on average, 1 false positive. If you screen 10,000 people in a population where the prevalence of the disease being tested for is 1 in 10,000 then you will get, on average, 2 positive results: one will be the true positive and the other will be the false positive you would expect from screening that number of people. If you are one of the people who receive a positive result, there is a 50% chance that it is wrong. Use the same test on 10,000 people in a population where the disease prevalence is 10 in 10,000 and you should expect to get 11 positive results: 10 are your true positives and 1 is the false positive. If you are one of the 11 people with a positive result the chances that your result is wrong is now approximately only 10%.

lines are drawn can have important practical implications. Treatment, insurance and counselling options may become open or closed. In later chapters I discuss how there are similar debates over how to classify Lassa fever; as diagnostics develop questions are asked about the relevance of virus or antibody in a blood sample. For patients these decisions are anything but irrelevant. This begs the question, is uncertainty reduced, and if so, how and for whom?

Figure 1 shows the different dimensions of incertitude and incomplete knowledge. Risk should be used when probabilities and outcomes can be known and predicted. Uncertainty is where outcomes are familiar but probabilities for predicting them are unknown. Ambiguity relates to disagreements about the scope, scale, and nature of outcomes; differences in how issues are framed can cause ambiguity as it makes comparison difficult. Ignorance is when neither outcomes nor probabilities can be known. Andy Stirling (2007) and colleagues (Leach et al., 2010a) have argued that ambiguity, uncertainty and ignorance are often condensed into a discourse of risk concealing the extent of what is not known or is not controllable. An underlying theme in this thesis is whether the weight afforded to sensitivity and specificity in assessing the value of diagnostic technologies may also be part of a narrow risk discourse. To illustrate this, I have added to figure 1 (in red) some of the questions which can be asked in the process of diagnosing Lassa fever.

Moving away from concerns over the introduction of new diagnostics, a more general comment is that uncertainty is deeply embedded in diagnostic and therapeutic work and not easily eliminated. I have already pointed out that medicine involves the negotiation of difference. Dawn Goodwin tells us that the practical implications of this diversity (of roles, perspectives, tools and places) means that at each stage practitioners have to piece together the clinical picture about a patient from 'partial stories' (Goodwin, 2010, p88). The potential for variation and diversity, therefore, is significant throughout the process and it should not be assumed that this diminishes once a patient reaches an official biomedical health care provider.

Figure 1 Dimensions of incertitude (adapted from Stirling, 2007)

Knowledge about OUTCOMES		
	Not problematic	Problematic
Knowledge about PROBABILITIES	<u><b>RISK</b></u> <ul style="list-style-type: none"> <li>• Probabilities and outcomes are known (i.e. for a known epidemic)</li> <li>• <i>Was the test performed correctly?</i></li> <li>• <i>Is prevalence of disease known in the population being tested?</i></li> </ul>	<u><b>AMBIGUITY</b></u> <ul style="list-style-type: none"> <li>• Contested framings, questions, assumptions, methods</li> <li>• <i>Does a positive result in a laboratory test mean that the symptoms are caused by Lassa fever?</i></li> <li>• <i>What happens when symptoms and test results disagree?</i></li> <li>• <i>Could symptoms be caused by a witch?</i></li> </ul>
	<u><b>UNCERTAINTY</b></u> <ul style="list-style-type: none"> <li>• Complex, non-linear, open systems</li> <li>• <i>Is this likely to be Lassa fever or malaria?</i></li> <li>• <i>Which other diseases are there which might look like Lassa fever?</i></li> </ul>	<u><b>IGNORANCE</b></u> <ul style="list-style-type: none"> <li>• Unanticipated effects</li> <li>• Gaps, surprises, unknowns</li> <li>• <i>Is Lassa fever spreading?</i></li> <li>• <i>What is the prevalence in West Africa and within Sierra Leone?</i></li> </ul>
Problematic		

Yet, despite the acknowledgement of uncertainty and multiplicity in these up-close ethnographic studies of diagnostic work (Goodwin, 2010, Mesman, 2010, Mol, 2002), diagnosis is still treated as a fundamental organising principle and goal in medical practice. Diagnostic practice has been described elsewhere as a continuous process of ‘making sure’ (Schubert, 2011). Even in Mol’s work, where difference is centre stage, there is an implied ‘coming together’. Alice Street has questioned this and pointed out that much of the literature presumes a kind of ‘hanging together’ (Street, 2011). She suggests that this stems from an assumption that closure is always a desired endpoint. Highlighting that this is an idea imported from science studies, she argues that it is not universally applicable to practice in biomedical health care settings. And I have already pointed out that most of these studies have been of biomedicine as practiced in the West in broadly similar and well equipped settings. Street shows that healthcare worker’s objectives and practice can be very differently motivated in more diverse settings. In her ethnographic observations of a hospital in Papua New Guinea, Street does not see a ‘hanging together’ of people and technology. She does not

see healthcare professionals strategically working towards ‘diagnostic closure’, but rather ‘practices of not-knowing’ where the value of keeping options open is emphasised over narrowing down in regards to particular causes and pathways for action.

Such practices might be considered subversive in traditional Western biomedicine but they highlight how in diverse contexts alternative strategies find their own rationales. The implication here is that healthcare strategies will have local contexts shaping them and diverse logics guiding them. Street’s case is supported by the work on malaria RDTs which I mentioned previously; in those studies the explanation for ignoring test results or clinical guidelines was because medical professionals were working to broader concerns and concepts of disease (Chandler et al., 2012). I develop these ideas in my empirical chapters. Universal ideals and standards, such as isolation procedures, do not always fit alongside the practical concerns of the West African Lassa fever context. This means they must be renegotiated on site. These negotiations run deeper than simply working out how to make do with scarce resources, they also concern differential ways of dealing with risk and uncertainty surrounding diagnoses.

This brings the very essence of the diagnostic process into question: what is actually being achieved during the course of this spread out, multiple, non-linear, interactive cycle? Is uncertainty reduced? Is order being created out of disorder? Or do those narratives conceal that the transition is not as smooth or complete as is hoped? Marc Berg (1996) has examined the use of a patient record and argued that it is a constructed artefact which artificially paints the diagnostic and treatment processes as linear and as a self-evident ‘natural’ progression, omitting from the record the uncertainty which was present throughout its creation. How is uncertainty dealt with during diagnosis? Might it be, as Berg describes, reminiscent of well know practices of consensus building and black-boxing (Latour and Woolgar, 1979)? Equally, what of the idea that closure may not be people’s primary objective? In her critique of the central role STS scholars have placed on stability and closure, Street’s argument contradicts that of Berg’s in an interesting way (Street, 2011). Stabilization appears not to be universal in medical practice and instead, in the Papua New Guinean context, dealing with uncertainty, rather than closing it down, is a prized skill. Street’s work may be especially germane because Sierra Leone, particularly the Mende areas where Lassa fever is endemic, is rich in the social cultivation of uncertainty; in the face of wide-ranging instability it has been argued that

strategies which maintain uncertainty are valued and can be used as a resource (Ferme, 2001, Murphy, 1990). This touches on another dimension, put forward by Murray Last (1981), that in some health care contexts not-knowing becomes institutionalised. Last characterises Nigerian traditional medicine as a 'non-system', on account of it being diverse and un-organised, and attributes the 'not-knowing' or indifference to knowing which he frequently observes, as a reaction to the ambiguity presented by the non-systematic nature of traditional medicine. According to Last, people 'switch off' from what cannot be known. He argues that in his Nigerian setting communities have devised codes of secrecy, suspicion and scepticism to cover up for the inability to know. For instance, knowing too much about sicknesses can be dangerous and lead to accusations of witchcraft.

Despite their differences, a lesson from Berg, Street's and Last's work is that the process of diagnosis is not simply about moving from uncertainty to certainty, or from disorder to order. While Berg points out that uncertainty is hidden, Street and Last point out that uncertainty can be valued and cultivated; either way how uncertainty is dealt with necessitates close attention. Uncertainty, risk, ambiguity, doubt and ignorance will be part of diagnostic journeys both for patients, their healers, and the people around them. The way this is viewed and dealt with may well be significant in shaping both the pathway and the patient's experience of it. Overall, to explore disease and diagnosis fully their respective systems should be viewed as complex, non-linear, and fraught with uncertainty, ambiguity and ignorance.

### **2.3 The diagnostic system: a mangle of practice?**

The preceding pages have called the relationship between uncertainty and diagnosis into question. They have also challenged assumptions about the process and practice of diagnosis. By highlighting the socio-technical assemblages and multiple enactments in medicine this chapter has presented an alternative view of diagnosis which is not neat, straightforward, or linear. However, notions of assemblages and enactments are themselves not entirely satisfactory explanations of diagnosis. Though they emphasise multiplicity they also presume convergence and eventually closure. If you take a broad view of the diagnostic system, and particularly if you look outside of high income settings which are dominated by biomedicine, this becomes less convincing. The notion of a 'socio-technical system' has been used to describe a combination of technological and social facets which perform functions in society (Geels, 2004). Here that could be diagnosis; in fact, in scientific and health policy literature

diagnostic and surveillance activity is often described in terms of systems (e.g. Nkengasong, 2009, Olmsted et al., 2010, Saijo et al., 2006, WHO and CDC, 2010). Yet this notion of a system also raises questions about the presumed unity and functioning of the parts within it. Diagnostic processes span a number of different settings (or ‘production contexts’) as they negotiate various socio-technical assemblages and enactments of disease. How do framings and practices across these settings interact and shape diagnostic pathways in this context? How will new diagnostics influence these processes? How can the multi-dimensional nature of knowing (and not knowing) be accounted for in the process?

In answer to the above questions I suggest the ‘mangle of practice’ Pickering (1993, 1995). The mangle of practice was intended as an explanation of scientific practice which was able to do justice to the richness of micro level practices.<sup>15</sup> Pickering perceived that the actual performance of science had been overlooked by STS being overly focused on macro level processes such as scientific closure and the social shaping of knowledge thorough interests. Similarly I have argued that the process and practice of diagnosis have been ignored by the sociology of diagnosis’ focus on themes such as medicalization and labelling. I have also highlighted that understandings of diagnosis must account for the contested nature of viruses which do not follow simple constructivist or realist lines. The mangle offers a way of conceptualising the complexity of therapeutic practice through which a diagnosis emerges across multiple settings.

Pickering tells us that ‘doing’ science involves a complex, reciprocal and inter-dependent pattern of behaviour. Human action, goals and theories are continually reconfigured through interactions with the material world they are attempting to understand or control. In Pickering’s mangle there are human and non-human agencies and these are “mutually and emergently productive of each other” (Pickering, 1995, p567). That is, they interact and respond to each other in a “dance of agency” (Pickering, 1995, p21). Science should be seen as the business of coping with material agency. An important concept in understanding the mangle is the idea of de-centred emergent becoming (Pickering, 2008). This is the idea that

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<sup>15</sup> Pickering (1995) makes a distinction between practice and practices: practice, in his usage, is the reproduction and extension of scientific culture and knowledge which involves skills and social relations, machines and material culture, and theories and concepts; practices, describes ways of doing things which are usually community or context specific. Practices can be articulated or non-articulated, material or social. Scientific practice can involve many practices. Thus, the practice of diagnosis involves many different practices.



theories, procedures, goals, problems, and functions emerge during the course of practice. There is no set pathway and the field of agency is diverse. An advantage of the mangle is that it is not hermetically sealed and it offers a theory of diagnosis which is neither socially constructed nor predetermined, in part, because material agency is taken seriously; a person's diagnosis develops in conjunction with its surroundings and is shaped by many hands (and things) in the process. The field of material agency in this thesis could be the Lassa virus itself. It is evolutionarily programmed to behave in mysterious ways. Equally it could be seasonal rainfall and muddy roads. They can all be said to exert agency on human practice as they are all involved in a dynamic relationship with patterns of human sickness as well as attempts to identify and deal with them.

Underlying all practice, Pickering tells us, is a pattern of resistance and accommodation between the human and material world. In these struggles, non-human agency is more restricted than human agency which can change its goals. Still, human practice must always contend with the resistance put up by material or non-human agency. Pickering's summary is useful:

*"Scientists are human agents in a field of material agency which they struggle to capture in machines. Further, human and material agency are reciprocally and emergently intertwined in this struggle. Their contours emerge in the temporality of practice and are definitional of an sustain one another. Existing culture constitutes the surface of emergence for the international structure of scientific practice, and as such practice consists in the reciprocal tuning of human and material agency, tuning that can itself reconfigure human intentions. The upshot of this process is, on occasion, the reconfiguration and extension of scientific culture – the construction and interactive stabilization of new machines and the disciplined human performances and relations that accompany them."* (Pickering, 1995, p21)

Pickering elaborates on the processes of resistance and accommodation by introducing the notions of goal orientated practice, modelling, tuning, and stabilisation. Pickering says that practice is goal-orientated, where goals are formulated and revised based on models of the world as that actor knows it. At some point, the interplay between human and material agency may become stabilised, for instance when a machine or an experiment works and can be repeated. This involves 'disciplined human action', such as is required when following a protocol (which provides an example of the influence material agency can have on human behaviour). Reaching stabilisation is a 'tuning' process whereby human conceptual frameworks can be applied to interpret the reasons for stabilisation (or non-stabilisation).

Politics are evident in people's practices and relationships with aspects of health, science, medicine and technology (see Ong and Collier, 2005) yet politics do not feature heavily in Pickering's presentations of the mangle. This is an area where the mangle could be usefully modified. This can be done by a consideration of framings within the mangle. Pickering does use the term 'framing' (Pickering, 1995, p83) though in a slightly different sense. For Pickering framing is about how the emergent agency of material objects is interpreted. I use it in a broader sense to acknowledge that the goals, models and practices of different actors in the diagnostic system will be framed differently, as will their interpretations of material agency. This structures what actors in the system intend to do and how they interpret diagnostic signs. In this sense human agency is path-dependent and frame specific. Politics is involved when people's understandings, knowledge and motivations diverge. Indeed, framings can be seen as a possible *source* of resistance in the mangle. Partial and subjective views of the world can conflict and may need to be negotiated.

The mangle of practice has been called a theory of everything (Pickering, 2008). So what is to be expected and gained by imagining the practice of diagnosis within Sierra Leone's Lassa fever diagnostic system to adhere to the principles of the mangle? Quite simply, the mangle tells an open-ended story. Besides an endlessly repeated pattern of resistance and accommodation, it imposes very little on whatever subject matter it is applied to. This is more appropriate for addressing diagnosis in Sierra Leone where it would be premature to impose more prescriptive theories, particularly those developed in higher income settings. Therefore, the mangle provides a way of exploring how technologies are incorporated 'into the thick' of existing practice. Importantly it resists the determinism implied in some sociology of diagnosis and technology.

The key aspects of the mangle are: first, the dance of agency; second, a dialectic of resistance and accommodation; third, goal orientated practice involving tuning and stabilisation; and fourth, de-centred emergent becoming. With regards to the first, I provided some examples of non-human agency previously. In the mangle of diagnosis doctors, patients, diagnostics and pathogens will have to negotiate each other's agencies and resistances. The inclusion of non-human agency seems appropriate in settings where the environment, the virus and the tools used to detect it may not behave as they 'should'. The mangle suggests that human attempts to define and identify Lassa will face some unruly resistance.

The implication of the second point, the interplay between resistance and accommodation, is fairly self-explanatory. Diagnostic pathways should involve trial and error and the modification of theories to interpret the case at hand. This pattern will occur in all settings. In a broad view of the diagnostic system, it would not be restricted to the application of scientific theories. As chapter five will demonstrate it can also include local classifications of fevers and how they are applied and revised over the disease course. By adding a concern for framing within the mangle a new dynamic between resistance and accommodation is revealed. Framings may become both a source of resistance and a tool of accommodation. Perceptions about Lassa fever determine how people deal with it, but as we have seen these are partial. Thus they can obscure significant details. For example throughout the empirical chapters I show how ingrained ideas about Lassa fever's prevalence in particular regions, or its manifestation in some 'classic' symptoms, serve to inhibit the recognition of cases which do not fit those moulds. As such, restrictive and inflexible framings of Lassa fever become a source of resistance within the system.

Concerning the third mangle characteristic, the goals, tuning and stabilisation will be context specific. This relates to the STS ideas explored earlier about the boundedness of 'machineries of knowing' and socio-technical regimes. Furthermore, within socio-technical regimes people have various framings which mean they enact disease and diagnosis differently. As later chapter show, in each setting attempts are made to create something stable and understandable. Even within specific sites such efforts come up against contingencies of agency and practice. However, being based on particular framings means that such stabilisations are always partial. A potential issue is that stability can be disrupted when divergent methods of making objects stable compete, both across and within sites. Stability in one setting may not equal stability in another setting. Even if particular technologies claim to be increasingly certain the potential for uncertainty remains across settings.

This brings me to the fourth point about the mangle. This would imply that the process of diagnosis is decentred and heterogeneous. This relates to Mol's work on difference in medical practice. I favour the mangle's emphasis on unplanned and unpredictable emergence over Mol's more problematic suggestion that multiple enactments somehow converge and hang together. However, I will continue to use her language of multiple enactments, assemblages or

amalgams as they convey the diversity of diagnosis clearly. However, returning to the theme of politics within the mangle, it is likely that some conceptualisations of Lassa fever will emerge more forcefully than others depending on differences in the agency, power and interests of those promoting them.

## **2.4 Conclusion**

In summary, the focus of my research is on the process of diagnosis, with a particular interest in the use of diagnostic technologies during that process. A closer look at the process of diagnosis in this chapter has brought into view the full range of people, technologies, relationships, practices and perspectives involved in health care. I have discussed the importance of framings and narratives about disease and diagnosis and have pointed to a 'specific disease' model of healthcare systems which is assumed to be universally applicable. It was suggested that the uncritical application of such models downplays the social, political and historical processes which shape approaches to disease and health in particular settings. This chapter has drawn together literature in medical anthropology and science and technology studies which have emphasised non-linear and informal aspects of diagnosis. I argued that diagnosis can be understood as a system, but that the system is composed of diverse elements within which there exist many ways to frame Lassa fever. Along diagnostic pathways various framings of Lassa fever can be enacted and assembled. The implications for uncertainty were discussed and the relationship between technology, increased specificity and uncertainty was questioned. Pickering's mangle of practice has been combined with framings to provide a conceptual framework to explore the differential processes and practices of diagnosis. I have tried to evoke these differences by studying the processes of diagnosis in three different settings within the diagnostic system. The next chapter will provide details of how this was achieved.

### 3 Research Methods

In the previous chapter I outlined the conceptual framework which I have used to explore diagnosis; it is based on a broad view of diagnosis, which is conceptualised as a system with diverse elements, where various processes and practices are mangled to shape diagnostic pathways. In this chapter I describe how in designing and carrying out my research, I applied this framework to answer the following questions:

How are developments in laboratory-based diagnostic technologies incorporated into the process and practice of Lassa fever diagnosis Sierra Leone?

- How is the diagnosis of Lassa fever framed and how do these framings relate to diverse narratives about the disease's significance and control?
- How is Lassa fever diagnosed in practice and how do different framings and practices intersect with each other?
- How do new diagnostics influence the uncertainty surrounding diagnosis?

My research strategy followed on from the fact that my questions ask *how* changes in diagnosis are occurring. As my aim is to understand the process and practice of such change, I chose an ethnographic method in order to capture the necessary descriptive detail. In the previous chapter I argued that to understand if, and how, new diagnostics make a significant impact on healthcare systems it is necessary to look at health and diagnostic processes as they occur in particular contexts, which requires a degree of depth and familiarity with the context. Assessing impact is often the domain of quantitative research and randomised controlled trials are a mainstay in the evidence base for diagnostics. Yet such methods are limited for understanding the change observed in particular settings (Cartwright, 2011a, Cartwright, 2011b). As I have pointed to the importance of social, political and historical processes which shape approaches to disease and health in particular settings it follows that my aim is not to produce a generalizable explanation of how *all* diagnostics will be introduced in *all* settings for *all* diseases: contexts, diseases and diagnostics are far too varied for that. A more general aim of this research can be understood as establishing in what ways it is justified to challenge narratives about innovations in diagnostics and health systems.

I have advocated a broad view of diagnosis, informed by ideas of systems but characterised more loosely as a mangle of practice (and practices), which reach past the boundaries of a hospital or laboratory, to include less central, formal, or biomedical elements. Within this diagnostic system, the premise is that different actors have diverse perspectives and that their actions have agency but are embedded in social contexts and socio-technical regimes. I highlighted the importance of *practices* and *framings* as a way of accessing these diverse perspectives and diagnostic activities. Clearly, as I have outlined, a non-positivist, qualitative, line of enquiry is required. But in exploring the ways Lassa fever is framed, diagnosed and responded to, I took an ethnographic approach because such processes are fundamentally social, cultural and political and so could only be gauged by being observed as they ‘naturally’ occurred which is central to ethnography (Atkinson and Hammersley, 1994, Hammersley, 1990). Without seeing how people behaved in those contexts, and without having some experience of them myself, I would be unable to answer my *how* questions. In doing so, I have been influenced by the insights of sociology of science and knowledge. They have shown how bodies of expert knowledge, including medicine, long held to be distinct on account of claims to scientific objectivity, are in fact, deeply cultural. Scientific and medical knowledge has been shown to flourish in just such a way within their expert communities, through shared beliefs, practice and artefacts (See Knorr Cetina, 1999, Latour and Woolgar, 1979, Pickering, 1992, Star and Griesemer, 1989).

Given the above, an ethnographic approach is particularly fitting; more specifically a multi-sited ethnography. In general, qualitative research can be good for probing values, perspectives and alternative social realities; it does not seek to establish causality in a measurable or generalizable way. Ethnography, literally translated as ‘writing culture’, is the process of observing and interpreting ‘culture’ in its natural setting and producing a written account of it, as far as possible from the perspective of the peoples whose culture it is (Mitchell, 2007). Clifford Geertz’s famous phrase “thick description” gives an indication of why ethnography is appropriate for this study; ‘writing culture’ involves not just observing and describing but also *interpreting*. It is that last element which merits the term ‘thick description’ (Geertz, 1973). It should be noted that this is not a one way activity: an ethnography is co-constructed by the researcher and the people and communities they work with.

### 3.1 Multi-sited ethnography

In using ethnography, my aim was not to understand some reified notion of 'culture' but to understand where, what, and how Lassa is diagnosed by different groups of people or individuals. I needed to see and understand the interactions between these contingent sets of framings and practices and so I took a multi-sited ethnographic approach because it renegotiates traditional ethnography's focus on long-stays in one setting for the study of dynamic multi-sited cultural landscapes. It looks at the changing significances of cultural objects as they pass through multiple actors, levels and boundaries (Marcus, 1995). By following the intersections and connections between different contexts it builds up a picture of the world system these objects are part of. George Marcus describes the approach as:

*"designed around chains, paths, threads, conjunctions, or juxtapositions of locations in which the ethnographer establishes some form of literal, physical presence, with an explicit, posited logic of association or connection among sites that in fact defines the argument of the ethnography."* (Marcus, 1995, p105).

A flexible approach is important when the object of study, and the influences on it, are not located in any single setting – as in the process of Lassa fever diagnosis - and so cannot be adequately characterised by collecting data from just one place as in traditional ethnography.

In this thesis, the diagnostic system is the ethnographic case. Over the next few pages I describe how I defined my case and how I researched framings and practices within it. Briefly, I did this by carrying out fieldwork in, and following pathways between, three sites which I identified as settings where important activities in the diagnostic system occur or where important material or technological elements of the system are located. These were: a Sierra Leonean village, the Lassa Laboratory at Kenema Government Hospital; and the clinical wards at Kenema Government Hospital (KGH), including the Lassa ward, although this was supplemented by data collected in other clinical settings in Sierra Leone.

To answer my overarching question about how diagnostics would be incorporated into practices of diagnosis I based my data collection and analysis around the three sub questions which overlapped somewhat in terms of the methods they called for. The 'hook' was practice: how is diagnosis practiced, how do framings and practices intersect? The separate questions on uncertainty and framings both tie back in to practice, for instance: how do the framings of the process of diagnosis or perceptions of uncertainty relate back to diagnosis as practiced in

Sierra Leone for Lassa fever? The backbone of my research was participant observation, backed up by interviews and documentary analysis. Participant and non-participant observation involves the researcher directly participating in (or just observing) the activities, or setting, which they are studying. To observe practice, and to comprehend uncertainties in practice, there is no more appropriate research method. I will describe what I did, and how I selected each site in more detail in the coming pages. To summarise quickly, my methods were simple: I spent days in the laboratory with the technicians, I observed wards and clinical routines at KGH and I went to stay in a Mende village. I carried a small note book with me to make jottings as things happened. If it was not appropriate or possible to write at the time, I relied on memory. These jottings were written up into fuller field notes as soon as possible. Conversations about diagnosis and related topics were conducted in each setting as much as possible, with individuals or groups. These parts of my fieldwork were not pre-arranged and were not tape recorded. These periods of observation allowed me to see practice as it occurred, not as I was told it occurred. This was also where uncertainty emerged to be an important theme: time and again the broader dimensions of risk, uncertainty and ambiguity came up in discussions.

To elicit framings and narratives I began, before I started fieldwork, with documentary analysis. I reviewed scientific journals articles, academic research applications, epidemic reports and notifications, and health policy documents from governments and international organisations. Funding, policy or academic documents can contain powerful narratives which are helpful for characterising dominant institutional framings of issues (Leach et al., 2010b). More often than not they contain idealised, normative, versions of events and subject matter: how things *should* work. I also searched for documents produced by different actors and institutions which would contain alternative framings or narratives: press reports, blogs, fiction and non-fiction books on Lassa and Lassa-like diseases, from the perspectives of non-scientists, or other interested individuals.

To gauge alternative framings, those which were not scientific, official, or sensationalist news reports of disembodied accounts separated from place and people, I again relied on participant observation and interviews. I explored these alternative framings by scrutinizing the practice of diagnosis in the three key settings which I describe below. In these settings I looked for how Lassa fever and diagnosis was being defined by people as they performed or



told me about their therapeutic activity: which disease categories or framings of diagnosis were being enacted? What boundaries were being drawn to define the disease and its significance? Documentary analysis also played a role here. Like policy documents, protocols and guidelines can also be seen as embodying institutional and formalised framings, but documents such as these which are integral to work routines have dual significance: they are based on particular framings, of entities and processes, but clinical records or guidelines do not simply record or instruct practice they also constitute it in a fundamental way (Berg, 1996). Thus seeing how they are used, adapted, or ignored in practice allowed me to see the intersection between framings and practices. Because of this dynamic quality I looked for documents which were part of laboratory, surveillance or medical practice and gave them a good deal of attention in my analysis: symptoms checklists and case definitions, safety notices, standard operating procedure, assay protocols and result forms, to name a few.

To probe framings and practices from another angle I conducted interviews with health workers, community members and Lassa patients, which concentrated on their experiences of Lassa fever: where it came from, how they thought other people got sick, how they thought they got sick, and of course, what happened when they did? Interviews can be used to assist in understanding experiences, events, and decisions (Rubin and Rubin, 2005) because they offer the researcher a window in to interviewee's unique perspectives. Interviews were necessary because there is much about health and Lassa fever which cannot be easily observed and because I wanted to triangulate my observations with people's accounts; and to compare the stories I collected in my research village to those of patients coming from elsewhere. I also conducted a limited range of interviews with health and government officials to triangulate with my initial documentary review of scientific and policy documents and with my observations of diagnosis in practice. I was interested to see if civil servants, WHO staff and scientists would relay different concerns about Lassa fever, or different dimensions of diagnosis, to what I had learned on the ground. Each of these interviews served different purposes. They were all semi-structured but they were conducted rather differently; some were more formal than others, in local community settings in particular it was sometimes hard to find privacy and what began as an individual interview turned into a group discussion. I describe how I conducted and sampled interviews in each setting in the relevant sections below. Although I organised all the interviews in advance, questions could not be sent beforehand because email/post are not widespread (except on a few occasions noted below).

Mostly interviews were conducted in English though a significant number of patient and community interviews were conducted in Krio (by myself) and a few in Mende with the help of a local translator. I recorded them all, with consent, except for the few occasions when I was asked not to.

The quality of research is commonly assessed by triangulation which is a strategy of collecting and comparing data generated in different ways to add depth, breadth, and rigour to investigations. Comparisons can be made between (Denzin, 1970):

- Data sources (e.g. different people, groups or communities)
- Investigators (e.g. multiple versus single data collectors/observers/analysts)
- Theories (e.g. different theoretical perspectives)
- Methodologies (e.g. within and between method triangulation)

Triangulation is often described as a technique of checking the validity of research data. The validity checking view has been challenged on the grounds that there is no single reality that can be objectively obtained from any collection of data sources. It has been suggested that because all methods are designed to investigate specific aspects of (subjective) reality they would not, and should not, produce concordant evidence (Ritchie, 2003). This thesis is designed around the principle of multiple perspectives and so it would not be appropriate to pursue a triangulation strategy that was concerned with checking if any one perspective was 'correct'. For this research I have triangulated a number of data sources in order to extend breadth and to provide as full an account of the diagnostic process as possible. I did this by collecting and comparing multiple perspectives of people (and institutions) involved in diagnosis in three very different sites. In my interviews, observations and reading of documents I sought to identify divergences. Where there was contradiction I asked further questions. In analysis I compared my data sources, for example in the laboratory I checked how my observations of practices fitted in with the written protocols. The same was done with 'case notifications' forms and observations on the hospital wards. I compared what I was told by different people and different communities; not just scientist's opinions versus doctor's, but from one village to the next. With some limitations discussed below, in all the sites that I chose I was able to access key actors and to ascertain degrees of coherence and divergence in perspectives between groups.

## 3.2 Research process

The basic stages of my research were as follows: first, I began a literature review which continued throughout; second, I carried out fieldwork which was an on-going process of ‘scoping out’ the diagnostic system and exploring framings and practices in field sites; and finally, I proceeded to analysis, in which I explored the data from these settings and the connections between them. I will now describe each stage in more detail.

### 3.2.1 Literature review

I was interested in academic, policy, health reports and ‘grey literature’, including blogs, news websites, and disease outbreak information websites like ‘ProMED’. I used internet search engines such as in Web of Knowledge, Google, and Google scholar. I also followed article citations manually. I asked experts in the fields for reading lists and key papers or reports. To keep up to date I set up a ‘Google alert’ for Lassa fever so I remained informed of any scientific or other developments. This was very useful for obtaining reports on the 2011 and 2012 ‘outbreaks’ of Lassa fever in Sierra Leone and Nigeria respectively. I also searched the WHO and UN websites for ‘epidemiological records’ and reports on Lassa fever. In Sierra Leone I asked research participants, at KGH and in the Ministry of Health and Sanitation (MOHS) for relevant materials.

### 3.2.2 Fieldwork

I carried out a total of 9 months fieldwork between 2009 and 2011 which was spread across three trips:

- 3 week scoping trip in April 2009,
- 7 month stay from November 2009 until June 2010
- 1 month return visit in April 2011.

I was based in Kenema<sup>16</sup>, a town in the East of Sierra Leone where the country’s Lassa fever activities are the most concentrated. Kenema and the approximate location of my village field site are shown in a map of Sierra Leone in figure 2. Before leaving for my fieldwork proper in November 2009 I made contact with Tulane University who coordinate, in partnership with

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<sup>16</sup> Kenema is Sierra Leone’s third largest city. Census data recorded the population as 128,402 in 2004 (SSL, 2006), however the city is likely to have grown considerably since then.

the WHO and Sierra Leone's MOHS, the Lassa Fever Research Programme<sup>17</sup>, based out of Kenema Government Hospital (KGH). This research programme forms part of the Mano River Union Lassa Fever Network (MRU-LFN) which also involves the Governments of Liberia and Guinea. Tulane staff agreed to let me to stay at their guesthouse in Kenema, giving me an entry point into Lassa fever activities in and around KGH.

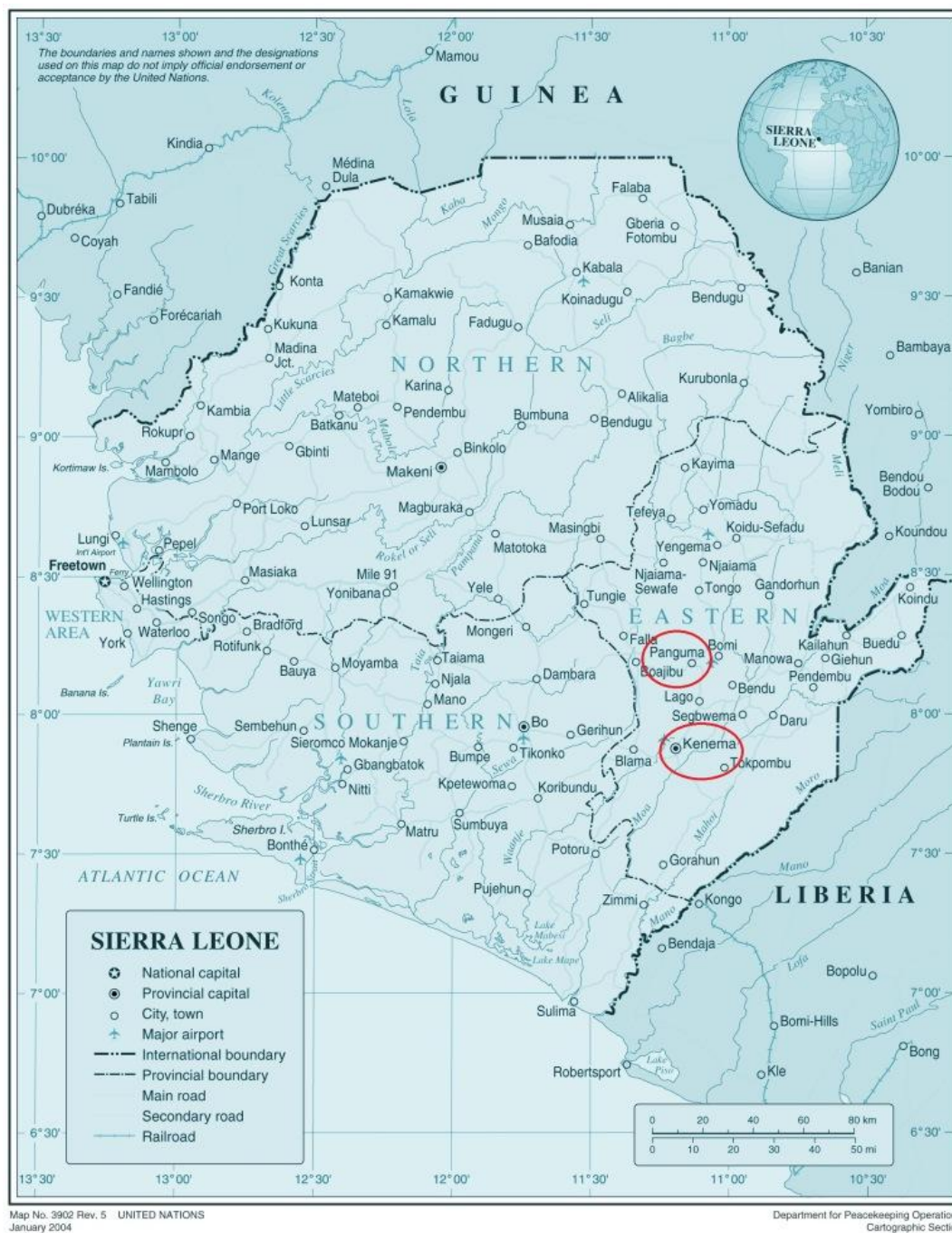
Researcher positionality is a constant issue in qualitative research like this. My accommodation at the 'Tulane' house gave me unparalleled access to the developments taking place within the laboratory at KGH but this access, as in every site, was something that I had to negotiate. How close should I get to people? How should I manage - and avoid - conflicts that arise between research subjects? Living in the same house as the Tulane researchers, and in the same room as the children of the family who put me up in my research village, meant that these were daily concerns. How I was seen, and how I interacted with people in each setting, influenced the way I interacted with my research topic - and eventually of course it will have influenced what I concluded. It was not only the relationships I made within specific contexts that mattered but the associations they carried with them outside and between these contexts mattered too; for instance, I was sometimes assumed to be a 'Tulane' researcher. I will try to describe these negotiations as I go through each setting and stage of research.

Running through all aspects of this research, including many of the questions above, is ethics. Although I had formal ethics approval (see section 3.3) this was not enough to prepare for the dilemmas which arose during the course of fieldwork and write up. I will discuss key issues in the following pages and conclude with some general comments at the end of this chapter.

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<sup>17</sup> Sometimes referred to as the Mano River Union Lassa Fever Program (MRU-LFP)

Figure 2 Map of Sierra Leone, with research site locations marked (UN, 2004)



### 3.2.3 Defining the system: selecting the case and sites

Even though qualitative research does not aim for the same generalisability of quantitative research, sampling is still an important issue and data collection sources have to be matched to the research rationale and questions. My primary unit of analysis is the diagnostic system so for the purposes of this research that is my ethnographic case. The case was selected for its intrinsic interest and capacity to learn *within* it, rather than for external generalisability (Stake, 1994). I was not seeking to test a specific theory but instead to explore an empirical question by blending aspects of the existing literature into a suitable theoretical framework. Furthermore, when it comes to health and disease, a typical case is unlikely to be found. As I outlined in chapter one, the diagnosis of Lassa fever in Sierra Leone represents a rather extreme case that has a number of points of interest. It is hard to diagnose because of its non-specific symptoms and for a long time real-time diagnosis was all but impossible because of inadequate technology and strict biosafety regulations. Yet since the virus has become a topic of international bio-political concern there has been dramatic and unprecedented investment in research. As such, there is a huge learning potential from Lassa fever diagnosis, both theoretical and empirical.

To study Lassa fever, KGH was an obvious choice. Sierra Leone has a particularly high burden of disease and KGH has the only treatment and diagnostic facility in the country. In fact it is the only dedicated Lassa fever isolation ward in the world. KGH is also the site of the MRU-LFN's most substantial diagnostic efforts, with a research project carried out by consortium of research institutions administered by Tulane University and funded by the National Institutes for Health (NIH). At KGH there would be both patients and laboratory supported diagnosis at one hospital site. Thus KGH became the anchor for my ethnography. Government health care in Sierra Leone is tiered and organised into: Peripheral Health Units (PHUs) which includes Community Health Centres (CHCs), Community Health Posts (CHPs), and Maternal and Child Health Posts (MCHPs) making up the first line of primary health care; District Hospitals provide secondary care; and Regional/National Hospitals provide tertiary care. In this system, KGH is a major regional hospital to which complicated cases are referred and after which the only option for unresolved cases is to be referred to a hospital in Freetown (if staying in Government provided healthcare). The situation is different for Lassa fever; all Lassa fever cases in Sierra Leone go to Kenema, it is the only officially sanctioned option.

To define the diagnostic system I was keen that the process of diagnosis took centre stage. I used Marcus' strategies of following the 'people' (patients) and the 'thing' (blood samples)<sup>18</sup> as they are the transient elements in the diagnostic process. I concentrated on blood *and* people because there are times when they diverge. Although the base was KGH there were parts of the system to map which were further afield. For the first 2 months of my 7 month fieldwork trip I was predominately based at KGH. I spent as much time as possible in the laboratory and on the hospital wards in order to get familiar with Lassa fever and the wider hospital and health care context. Following the pathways of patients and blood samples, I noted the procedures, people and places involved in Lassa fever diagnosis around the hospital. To explore beyond KGH I accompanied the Lassa fever outreach team on their sensitization and 'contact tracing' trips which were usually between 1-3 days long; on these trips they often investigated old and new cases so our interests in 'following people' were aligned. By joining them on these trips I became familiar with a number of villages and chiefdoms in the 'Lassa belt'. The 'Lassa belt' is an area in the Eastern region of Sierra Leone, also known as the 'hyper-endemic' zone, which is considered to be most heavily affected by Lassa fever. As the next chapter notes, the higher detection rates in this area may be a symptom of increased surveillance in them. During these trips I also visited some of the hospitals and PHUs which serve these 'hyper-endemic' communities and which refer cases on to KGH (described later); KGH is actually located outside of the 'Lassa belt'. Returning to the literature, particularly surveillance policy and strategies, enabled me to contextualise the system 'in practice' with the system 'as planned'.

I settled on doing ethnographic work in three sites: the 'Lassa Lab' at KGH; a village located in a chiefdom (Dodo chiefdom), which has seen a relatively high number of recorded Lassa cases; and the KGH wards. At this point some clarification on what I mean by 'sites' is needed, as well as an explanation of their place in the diagnostic system which is my ethnographic case. The 'sites' represent settings where aspects, or framings, of Lassa fever are enacted in various diagnostic processes, along various diagnostic pathways. These multiple processes, pathways, framings and enactments make up the diagnostic system, along with the assemblages of people, pathogens and things which they entail. Crucially, the 'sites' should *not*

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<sup>18</sup> Marcus identifies six methodological strategies: follow the people; follow the thing (i.e. a material object); follow the metaphor; follow the plot story or allegory; follow the life or biography; or follow the conflict.

be understood as the only places where diagnostic activity goes on; neither are they necessarily physically distinct locations. They are not in themselves parts of the system; they are locales where facets of the system interact. The diagnostic system, as I explain in the next chapter, is comprised of people, places, blood, technology, multiple healthcare providers, governments, universities and international organisations, to name a few; it also includes institutional cultures, policies, regulations and norms. Those elements are more aptly described as parts, facets, aspects, even components, of the system. Within this assemblage of parts, there are some more formal aspects of the system (e.g. those centralised and converging at KGH) and some more informal aspects (e.g. the un-official health providers who do not have strong links with KGH). The distinction between formal and informal should not be taken too strongly however, as I will show there is much that is informal within the formal. Nevertheless, when discussing Lassa fever specifically there is some merit in using the term formal as the drug for Lassa fever is only available in at KGH.

The selection of sites presented different challenges and opportunities. To various degrees they overlapped or diverged. Some, such as the laboratory, were more distinct; the Lassa Lab is the only laboratory diagnosing Lassa fever in Sierra Leone. The clinical and village settings however, were not unique; there are many villages and health posts which have experience of Lassa fever. To an extent, they also spill over into each other, with health providers being stationed in villages or health workers visiting rural areas. Each setting provides different opportunities for understanding linkages between parts of the diagnostic system. Being based at KGH, with the official Lassa fever laboratory and Lassa fever ward, my case was anchored in the institutionalised and formal aspects of the system. This was inevitable and deliberate because of my research interest in laboratory technology. However, I wanted to explore the unofficial aspects of the system as much as I could, to understand the way in which cases are missed, or slip out of the official KGH based system. I engaged with these aspects of the system in my ethnographic observations and interviews with local communities, particularly in my research village, to try to elucidate the range of health care options they used.

Spreading an ethnography across multiple sites gives the research additional breadth but it can be at the expense of some of traditional ethnography's depth (Marcus, 1995).

As extended periods of fieldwork were not possible in each site I had to gather data efficiently. I split my time roughly evenly between the three sites. At first I tried to do this in separate



blocks in an attempt to immerse myself in each of the very different settings. However I learnt early on that it was not always possible to divide my time so neatly when my plans to spend a week on the Lassa fever ward were scuppered; it was to be my first experience of the famed isolation ward, and still wary of it, I had pre-arranged it with the ward's head nurse. When the time came there were no patients at all, no referrals, no suspect cases and no admissions. When I was in Kenema I had to be flexible in the way that I split my time; there were times when the Lassa ward was particularly 'hot' and so I would maximise time there or vice versa if the laboratory was busy. By the time the faster laboratory tests were being introduced, from around January 2010, I had settled in to a routine which followed the rhythm of work in both places: I would accompany the doctor on ward rounds in the morning, go to the laboratory as the technicians started to run the tests (which the doctor had ordered on his rounds) and when the results were ready I would return to the wards, either the general wards or the Lassa fever ward, and stay there keeping up with general activities or a particular patient's progress. The village level research was done in distinct blocks of time, described below, because it entailed being based in a remote settlement hours from Kenema.

### **3.2.4 Laboratory**

Observing laboratory practices was relatively straightforward, understanding the framings and logics involved in them was less so. I would join the Sierra Leonean technicians, and the Tulane researchers, in the laboratory while they were preparing, running and analysing tests. There was only one 'Lassa lab' and so being at the centre of the action was not difficult, especially as routines were well established and timed. However, having stopped studying science at the age of 16, let alone having any kind of background in molecular biology, it was a steep learning curve. Though my ignorance may have been a blessing as my endless questions about what they were doing, which were all answered with incredible patience, enabled me to see the framings that were being operationalised. Why were they adding a solution to a sample at a particular time, at a particular temperature, or why were they using a particular machine to perform a certain task? If I had been familiar with what was happening I would have been blind to some of the underlying assumptions. Because of safety and quality control I did not participate in any of the assays or sample preparation. Occasionally I would help to clean up, set timers or oversee the plate washing machine. As well as the work inside the laboratory there was also activity outside of it: maintaining supplies, collecting samples from further afield such as the Liberian border, delivering results to other health units or to clinical

staff at KGH. There was also lots of waiting. Waiting for tests to run or waiting for samples to come in.

I spent a lot of time with the Sierra Leonean technicians during which we explored aspects of their work and discussed specific cases. I did not do formal interviews with them as I already had so much contact with them, often in one on one almost interview like scenarios. A concern in ethnographic research is how open people are with the researcher and how the researcher is viewed by the research participants. At KGH, both the technicians and the hospital staff were more than used to students and researchers passing through on different research projects. What was unusual about me was that I was not attached to Tulane or on a medical elective, so I fell in to a strange category. I did not encounter suspicion from the laboratory staff; the technicians were always very welcoming to me and would actively involve me in their work, calling me when samples came in and asking if I wanted to come in to the laboratory. I think it helped that I was not there in any kind of capacity that may have been experienced as judging or assessing the quality of their work; I was not there to train them and I was not another laboratory scientist who needed to use them and the laboratory equipment to run samples for any associated project. I was sanctioned to be there by their bosses, Tulane and authorities at KGH, but I had no other guise other than being there to learn about a subject on which I was clearly an amateur. It helped that sometimes, when Tulane staff would bring a new protocol or piece of equipment, that we were learning together. I think I also earned some favour and acceptance among the Mende technicians by being one of few visitors, particularly from those associated with Tulane and the laboratory, to learn some Mende and spend time in villages.

I initially considered including a site to represent the research and development (R&D) of the diagnostics, which would have included fieldwork in the US to supplement data on the field testing at KGH. However although R&D is vital for maintaining and improving the supply of diagnostics for Lassa fever, it was not strictly speaking a 'site' where negotiations over individual diagnoses took place.<sup>19</sup> Nevertheless, it was still important to trace the way R&D processes influenced routine laboratory work; fortunately the steady flow of researchers in and out of Kenema allowed me to keep up with developments and, most importantly, to see how they were implemented into diagnostic practice at the KGH site. The visits from

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<sup>19</sup> Results were debated but it was from an R&D perspective, the result was not of immediate clinical importance. However, some of these debates are relevant and are included in reports here.

researchers and field-testing of the new diagnostics gave me ample opportunity to gauge the on-going interaction between R&D and clinical diagnostics. This presents a limitation in this research, there were people and organisations involved in the development of the diagnostics who I did not meet. However as my research is on the use and implications for clinical practice this is less important. A perhaps more pressing difficulty was that not only was the research difficult to keep up with, but some of the uncertainties I saw may have been a product of the on-going research and as such will be short-lived. But another way of looking at this is that these are the uncertainties which get ironed out and forgotten, or 'black boxed'; in that sense I am looking at 'science in action' (Latour, 1987) before its closure and presentation as a finished product.

It was, therefore, important to spend time around the laboratory when Tulane researchers and students visited because each time they came they would bring new equipment and protocols with them. The core Tulane research team made three visits during my fieldwork period, each staying for different amounts of time, from a week or so to months. Their trips were always very busy, more than once depleting the energy supplied by the solar panels. Evenings were time for unwinding, reviewing the day and trying to unravel puzzles; by staying in the same house as the Tulane researchers I was able to participate in these discussions which could be very revealing about how the day's events and data were being interpreted and how it fitted into their ideas about the bigger picture. Days in the laboratory could be extremely fast paced with a number of different procedures going on at the same time. Without these evening discussions I would have missed the broader significance of much of this work.

As well as the scientific papers which presented particular perspectives on the diagnostics and the virus, the laboratory was full of the more practical documents I was so interested in. There were assay protocols, safety instructions and general laboratory standard operating procedures (SOPs), plus documents which formed part of the diagnostic process: results forms, graphs, spread sheets and the laboratory records book. The material culture of the laboratory was important too: the layout, the ELISA<sup>20</sup> plates, the colour of the wells in the ELISA plates, all of which I photographed. In none of my other settings was the instrumentation of diagnostic enactments so clear; in the standardised equipment and the

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<sup>20</sup> ELISA is shorthand for Enzyme Linked Immunosorbent Assay, the diagnostic technique of choice in the Lassa lab. The technique will be explained in detail in chapter six.

standardised instructions. Outside of the laboratory I sought other documents to compare and contextualise my observations and the evidence presented by other documents in the laboratory, for example textbooks which the researchers used and which set out the principles of ELISA testing procedures. Funding applications and project proposals which presented the rationale behind the research were instructive concerning the idealised and scientific framings of Lassa and diagnostics.

I became interested in disjunctures. Between the built environment and the patterns of use within it, between the formal and codified knowledge and protocols and what people did in practice. Narratives and frames were more easily visible when oppositions emerged: for instance, when everyone in the laboratory would be dressed in barrier clothing including wellington boots, goggles, face masks, lab coats and gloves and the engineer would walk in wearing shorts and flip flops. Oppositions were not just between formal and informal or framings and practice, but between people, different members of the Tulane research team, or between Tulane researchers and Sierra Leonean laboratory technicians. These differences were all revealing of people's perspectives and how they related to the various frames at work. It is not an underestimate to say that there were differences of opinion within the Tulane team about how to interpret the diagnostics. As time with the Tulane researchers was more limited, I conducted some interviews to get an overview of the project development and history, as well as, activities in the US. It was also a chance to compare perspectives and explore some of these disjunctures. I interviewed four Tulane 'researchers' (out of the nine Tulane-associated people whom I had contact with, some of whom were logistical staff or research assistants). My interviews were with: one doctoral student who was a laboratory scientist and heavily involved in the diagnostics project; another doctoral student researching disease and rodent ecology and helping out in the laboratory as well as using the diagnostics in their own work; and two medical doctors who were involved in the diagnostics project as well as other clinical research on Lassa fever, one replacing the other during my fieldwork period. They were all involved in different aspects of the diagnostic project and because of their different backgrounds they could reflect on a range of dimensions in diagnostics work.

### **3.2.5 Clinic**

As I have previously outlined, this part of my research was based at KGH. To explore practices and framings in a clinical context I decided that it would be beneficial to have a main site

where I could get to know, and become trusted by, the health workers there. Again, because this was a setting and a world I was unfamiliar with concentrating efforts in one setting allowed me to get in-depth data quicker than if I had moved from site to site. Thus, KGH was the main observational setting for this 'site' as it was the location of the Lassa ward and laboratory so I was guaranteed to see more 'confirmed' diagnostic activity there. Nevertheless, I did visit other settings as I will describe.

To ascertain the narratives and practices I focused on disjunctures, again looking at how what people did contrasted with what they or others reported, or what formal documents such as case definitions described. I reviewed published papers on the clinical aspects of Lassa fever and looked at MOHS policy documents. I also examined forms and documents used in clinical settings and on the Lassa fever ward including: case definitions, case notification forms, clinical data collection forms and ward logs and records. I looked at the kinds of data these forms tried to obtain and the ways they were supposed to be used, for instance as referrals. I did not use them to compile case histories because the data was frequently not sufficient, as I describe in chapter six. I did initially spend some time trying to follow cases through these documents, laboratory forms, referral forms and ward reports, but found it very difficult to track them down and the information on them limited. I came to realise that this is a feature of diagnosis in Sierra Leone. Documents which are filled out regularly have special status such as the 'Lassa Bible' a record of people tested or admitted to the Lassa ward with brief notes of symptoms, results and outcomes. A routine computerised database was being developed while I was there but most things are done in person and on paper.

The doctor in charge of Lassa fever is also responsible for some general wards (see chapter four for an overview of the hospital) and I started by shadowing him on ward rounds to get familiar with the way the hospital worked. Later I did this with the obstetrician on the maternity ward, as Lassa in pregnant women poses particularly high risk both for the women and nursing staff so it was an important domain to observe practices. As I got to know the hospital better I moved about more independently, although ward rounds remained particularly interesting not only for the updates on patients' conditions but also as a chance to see interactions between the doctors and nurses. The doctors were quite used to students following them round, from within Sierra Leone and abroad. Although my shadowing was not unusual I had the impression that when students, like me, were there the doctors took longer

to explain things. However, the longer I was there the more my presence on the rounds and wards seemed to make less difference; we moved past patients quickly and cases weren't explained to me in so much detail, but rather questions and comments were directed at the ward's nurses. I also sat in on this doctor's outpatient consultations. I would watch from a chair in the corner of the cramped 'container' (as the transformed shipping container where outpatients were examined was known). There were usually others people coming in and out throughout patient's consultations and my presence in the corner was of minimal disruption. The doctor would sometimes ask me to write the prescriptions he dictated or to check things in his medical textbooks.

I had a huge amount of access to clinical routines and to patients, which initially felt too much. I was sometimes mistaken for a doctor and I was invited to examine patients (which I refused). I sat in on some very intimate, and harrowing, moments. It goes without saying that I would not have been allowed such access in the UK healthcare context. However, the same concepts of patient privacy do not exist in Sierra Leone and I had to determine what was acceptable for myself. Trying to limit my access on the grounds that it would be considered an invasion of privacy in the UK seemed odd, especially if other people, and students, were also walking in and out of these situations. I stuck to observation only; although I was happy to check textbooks and write prescriptions as instructed I did not think it appropriate that I should start examining patients, except perhaps when the doctor insisted I felt a fever on someone. It was not that I thought I would do any harm or upset patients, but invariably patients appeared unable to refuse and it was an unnecessary coercion that was not of much benefit to my work.

On the Lassa fever ward I was aware that my presence during active care giving could be a risk not only to myself but also to the staff and patients who were already in a high pressure situation. Unless I was invited to observe specific procedures by nursing staff, for example washing and decontaminating a corpse, I refrained from straying beyond the point at which protective clothing needed to worn and only nurses should go. There was a red line painted on the floor across the ward's reception area to make this point clear, although it was faded. This 'do not cross' line was the dividing line between the open parts of the ward and the supposedly isolated parts of it where only nurses or patients should be; in practice, as later chapters show, it was more porous than the line and warning signs would suggest. My

observation of this safety line was not as detrimental to my research as it may sound because most of the diagnostic deliberations and decision making happened outside of the ward, or at its entrance. Doctors and nurses did not want to spend endless hours 'gowned up' in the tropical heat. In fact, the doctor did not always go on the ward and many times the patients were often not behind that red line themselves. One doctor joked with me that he did not need to go on the ward because the patients were all running around anyway; it certainly was not an isolation ward in the way I imagined one.

A limitation of this research was that I was based very much at the heart of the centralised diagnostic system and so lacked perspectives from PHUs and other clinical contexts. Accompanying the outreach team was a helpful way of reaching these settings and involving myself with wider aspects of diagnosis. The outreach team would make visits to particular villages, clinics and hospitals for case investigation, sensitization and training. To supplement my ethnography at KGH I went on five outreach trips and visited eight PHUs. After familiarising myself with the services in various chiefdoms through these trips, I concentrated on two PHUs in particular: one in Tongo fields (a mining town) and one in Dodo town (near my village research site). I stayed in each town for a week in total, spending time at the clinics discussing their work and Lassa fever with the staff. Another site I spent time in was Panguma hospital which is the nearest major hospital to my research village and the source of many referrals to KGH. I stayed there for a day or two on trips to and from the village, for a week in total. I was able to discuss Lassa fever with the long serving local staff there and the European doctor who was in charge of medical treatments at the hospital. At Panguma I conducted three interviews: one with the European doctor and two with senior nurses, one in charge of outpatients and the other in charge of the children's ward. These trips were important in widening my gaze past Kenema, in particular to the hospitals which are in the middle of the so-named 'hyper-endemic' Lassa fever area; they opened my eyes to the concerns of the actors who were not at the 'centre' (i.e. at KGH) of the diagnostic system, in particular how their perceptions of risk and distance were important.

The clinical setting posed considerable challenges for collecting data. It was both varied and expansive. It was near impossible to feel 'on top of' activities at KGH, let alone at other PHUs and hospitals. The flows of patients and staff were too many to follow. A few more months

spent at KGH and other clinical settings would undoubtedly have made this part of the research stronger.

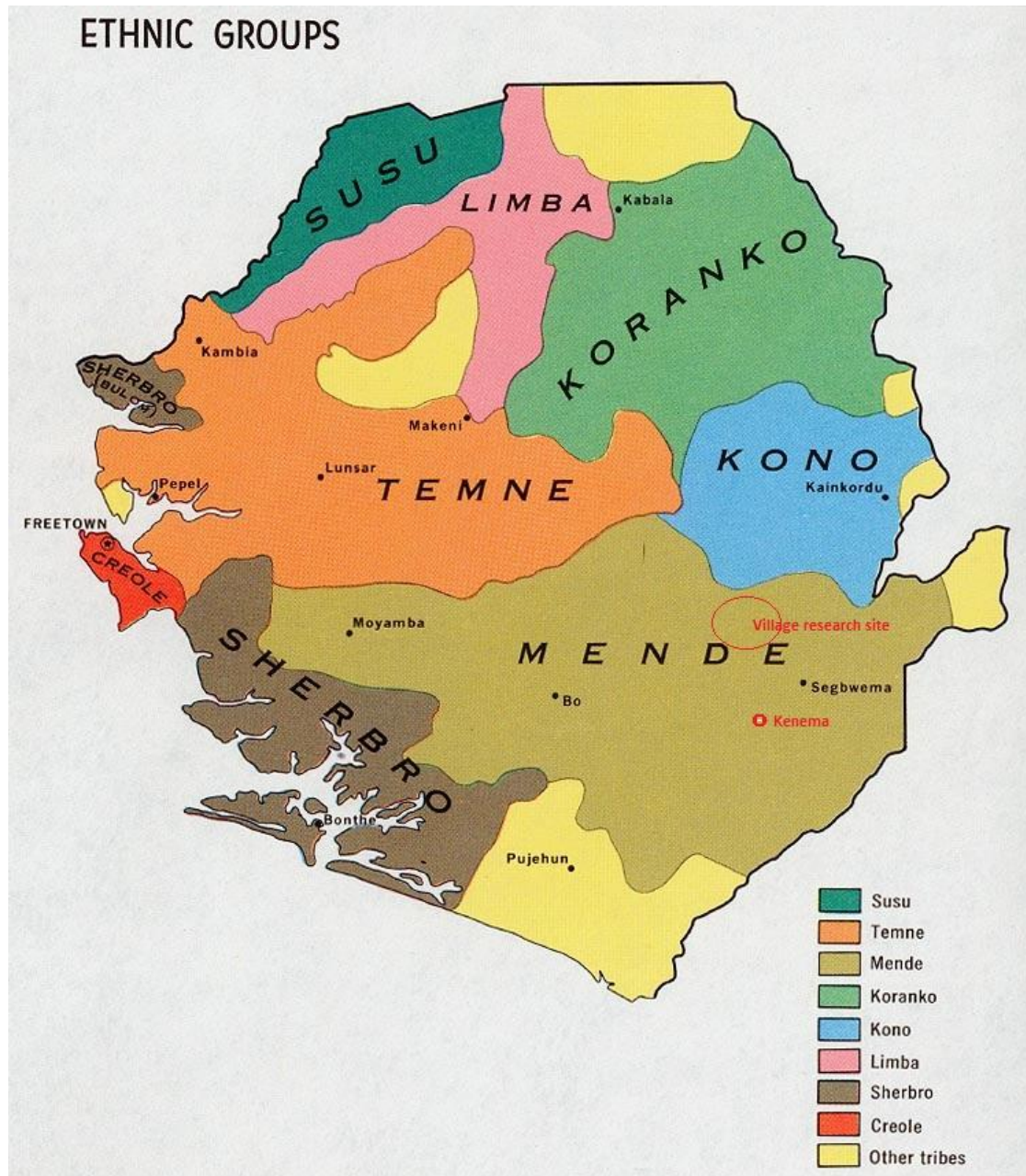
### **3.2.6 Community**

My community level data comes mainly from one village which I will refer to by the pseudonym ‘Tokenga’ (my strategy for anonymising people and places is described in section 3.3). This was the only place where I spent distinct blocks of time. There I focused on Lassa fever in the village’s wider healthcare landscape in order to determine how Lassa fever narratives and diagnostic practices were part of them. As with the clinic, I decided that the limited time I had was best spent getting to know the therapeutic landscape of one village in as much detail as possible. This was as an alternative to the increased breadth (but limited depth) which data collection across a number of villages and urban settings would have offered. As I explain, when delving into subjects like witchcraft and deaths from Lassa, it was beneficial to have built up some degree of relationship between myself and research participants. I did however make efforts to visit other villages and interview Lassa patient’s from other areas to add some generalizability to my ‘village’ findings. Tokenga is located in the Mende region of Sierra Leone. Figure 3 provides a basic map of ethnic and language groupings in Sierra Leone. Mende, a tonal language, is spoken in Mende regions. Krio, an English-based Creole originating from the area on the map marked Creole, is now widely spoken throughout Sierra Leone. In this part of my research I have made use of anthropological and ethnographic literature on Mende social life as a way of making up for the limited time I had for my ethnography. In the laboratory and around the hospital I could at least talk relatively freely with people in English, but this was not the case in Tokenga. I needed this anthropological literature to quickly get to grips with the rules and principles of this social setting.

I saved the community level part of my research for later on in my fieldwork, in March, so that I had sufficient time to learn Krio and some basic Mende. When identifying a village my main requirement was to find one with recent experience of Lassa fever, as documented in records at KGH. There were also practical considerations such as availability of water, accommodation and someone able to speak English and translate.



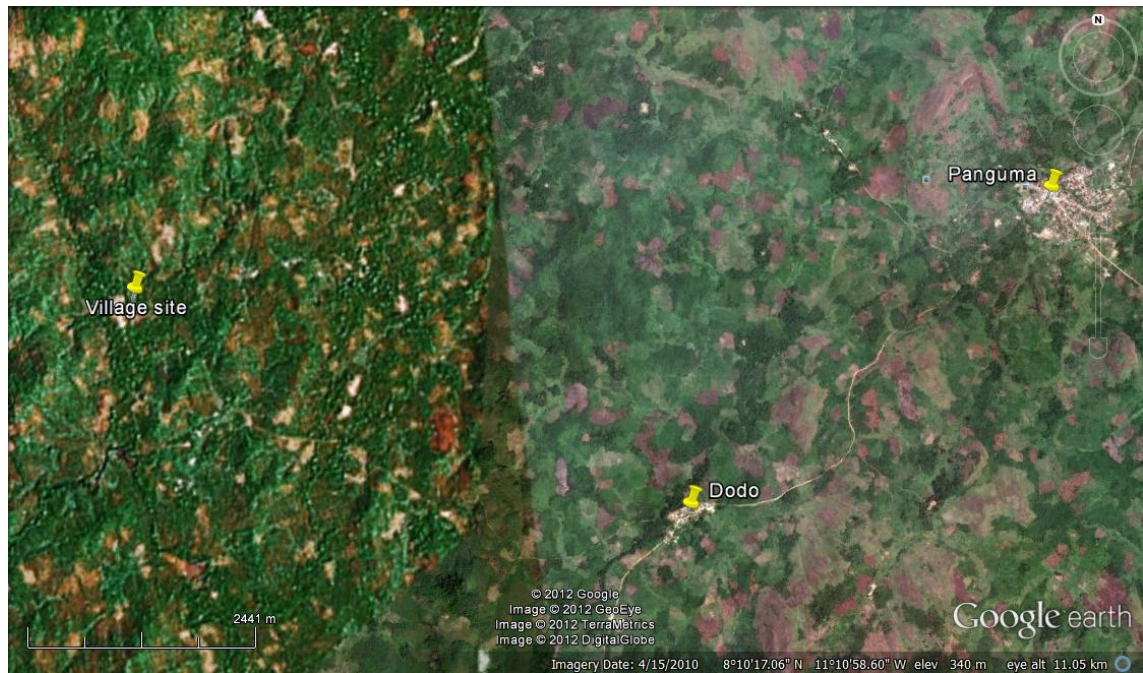
Figure 3 Ethnic and linguistic regions in Sierra Leone (CIA, 1969)



I set off for Dodo chiefdom for a preliminary scoping trip as the chiefdom had suffered a significant number Lassa fever cases from the year before and also some of the earliest ones for 2010. I had been to the chiefdom headquarters, Dodo Town, with the outreach team and had already met with the nurse there so it seemed a good place to begin. I met with the paramount chief (**ndolo maha**) and stayed with a family in Dodo Town for a week during which I visited surrounding villages, with advice and assistance from the nurse and an English

speaking teacher. Most of these villages were very small and had no water supply except streams and some were without even basic pit latrines. Although I was rarely sick, I thought it would be unwise to base myself in one of these villages as I had a limited amount of time and could not afford to lose some if I fell ill. There was one village which the nurse told me about where a young woman had recently died of Lassa. It also had a water supply, latrines and a teacher who could speak English. This may have meant the village's overall health was marginally better; however in terms of Lassa fever I came to learn that, anecdotally, Tokenga was perhaps worse than others.<sup>21</sup> As Tokenga was a three hour walk from Dodo Town (estimated to be 6 miles away) my plan was to go and stay at least one night to see how it was. I ended up staying for 4 weeks and made two subsequent trips of 10 days (May 2010 ) and 2 weeks (April 2011) totalling just under 2 months. Though this is considerably less time to spend in the village than in traditional ethnographies it must be seen in the context of a multi-sited approach. Figure 4 shows a map of the area, with Dodo Town and an approximate location for Tokenga marked on it. Panguma, which has a hospital, is also shown. The whole area is considered to be in the 'Lassa belt'.

**Figure 4 Satellite image of Panguma, Dodo Town and village research site**



<sup>21</sup> In addition, a Tulane PhD student studying rodent ecology trapped rodents in the village prior to my visit. Seroprevalence of Lassa virus was found to be high (unpublished data) amongst the host species, *Mastomys natalensis* (see chapter four).

Gaining trust and access required effort. When I first arrived in Tokenga I met with the village chief (**ta maha**), and the section chief (**pati maha**<sup>22</sup>) to explain and get approval for my research. A village meeting was called where I was introduced to ‘everyone’ and I explained what I was doing there: that I wanted to learn about life in the village and hear about their experiences with health and Lassa fever. The reception I was given was extremely welcoming. Being a **puumɔi** (white person) and a woman on my own, I was never going to fade into the background. To settle in I joined in village activities whenever possible: helping to prepare food, visiting people’s compounds and talking, preparing palm oil, going to farms and exploring with the children who followed me everywhere. I had to overcome the special status I was afforded as a white ‘stranger’ which at first meant I was not involved in everyday life: everything was done for me, I was discouraged from doing anything remotely arduous such as fetching water or even helping to help cut ‘greens’ (for instance the cassava leaf used to make a sauce in cooking) in case I cut myself. When I first arrived I was housed in the ‘best’ house in the village, a new and unoccupied house built on the edge of the village which meant I remained largely separated off from the routines of community life. I did not have long in the village and it was important that I overcame such barriers quickly. Not wanting to appear ungrateful, I asked if I could stay somewhere more integrated into the village. It was an on-going process for me to convey to people that I did want to be involved in village life and that, despite my white skin which people assumed meant I was weak, I was strong enough and willing to participate.

I moved to the household of a married couple, Vandí and Aminatta (also pseudonyms), and their children. Vandí was a teacher at the small school in the village. He spoke and read good English and could assist me with Mende translation. He was interested in my research and, having studied an ethnography of a Mende village which I brought with me, he understood my interest in social life. I could converse easily with Aminatta as she spoke Krio as well as Mende. Vandí’s family were from Tokenga originally, whereas Aminatta had only come there when she married Vandí. Both helped me enormously by acting as guides to Tokenga’s social, cultural and political life. One limitation is that I was very much aligned to this family, at least initially. However, as I had less time than is usual to carry out an ethnography, I depended on key informants a great deal and embedding myself in a family was a way to do this quickly.

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<sup>22</sup> Chiefdoms are divided into sections which contain a number of villages. After the Paramount chief the next level in the chieftaincy hierarchy is the section chief, followed by the village chief. Tokenga was a section headquarter village so it had both a section chief and a village chief living there.

Fortunately Vandi and Aminatta were forthcoming and perceptive with their explanations and introductions to aspects of Tokenga and health.

Though my initial reception had been positive there were both high expectations and suspicions to navigate throughout my stay. The expectations ranged from funding, marrying or taking people to England, to issues to do with my research for instance that I could get a PHU set up in the village or that my work would “stop the Lassa”. In terms of suspicion, women seemed to be more guarded towards me. For instance, on a women’s fishing outing (to which I had been invited) I was questioned by some women as to what I was doing there. There were also rumours amongst some of the older women that I was an investigator or a reporter; the photos which I took (or was often ordered to take) and the notes I made aroused their suspicion. On both these fronts there was little I could do except carry on and be careful about when and where I took notes or photos. I also spoke again to those present at a village meeting to reiterate my reasons for being there. I was lucky to have members of the community who would vouch for me. I think in general I was regarded as a novel curiosity. The rare times that other **puublaa** (white people, plural of **puumɔi**) came they were generally attached to non-governmental organisations (NGOs), turning up in a 4x4 and staying only few hours. The fact that I stayed with a family, walked hours to get there, and visited other villages seemed to please people; but while my efforts may have been appreciated I think it also meant that I was seen as a bit of an anomaly who did not fit any of the usual categories associated with strangers (i.e. NGO worker, Lebanese<sup>23</sup> or increasingly, Chinese) which could have been a reason for some of the suspicion.

Language was a limiting factor. I could not speak Mende well and although my Krio was passable it was not spoken by everyone in Tokenga. I had a Practical Introduction to Mende (Innes, 1971) and a Mende-English Dictionary (Innes, 1969) to assist me and so was able to relate to key words and concepts, such as **kɔle** (fever) and **hale** (medicine, secret society, and in a broad sense an object with power to achieve certain ends with supernatural means). Men seemed to speak Krio more than women, perhaps a result of having travelled out of the village more, so I was able to converse with them more naturally. There were also a handful of men who could speak English and seemed to enjoy having an opportunity to speak it with me. I was conscious not to spend too much time only with men, because (aside from the gossip it

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<sup>23</sup> There is a relatively large Lebanese community in Sierra Leone who are very active in the business and commercial sectors.



would create) women's views would be underrepresented in my research. Over time I developed good relationships with women, spending time with them in their gardens<sup>24</sup>, farms, and kitchens. My relationship with Aminatta was also very important; we struck up a good friendship and she provided me a woman's perspective, took me under her wing and introduced me to other women which helped overcome some of the initial suspicion. I found that by interviewing local health practitioners and heads of households (see below), many of whom were women, I got to know key female members of the community in the process. I spent more time with the younger generation of women, helping to look after children or being ridiculed for my lack of hair braiding skills.

Given that Lassa fever starts with non-specific symptoms to understand how it fitted in to rural framings of disease and healthcare practices my ethnographic focus could not be Lassa on its own. I had to engage with the broader therapeutic landscape in Tokenga. However, health and sickness was not something easily observed. Although it was common to see aspects of medicinal practice, such as discarded packets of western medicine or amulets worn around children's waists and necks, the patterns behind these visuals were less obvious. I conducted informal conversations with as many people as I could. I found that asking about the medicines was a good way in to understanding health, for example asking people to point out leaves and barks as we walked or to go through the western medicines (i.e. a drug inventory) sold on the petty trade stall in the village. People would also come to talk to me and show me their ailments as they knew I was interested, sometimes in the hope I would have medicine for them. In doing so I had to navigate other social codes: I took a while to learn what kinds of things I could discuss openly, initially I could be hesitant to ask questions, worried about being rude or insensitive when there was no need whereas at other times I was more direct than I should have been. My questions about common illnesses, discreet or not, did get people discussing local health matters with me and while not comprehensive enough to be a full survey, it helped illuminate how people talked about sickness, and how diseases were labelled and dealt with. As my relationships strengthened with particular people, I was able to ask about more sensitive issues, such as witchcraft or specific cases of Lassa in the village.

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<sup>24</sup> 'Gardens' were often separate to a family's main rice farm. They were primarily the domain of women.

I conducted a number of key informant interviews: first, I did interviews with the male and female heads of Tokenga's five<sup>25</sup> households. These focused on health and sickness in general, but I did ask specifically about Lassa too. My plan to interview men and women separately did not work out and often other family members would join. It was difficult to control the environment for all of these interviews. However, the household interviews were largely exploratory and were also designed as a way of introducing me to the different households, which they did very well. Once I had settled in I conducted interviews with the actors whom I had identified as being most involved in healthcare and other relevant aspects of society (n=6) these were: the visiting drug peddler, the unofficial 'nurse/pharmaceutical medicine dispenser, two elderly female herbalists, the 'witch doctor'<sup>26</sup> and the Imam. Unfortunately this did not include the traditional birth attendants (TBAs) who were important given so many of the recent cases had been pregnant women. There were two TBAs in the village and though I was able to discuss Lassa fever and the recent cases with them briefly, I did not get to interview them fully. One TBA was away for a good deal of my stay and the other, the main TBA, was either very busy or ill when the time came to talk. As several of the arrangements I had made with her were broken I suspect she may have been unwilling to talk with me. As with all my interactions and interviews, there were social codes including secret societies and secret knowledge which I had to be sensitive to. The TBAs will also have been officials in the female secret society which may have had something to do with why I was not able to speak with the main TBA.<sup>27</sup>

I was mostly very cautious, perhaps more than I needed to be. However, I did get it obviously wrong on one occasion, with the man known as the 'witchdoctor'. I was on good terms with this man and many people had told me about his abilities; thus I thought I was on safe ground to ask fairly direct questions in an interview. My tactlessness was clearly not appreciated and he closed up on the subject entirely. Thus a limitation of this thesis is that much of the more

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<sup>25</sup> As the chapter will explain, Mende villages are often organised around long-established settler households. A household would traditionally have farmed together and would have been large in number. This explains why Tokenga, a village of approximately 500 people, is described as having only five households.

<sup>26</sup> This is someone who can 'fight witch'. Healing specialists are described in chapter four and five.

<sup>27</sup> In Sierra Leone, and much of West Africa, the initiation of adolescents into male and female sodalities is common. In the region where this fieldwork was conducted the male society was known as the Poro and the female society as the Sande. The initiations and knowledge obtained from it are to be kept secret from the uninitiated. The societies are hierarchical, and initiates are differentiated by further layers of society knowledge and skill. Childbirth is a strictly Sande domain and traditional midwives are Sande officials (Ferme, 2001, MacCormack, 1984). The societies shall be described in more detail in chapter five.

secretive aspects of Mende healing remain a mystery. Probing to this level of practice would have required a far more extensive ethnography than is possible in a multi-sited approach.

I also did 6 patient history interviews of victims of Lassa fever in Tokenga: two with survivors still living in the village (both men in their 40s, one contracted Lassa fever in 1997 the other reported falling sick a few years after the war had ended, in approximately 2005); and four with the kin of villagers who had died. Three of these had been pregnant women (one in 2007 and two in 2009) and the fourth was a man who fell sick at the end of the war (in 2002). Recall bias could be an issue for all of these interviews, particularly for the less recent cases. Interviews with kin provided rich information as they had been closely involved in the patient's care. In fact their memories are likely to be more reliable and complete than the patients themselves who often report being unconscious or in very disturbed states. This was a common problem I encountered in the patient interviews described below.

A potential limitation in this setting is that I relied heavily on a few people as 'gatekeepers'. The family I stayed with in particular introduced me to many aspects of *their* therapeutic world. Inevitably this was the trade off with a relatively short period of ethnographic research in a village where I could not speak the main language: I had to rely on some key informants. I did ensure that these key informants were not all from the same family, and I built up relationships with people in other parts of the village and from other households. Based on this, I am confident that I accessed the key principles and actors of Tokenga's therapeutic landscape, although I cannot claim to be able to describe all of Tokenga's inhabitant's perspectives fully by any means.

### **3.2.7 The wider system**

In recognition that a lot of diagnostic work went on in other health settings or villages outside of Kenema, particularly in the 'Lassa belt' I went on the aforementioned outreach trips. In addition, during my stay in Tokenga I visited surrounding villages, although many of these were smaller and tended to use Tokenga's informal health providers. There was also the time I spent in Tongo Fields which is a mining town with a notoriously high Lassa fever incidence, and Dodo town.

In urban settings it was much harder to get to grips with the less centralised and official aspects of the diagnostic system. In the towns of Bo and Kenema for instance there were countless other providers competing with the government's provision, including: pharmacies, laboratories, Chinese health centres, NGO clinics or small private hospitals, as well as the more traditional healers or and 'drug peddlers' and 'pepper doctors'.<sup>28</sup> Inevitably I missed out on the dynamics of much of this. To make up for this and in an effort to describe health seeking behaviours more generally I conducted interviews with ex-Lassa fever patients. In these I explored their experiences and perspectives on Lassa fever including a detailed account of their symptom and treatment history. In total I interviewed 23 people: 21 confirmed positive Lassa fever cases and 2 suspect cases which proved negative. Sampling was purposeful, interviewees were selected from ward and laboratory records of people tested for Lassa fever since 2006. My original selection criteria had been: cases from 2008 onwards (to reduce recall bias), over 18 years old and I had aimed to include an even balance of male and female. With the 2008 cut off I found it difficult to track down enough patients. When recruiting interviewees ground to a halt at 16 interviews I extended the date of onset to 2006. Sadly, there is of course a 'survivor bias' too. Given that late presentation is associated with high fatality this may mean that the evidence I have represents people who sought care sooner. I stopped these interviews at 23 when the views and experiences I was hearing began to form a (broadly) coherent picture. These interviews drew on the perspectives of people living in a range of environments and I spent a good deal of time clinging on to the back of motorbikes while journeying around Kenema district's mud tracks, villages and police checkpoints to reach them. As well as people from rural subsistence farming communities like Tokenga, these interviews included those living in urban centres like Kenema, ex-refugee camps, established mining communities such as Tongo Fields as well as smaller mining-heavy villages.

Finally I conducted interviews with WHO officials (n=2, one in Freetown and one in Geneva) and a senior official (n=1) in the MOHS's Directorate of Disease Prevention and Control. These contributed valuable alternative institutional perspectives on Lassa fever and the diagnostics. Although I was able to have informal discussions with people in the MOHS, ideally I would have conducted more interviews. Indeed I did have further interviews set up at the end of my last stint of fieldwork but they were cancelled and unfortunately I did not have time to

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<sup>28</sup> Both pejorative terms used to describe untrained people who deal in and treat people with, primarily Western, medicine.



rearrange them. It is shame that I do not have more data on the official perspectives within Government or the WHO. Unfortunately there is considerable tension between the partners involved in the MRU-LFN and the WHO is an increasingly distant partner. Getting ‘on the record’ interviews, and drawing a line between personal and institutional politics proved tricky. As a result, to an extent, the data presented here is de-politicised because disagreements and different perspectives could not be freely or fully explored. Equally, there are many clinical settings which are not included in my data collection. Observation of practice in additional peripheral or non-Government providers of health services across Sierra Leone would undoubtedly have strengthened the work, but it would have involved many more months of fieldwork to do well.

### **3.2.8 Data processing**

As I described in the section on data collection, when I was in the field I made jottings throughout the day which I then wrote up into more extended notes. I tried to do this on the same day for depth and accuracy. Sharing a house with Tulane researchers in Kenema was a rich source of data as they would continue analysing, interpreting and discussing the day’s events in the laboratory over dinner and into the night; finding time to get it all written up was a challenge. However in Tokenga, once the sun had gone down I had plenty of time and space to sit with a torch and write. I wrote these notes up by hand or electronically depending on where I was and whether power was available, which it often was not. I ended up with 8 notebooks as well as folders of word processed notes. In addition, I had 50 interview write ups. Many interviews involved numerous people, were translated from Mende or conducted in Krio. Given the number of people and languages involved, these were difficult to transcribe word for word, but they were written up in as much detail as possible with extended passages and quotes. Table 1 summarises the interview data. On top of this were the documents and photos I had collected.

As I moved from site to site throughout the day my original jottings and field notes featured a mix of the day’s events from across the settings. Even though I was not consciously starting to analyse, data processing started in the field; it was evident in decisions over which activities to follow and how what I chose to write about developed. Field notes should be descriptive rather than attempts at analysis but to separate the two is misleading as the process is more one of ‘analysis-in-description’ (Emerson et al., 1995). Initially I described everything, sights

and sounds as well as all activity, but subconsciously I became more selective as time went on and concentrated on themes I was finding interesting. I also began to re-organise my notes when I was in the field, so for the word processed field notes I was able to copy and paste them in to distinct files for each site: 'LAB', 'CLINIC' and 'VILLAGE'. 'RESEARCH' was merged in to 'LAB' once back home. My hand written notes had to wait until I was back in the UK where I scanned them all and then cut and paste the various pages in to the distinct files. These were ordered chronologically. Throughout fieldwork and once back home I kept files for thoughts and analytical ideas as well as some miscellaneous notes which did not fit into the distinct site notes, for instance those covering outreach trips.

**Table 1 Interview summary**

<b>Interview Category</b>	<b>Total (no. electronically recorded)</b>
Lassa histories Tokenga	6 (6)
Lassa histories other (positive)	21 (19)
Lassa histories other (negative)	2 (1)
Tokenga's healing practitioners	6 (4)
Tokenga household general health interview	5 (5)
Tulane	4 (3)
Clinical (Panguma)	3 (3)
WHO/MOHS	3 (1)
Total	50 (42)

As I had this combination of typed, hand written and, later, scanned notes I decided not to use qualitative research software for my analysis. I had a lot of handwritten notes which I thought would take an unnecessarily long time to word process. Instead, I printed out all my scanned and typed field notes along with interview write ups and documents I had collected, and worked on coding them by hand. In coding I tried to pursue member's categories and meanings (Emerson et al., 1995) particularly those concerning disease, fever, medicine, healthcare options, to see how these were used and mapped on to what people actually did in diagnostic activity.

My aim was to identify framings, practices and narratives in each setting. Practices were relatively straightforward. There were codified procedures used in the laboratory and some explicit rules surrounding medicine use. Observations of people performing routines also revealed tacit knowledge and differences in stipulated rules and actual practice. Accounts of sickness also revealed broad approaches to therapeutic practice. In my coding of

observational data I also used artefact, technique and regime as labels to explore the use and practice of technology in a way which suited my conceptual framework. I also used Stirling's dimensions of incertitude matrix (figure 1) which I presented in the previous chapter to review my data. To identify framings I concentrated on a simple formula of questions, probing the who, what, where, when and how's contained in my data which helped to illuminate values, problems, boundaries, expectations and uncertainties in the way people described Lassa fever and health. For instance was Lassa fever an old or new disease? Who would it effect and why? Identifying narratives, and making links between framings and narratives, was more of a leap. Some aspects of narratives were easy, as there was fictional and non-fictional popular literature which spelled out particular stories very clearly. Others I have to piece together: for instance, in the next chapter I identify a 'global threat' narrative about Lassa fever. As well as the horror stories in the press and various books, this came from documents such as the WHO's International Health Regulations (IHR) and the Integrated Disease Surveillance and Response (IDSR) which was developed by the WHO and adapted by the MOHS in Sierra Leone. When reading the IHR the 'who' was clearly not confined to West Africans. The 'what' was a break down in social and economic order precipitated by disease outbreak, hence the 'global threat' narrative. Piecing these narratives together had to be done by thematically arranging framings used by particular actors into a coherent storyline. During this process I began writing extended analytical notes, exploring relationships within my data, which became the basis for chapters. Writing my empirical chapters was an important continuation of the analytical process; the process of analysis, for me, kept going up until the final drafts. The whole process involved induction and deduction, re-interpretations and new juxtapositions which made new aspects of data seem significant right until the end.

### **3.3 Ethics**

This work was approved after going through University of Sussex's ethics procedures. It was also approved by Sierra Leone's Ethics and Scientific Review Committee. In all of my ethnographic site locations I sought, and gained, appropriate consent and approval: from KGH hospital administration, the Kenema District Medical Officer, Panguma hospital administration, Tulane University and the traditional authorities in Dodo Chieftdom and Tokenga village. As well as official approval I sought individual permission from the key health care workers I would be working with, in particular the doctor responsible for Lassa fever and the head nurse on the Lassa fever ward. All interviewees were provided with

written or verbal information on my research and I made it clear that participation was not obligatory. As such, I collected verbal 'informed consent' from all interviewees and institutions involved.

In reality both the ethics reviews and the collection of 'informed consent' can only go so far in preparing for and dealing with the ethical issues which arise during fieldwork. Each site presented different challenges and I have indicated some of these issues in the preceding pages. Avoiding negative consequences of being involved in my research was paramount. I have outlined how my actions in the field dealt with this but once back in the UK and writing new challenges arose. The anonymity I had promised in interviews was difficult for some sources. The Lassa fever research world is very small and Kenema even smaller thus my reporting of activities there could be identifiable. This was more of a problem than in the village where people and places can be easily anonymised. However, the clinic and laboratory are also in a position to be more understanding of what being involved with my research could entail and this kind of implication. I did make my intentions to write up what I was seeing and being told clear at every step. With them 'informed consent' was more meaningful than it was in Tokenga and other communities. Also, some of the developments I discuss in this research have been the subject of published scientific papers by the researchers themselves already so my work does not pose any heightened risk of 'exposure' for them.

With regards to anonymity, I have referred to well-known places or organisations, such as Kenema, Tulane or Panguma, by their real names as it would be confusing not to; I use a pseudonym, Tokenga, for my village site. I also use pseudonyms for people in the village (such as the family I stayed with or the people I interviewed) whose stories I tell in detail. None of these people indicated that they were concerned about their anonymity but I am working on the principle that it is best to be cautious. For interviews with patients, Tulane or clinical staff I distinguish them by category, for example: 'Tulane laboratory scientist'. As discussed some of these categories may be revealing as the Lassa fever world is small. All interviews are referenced by a footnote containing their pseudonym or category along with a place and date. Appendix 1 has a record of all the interviews including details of how they are referenced in the text.

The level of consent, motivation, expectation and effort that was involved or required of people when partaking in my research varied. What people would have to put in and what they might get out was always a fine balance. Although I had access to patient's records, in an effort to satisfy the kind of privacy and ethics requirements in UK healthcare research I had enrolled members of the nursing staff and outreach team who already had contact with these patients to approach interviewees first, using my sampling criteria. However, sometimes I found patients to be under the impression that they were required to talk with me, so when explaining why I wanted to interview them, I made it very clear that they did not have to talk to me to avoid coercion. After interviewing patients, but without their prior knowledge, I offered them a small cash gift for their time because I was conscious that this research was not going to be directly beneficial to them but that, in very poor communities, even a small amount of extra cash would be. Elsewhere, in the end, I tried to simply treat everyone one with respect, and to be aware of what was expected or appropriate for the context. My worries about getting too close I realised were largely irrelevant. Of course I would get close to people and that was the point. I could not give people everything they may have hoped, or stopped Lassa, but I could be a respectful 'stranger' who would keep up connections forged in the field. In Tokenga I was able to assist with one of their aspirations. The community had been campaigning to get a nurse instated in their village but had been told that they first needed to build an appropriate building to house the nurse and the clinic. On my return trip in 2011 I was able to give donations from family and friends to use for building this clinic.<sup>29</sup>

Feedback to participants cannot be symmetrical. I have no current plans to return to Tokenga and the feasibility of sending a hard copy of my thesis to them is limited (many people are unable to read and there is no postal service in that area). I was able to relay my initial findings to villagers in Tokenga on the return trip I made in 2011 and little has changed since then. After examination, I will email copies to participants from Tulane, KGH and where possible other interviewees.

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<sup>29</sup> The villagers had also been told that there was a freeze on opening new clinics in Kenema district because it had a higher number of clinics than other districts; they remained hopeful because they were told that a nurse could be officially registered in an existing clinic but in practice be based in their village – in a building they would have to provide independently. Although I was told the same story by a district official in Kenema, I was not convinced that a nurse would be sent. In that case, rather than having built a building for nothing it was suggested that the building could be used for the school which was in poor repair (and has since fallen down). It is my understanding that the building is currently being used as a school, but the campaign for a nurse is still on-going.

### **3.4 Conclusion**

In this chapter I have made the case that context specific processes are central to the use and impact of new and old diagnostics. To understand some of these context-specific processes I have conducted a multi-sited ethnographic study of Lassa fever diagnosis. I chose three sites, a village, KGH and the Lassa laboratory, to explore aspects and intersections within the diagnostic system. I have detailed how, with some limitations concerning time and language, I was able to collect interview and observational data from each of these settings. I also described how I have organised and analysed this data. In the next chapter I will present the framings and narratives about Lassa fever and diagnosis which I have identified and I will introduce the research sites in more detail.

## 4 System Context: narratives of emergence and response

I start this chapter with some background on Lassa fever in Sierra Leone. Although brief, this provides context to the policy narratives which have developed around the disease and which are the focus of this chapter.<sup>30</sup> Three prominent narratives about Lassa fever can be identified. They each put a different slant on the virus's emergence and control by framing the risks, origins and scope of the disease in different ways. As outlined in chapter two, by framing I refer to partial and differential interpretations of the world and its contents (Jasanoff, 2005, Schon and Rein, 1994). Diseases are understood as complex systems, involve interlocking social, technical, cultural, political, economic, ecological and biological dynamics, which can be framed differently (Leach et al., 2010). By narratives I refer to the piecing together of certain framings into persuasive, but ultimately unbalanced, stories (Roe, 1994, Wald, 2008) which find traction in particular institutions or communities. In the first narrative Lassa fever is articulated as a global threat which could escape traditional boundaries and wreak havoc internationally; in the second it is an endemic problem confined to a few countries in West Africa and linked to risky local practices; in the third it is a neglected disease, overlooked by global health actors. These narrative storylines have different beginnings but they converge towards the same ending: that the problems Lassa fever presents can be effectively addressed by science and technology. Once these narratives have been mapped out I describe how their convergence around the promise of science and technology has resulted in a push for improved diagnostics and standardised protocols for the surveillance, referral and treatment of Lassa fever. I then describe how this kind of approach is taking shape in Sierra Leone by examining formal protocols and policy documents. A version of the diagnostic system as it was planned and envisaged as working is outlined. However, I suggest that the reliance on diagnostics, protocols and algorithms reveals a narrow and optimistic view of disease control and, as later chapters in this thesis demonstrate, an idealised view of how such technologies work in practice. As an entry point for exploring these issues, I point to some aspects of Lassa fever which have been overlooked and which are not adequately represented in the formalised conceptualisations of the diagnostic system. These are the longer term dynamics of Lassa fever and Lassa fever as part of everyday practice. I then introduce the health care context in more detail and conclude this chapter by introducing the sites in which I have

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<sup>30</sup> For an up to date comprehensive review see Bausch et al. (forthcoming, 2013)

chosen to explore these alternative framings and practices within the diagnostic system: a village, Kenema Government Hospital (KGH) and the Lassa laboratory.

## 4.1 Disease dynamics

The following background information is gleaned from scientific and policy literature and so it represents a particular, inherently biomedical, view of the disease. A quick foray into the scientific literature on Lassa fever shows that there are more questions than there are answers and that this sense of the unknown feeds into some of the narratives which are identified in this chapter. In later chapters the perspectives of those living and working close to the disease are explored as a means of adding to, and contextualising, this biomedical view.

Lassa fever is a zoonotic<sup>31</sup> disease caused by the Lassa virus, a member of the *Arenaviridae* family of viruses (Ogbu et al., 2007). It can cause a viral haemorrhagic fever in humans. Lassa fever was first identified in 1969 after missionary nurses working in the town of Lassa, Nigeria, became infected (Frame et al., 1970), although it is likely that the virus and disease had been around for some time before that (Monath, 1975). After the 1969 Nigerian outbreak, the reservoir host for Lassa virus was found to be the rodent *Mastomys natalensis*, identified during a subsequent outbreak in Tongo and Panguma (both are near my village research site), Sierra Leone, in 1972 (Monath et al., 1974). Exact transmission routes are unclear but evidence suggests the Lassa virus is transmitted from its rodent host to humans through contact with rodent bodily fluids, either through direct (e.g. from butchering of rodents) (Ter Meulen et al., 1996) or indirect (e.g. urine contaminated food or water) (Walker et al., 1975) pathways. The virus can then be passed from human to human by contact with infected bodily fluid (blood, vomit, urine, semen) making nosocomial outbreaks (e.g. in a health setting) common (Carey et al., 1972, Monath et al., 1973). There is some limited evidence of aerosol transmission, though it appears this is not a major transmission route (Borio et al., 2002, Carey et al., 1972, Stephenson et al., 1984).

The effect of infection with Lassa virus appears to vary considerably in humans with some people experiencing mild or no symptoms while others experience severe and fatal effects including haemorrhaging, multi-organ failure and shock (Khan et al., 2008, McCormick et al., 1987a). The reasons behind disparities in disease severity and the proportion of symptomatic

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<sup>31</sup> Zoonotic disease are those which have an animal host from which it transfers to cause disease in humans.

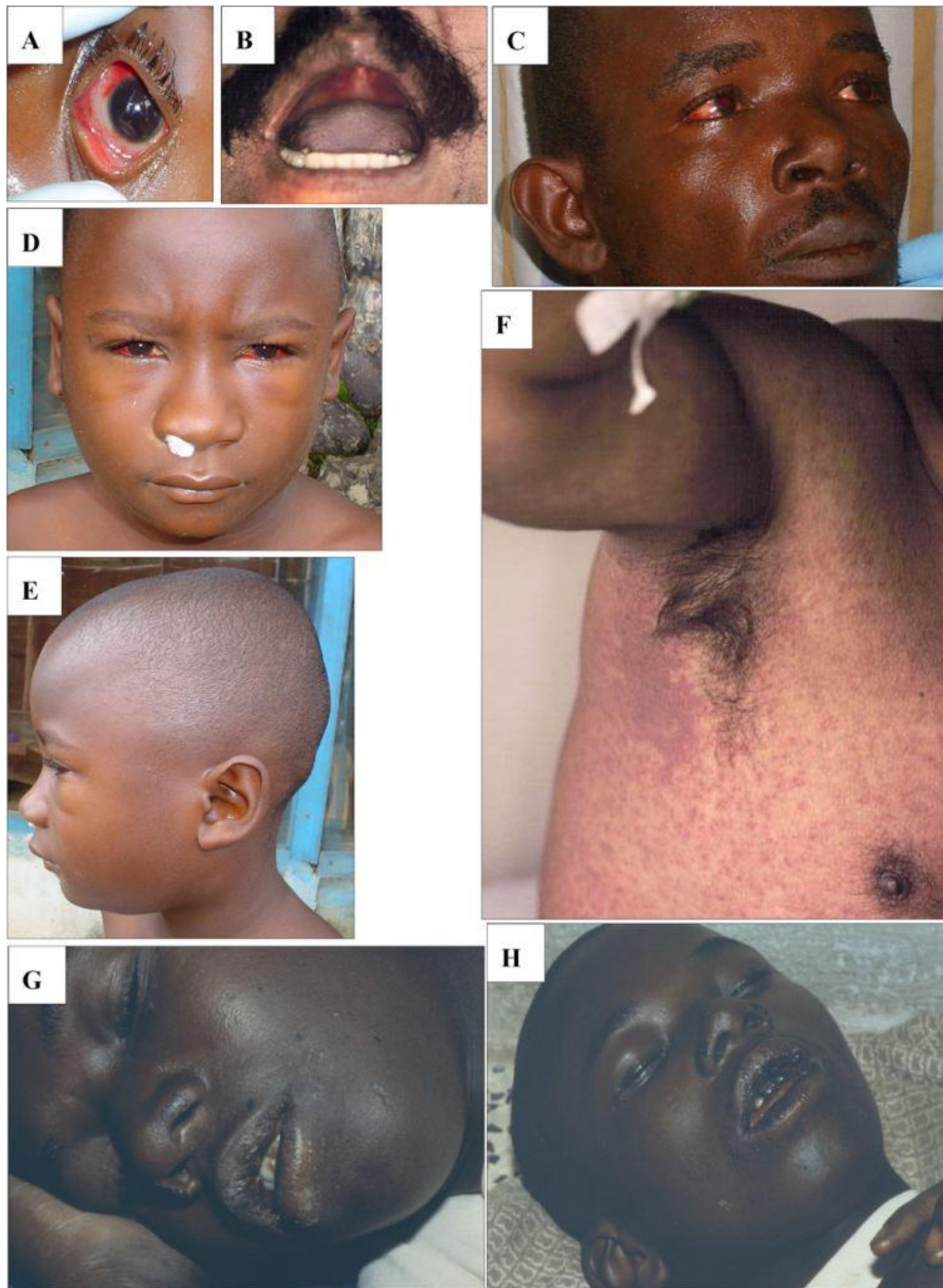


to asymptomatic cases are not known; differences may be to do with dose of infection, co-morbid conditions, genetics (Khan et al., 2008), misclassification or virulence of the virus strain (Bausch et al., forthcoming, 2014). Incubation period for Lassa fever is approximately 10 days (but can range between 3 and 21 days) and in symptomatic clinical cases the disease is recorded as progressing as follows:

- Early symptoms: gradual onset of intermittent fever, headache, anorexia, malaise and weakness.
- Later symptoms: sore throat, retrosternal pain, tinnitus, conjunctival infection, nausea and vomiting, myalgia (muscle pain), lumbosacral pain (in lower spine), abdominal pain, tenderness, diarrhoea, occasionally a dry cough. In fair-skinned patients a reddish flat (maculopapular) rash is sometimes visible on the thorax, face and arms.
- Severe late stage symptoms: after 4-7 days some patients suffer severe vascular instability which can manifest as edema (swelling) of the face and neck, bleeding, hypotension (low blood pressure), shock and proteinuria (an excess of serum proteins in the urine). Bleeding occurs in approximately 20% of clinical cases. Patients' central nervous system can also be affected, resulting in disorientation, convulsions and coma. Figure 5 shows photographs of Lassa fever symptoms.
- Death: death may occur 10-20 days after the onset of symptoms. Poor prognosis is associated with those severe symptoms listed above and also with high levels of virus. The case fatality rate for hospitalised cases ranges from 15% to 50% (figures from unpublished data from KGH, see Moses et al., 2012), 20% has been suggested as a good estimate for hospital cases, and under 5% for all infections including mild and asymptomatic ones. Pregnant women are especially vulnerable. Maternal and foetal mortality rate have been reported as approximately 90% in the third trimester (though this has not been a consistent finding).
- Sensorineural (from the inner ear) deafness has been reported in survivors. This has been reported as affecting as many as 25% of patients, but this increasingly looks like an overestimate

(For more details see Bausch et al., 2001, Bausch et al., forthcoming, 2014, Branco et al., 2011a, Cummins, 1990, Frame et al., 1970, Khan et al., 2008, McCormick et al., 1987a, Price et al., 1988)

**Figure 5 Pictures of Lassa fever symptoms (from Khan et al., 2008)**



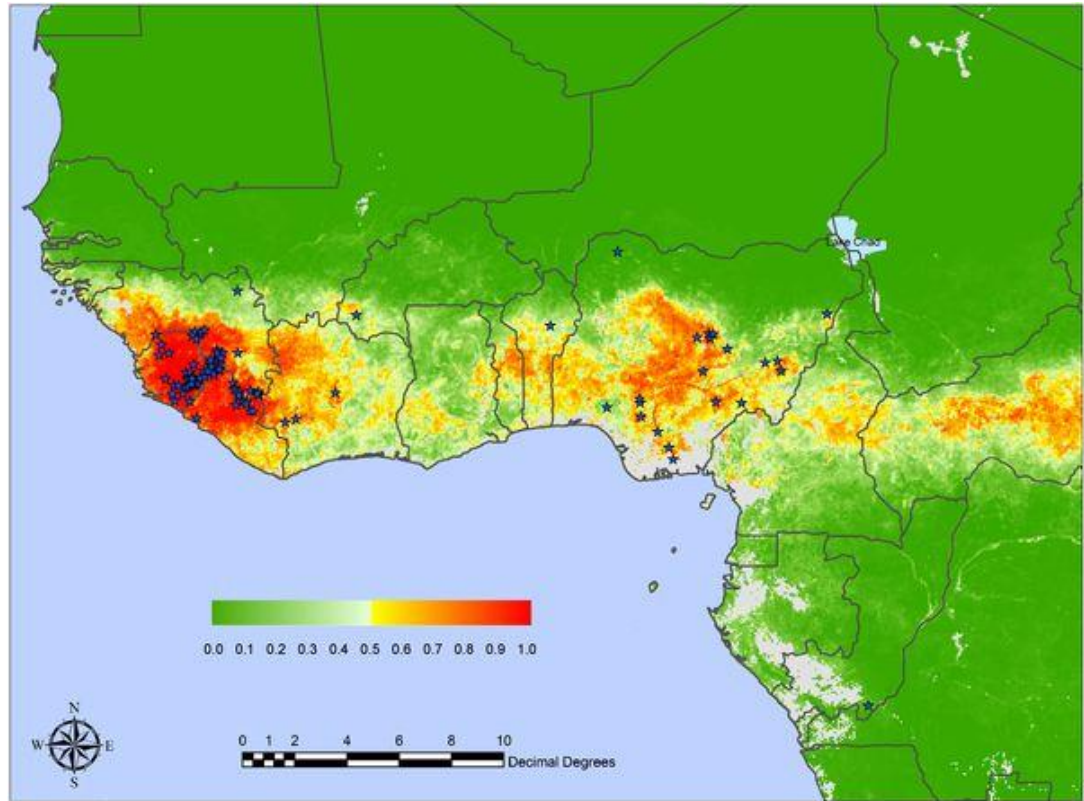
Treatment for symptomatic Lassa fever is with the broad spectrum anti-viral Ribavirin which is administered intravenously for 10 days. The effectiveness of Ribavirin is greater if administered early: it has been shown to decrease mortality (from 55 to 5%, though that is with dubious diagnostics) if begun in the first 6 days of illness (McCormick et al., 1986). This

makes early diagnosis critical, however due to the initial non-specificity of Lassa fever symptoms, this is often difficult to achieve. Ribavirin can have some unpleasant temporary side effects (such as nausea and vomiting), but they are not usually severe or long lasting. However, it can cause anaemia (Bausch et al., forthcoming, 2014, Khan et al., 2008) which although not normally serious, in the Sierra Leonean context it can be, as levels of anaemia are often already high and treatment is not as available as it is elsewhere. Ribavirin has also been demonstrated to cause foetal loss and malformation in laboratory animals which would usually rule it out as a treatment for pregnant women. However due to the high maternal and foetal mortality rates for pregnant women infected with Lassa fever the advice has been to treat anyway (Bausch et al., forthcoming, 2014). For these reasons, in addition to possible psychological trauma associated with isolating and treating patients for Lassa fever, decisions over administering Ribavirin can be complicated, especially when the diagnosis is not certain.

There are four recognised strains of Lassa virus, three in Nigeria and one in Sierra Leone, Guinea and Liberia; on top of which there is considerable genetic heterogeneity within strains (Bowen et al., 2000). The burden and spread of Lassa fever in West Africa has long been a puzzle: the disease appears concentrated in Sierra Leone, Guinea, Liberia and Nigeria but not (or much less) in the countries surrounding and in between them. Estimated annual infections range from 100,000-300,000 with as many as 5,000 deaths (McCormick et al., 1987b) to as many as 3 million new infections a year, and 67,000 deaths (Richmond and Baglole, 2003). Fichet-Calvet and Rogers (2009) compiled evidence of human and rodent Lassa fever between 1952 and 2007, combined it with climatological factors (rainfall, vegetation, temperature), to produce a risk map of Lassa distribution in West Africa. Their maps (one of which is shown in figure 6) suggest a much wider distribution of Lassa fever (up to 80% of Sierra Leone) than is commonly reported or recorded. There are doubts over the quality of the diagnostics, research methods or surveillance coverage, thus the picture of Lassa fever in West Africa remains unclear (Bausch et al., forthcoming, 2014). In 2011 Nigeria experienced what appeared to be a particularly extensive epidemic of Lassa fever: by the 6th July 2012, a total of 933 suspected Lassa fever cases were reported with 147 laboratory confirmed and 93 deaths. Out of the 26 states in Nigeria, 23 reported cases, many for the first time (ProMED, 2012, WHO, 2012b). How to interpret these developments cuts to the core of the above debates; questions have been raised about whether the observed epidemic in Nigeria is an expansion of Lassa fever or whether it is a sign that improved diagnostics are in place. It was

suggested at a workshop I attended that the cases in Nigeria could be an “epidemic of detection”.<sup>32</sup>

**Figure 6 Risk map of Lassa fever (Fichet-Calvet and Rogers, 2009)**



*Mastomys natalensis*, is found throughout Sub-Saharan Africa but as yet Lassa virus has not been identified in *Mastomys* rodents found outside of West Africa (Ogbu et al., 2007). The reasons for this are unknown. The rodents are prolific breeders but it is unclear if the virus passes between them vertically or horizontally. *M. natalensis* has been described as ‘peridomestic’ (Moses et al., 2012). They are burrowing rodents and are found in close association with humans, often in homes and agriculturally cultivated fields close to rural villages. They have been trapped in high numbers (up to 50% relative to other species) in homes (McCormick et al., 1987b). Housing construction can influence abundance and dirt floors have been associated with higher *M. natalensis* presence (Bonner et al., 2007). It is likely that dirt floors provide opportunities for burrowing. The relationship(s) between LASV, rodent

<sup>32</sup> The workshop was for the Dynamic Drivers of Disease in Africa Consortium (DDDAC) and was held at the Institute of Development Studies in June 2012. Lassa fever is one of the consortium’s case studies.

populations, habitat, and biodiversity across village-farm-bush landscapes is an area of on-going research (Moses et al., 2012).

More cases of Lassa fever are reported in the dry season. Seasonal fluctuations may be due to the stability of the virus in different temperatures and humidity linked to rainfall, and ebbs and flows in infected rodent populations (Fichet-Calvet et al., 2007, Fichet-Calvet and Rogers, 2009). Factors such as access to roads during the rains, agricultural duties and lack of funds in conjunction with harvesting patterns have been suggested (Bausch et al., forthcoming, 2014) but these are unexplored hypotheses. Moreover they relate to accessing care, not exposure. Consumption of rodents is suggested as a risk factor for infection (Ter Meulen et al., 1996). There has been almost no research looking at socio-economic or ecological trends which may drive exposure, for instance seasonal agricultural practices. There are important questions about changes to farming and grain storage practices in communities, perhaps linked to longer term shifts in social and agricultural traditions (some of which are described in chapter five). Other questions concern the impact of the civil war and socio-economic influences such as trends towards large scale agriculture or mining activity.

As the above discussion makes clear, there are a lot of unanswered questions about Lassa fever. It is clearly endemic to some areas but what is the scale of the problem in West Africa? Does it pose expanded epidemic threats, and to whom? Are local cultural practices at the root of transmission or might longer term socioeconomic and environmental changes be driving it? Issues of diagnosis run through the entire disease system. By their design diagnostic technologies represent particular framings of Lassa fever but they can also become part of framings and narrative. This is exemplified in the recent article which asked whether Lassa was really an emerging disease or if it was a case of “emerging diagnoses” (Gire et al., 2012).

## **4.2 Narratives of Lassa fever**

The three narratives described here present alternate views of Lassa fever’s emergence and approaches to its control. They are not, however, mutually exclusive, indeed they co-exist and overlap. At different times they are promoted by scientists, and organisations such as the Centers for Disease Control and Prevention (CDC) or the World Health Organisation (WHO). They are evident in scientific papers and policy documents produced by these organisations. For some of these narratives it is possible to make links between framings of the disease and

strategic attempts to level resources. However, these narratives are not confined to health and science policy circles, as I will try to indicate, they are also widespread in popular perceptions.

#### **4.2.1 An emerging global threat**

This narrative casts Lassa fever in a similar light to other much hyped VHF's like Marburg or Ebola despite some important differences between them. The story goes they have emerged recently and usually in Africa, but now have the potential to threaten large populations on a global scale. The risks of a newly emerged disease such as Lassa fever are increased by the trappings of modern life, with air travel and globalisation meaning we are increasingly connected. This narrative calls for responses to these increased threats which are based on extraordinary measures and rely on technologies to protect (usually rich and so previously well protected) populations. The global threat narrative is evident in the policy discourse of Northern Governments and International Organisations involved in the governance of global health. It is found in WHO policy documents such as the International Health Regulations (IHRs), in biosafety classifications, and in US biodefense funding priorities.

An outbreak narrative (Wald, 2008) is pursued: at first mysterious infections beginning in distant lands but moving to Northern populations, making use of modern day transmission routes such as planes or deliberate acts of terrorism, to cause economic costs and break down in social order. This was basically the plot of the 2011 Hollywood film 'Contagion'. Risks are framed as international, transcending normal geographical boundaries. They are also economic. The threats are great because there is no vaccine for Lassa fever, and treatment and diagnostics are not widespread and readily available. This perspective has been institutionalised by Lassa fever's inclusion on the WHO list of 'priority epidemic prone' diseases which in certain circumstances merit notification under the IHRs (MOHS, 2008). The staff in Geneva who are responsible for overseeing the WHO's work on Lassa fever are based in the Global Alert and Response (GAR) programme which is responsible for assisting member states to develop national capacity for epidemic preparedness. Epidemic preparedness involves implementing the IHRs, strengthening biosecurity and developing standardized responses to epidemic prone diseases. As well as carrying the weight of some of the more draconian aspects of the IHRs, Lassa fever is classified as a biosafety level 4 (BSL-4) pathogen. This requires samples containing the virus to be kept in high security environments to avoid any such outbreaks. Level 4, the highest biosafety level, "is used for the diagnosis of exotic

agents that pose a high risk of life-threatening disease, which may be transmitted by the aerosol route and for which there is no vaccine or therapy” (CDC, 2012c). After reviewing records of ‘imported cases’ (i.e. cases exported from West African endemic regions to anywhere else worldwide) a recent article noted “LASV is arguably the most prevalent Biosafety Level four agent and a prominent threat to human health worldwide” (Sogoba et al., 2012, p43).

Despite an initially relaxed approach to working with Lassa or similar pathogens when they were first discovered (Fuller, 1974), biosafety has become more of a concern. Although not legally binding, biosafety norms are now institutionally embedded and have significant impact on where, and by whom, Lassa fever can be handled. One side effect is that this makes research much harder to carry out in the places where the disease affects people the most. High containment facilities are few and far between in places like Sierra Leone. The framing of Lassa virus as a pathogen of international concern, necessitating high levels of control, opens up disjunctures between the local conditions of the disease and the global ‘potential’ ones. A further disjuncture can be seen in the ‘securitization’ (Elbe, 2010) of Lassa fever which reached a height after the 9/11 terrorist attacks in 2001. Lassa virus was assessed for its possible use as a bioterrorist agent (Borio et al., 2002) and is now categorised as a ‘Category A agent’. Category A is the highest risk level (of three) in the CDC’s classification of ‘select agents’ with potential use in bioterrorism on account of their ability to spread easily and to cause major public health impacts, including high mortality (CDC, 2012a).<sup>33</sup> As such, Lassa virus has clearly been framed as a US national security threat which has opened up new, but limited in important respects, research funding possibilities which I explore in chapter 5. The hybrid global threat-security narrative has also been applied within Sierra Leone but referring to UN peacekeepers (Ter Meulen et al., 2001).

With Lassa fever there seems also to be an accompanying sub-story of brave Westerners tackling dangerous diseases in exotic places, for instance one article described Tulane’s Kenema operations as a “U.S. anti-terror outpost” (Akam, 2011). While this article was felt by some Tulane scientists to be inaccurate and unhelpful, other scientists involved in Lassa fever research over the years have played on this narrative themselves. Two early CDC researchers build the hype with their book “Level 4: virus hunters of the CDC” (McCormick et al., 1999).

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<sup>33</sup> Other category A agents are: Anthrax, Botulism, Plague, Smallpox, Tularemia, Viral haemorrhagic fevers, which includes Lassa along with others like Ebola, Marburg and Machupo.

Another was a young North American doctor who came to work at the Kenema Lassa fever ward for a few months, writing a book with the excruciating title “The Lassa Ward: one man’s fight against one of the world’s deadliest diseases” (Donaldson, 2009). This is especially inappropriate as he had worked with Dr Aniru Conteh who, by all accounts would have been far more deserving of that title, having devoted 25 years of his life to caring for patients on the Lassa ward and who died in 2004 from Lassa fever after a needle-stick injury (Bausch et al., 2004).

Overall, the core dynamics in this global threat narrative are to do with flow of pathogens and interlocking modern conditions such as geopolitics, mobile people, and in the IHR the economic costs of disruption. The framing of Lassa virus as a highly infectious pathogen with an international reach invites responses based on high security, high containment and extraordinary policy interventions, all of which are based on the ability to detect the virus rapidly and accurately. In the following sections I show how this has meant that the development of biotechnology-based countermeasures has been prioritised.

#### **4.2.2 An endemic disease caused by risky local practices**

The second narrative emphasises the endemic West African aspects of the disease which contrasts with the global threat narrative. In this narrative Lassa fever is the result of a toxic mix of local traditions and the failure of development, the combination of which poses persistent threats to populations in an apparently miserable and disease ridden part of the world. As with the first narrative, transmission routes are important but in this telling the mechanics are local and related to certain ‘African’ conditions (i.e. overcrowding, poor hygiene at homes and hospitals) and cultural practices (i.e. traditional funerals, eating rodents), which are perceived to be the key drivers of disease. Agency and blame are attributed narrowly onto people’s behaviour as opposed to broader socio-economic dynamics. Consequently, prevention is focused on knowledge deficit and behaviour change models.

The underlying framing of Lassa fever is of a disease with a local scope rather than an international one. It locates the risks factors associated with Lassa fever to be confined to practices and conditions in West Africa, or more specifically to the conventional endemic and ‘hyper-endemic’ zones within Nigeria, Sierra Leone, Guinea and Liberia. The limited number of cases exported out of these regions (29 in total) is evidence of the localised nature of risk



(Sogoba et al., 2012). Within these endemic regions, there is expectation and acceptance of some degree of morbidity. The response is to build surveillance systems to monitor it. In Sierra Leone, the spatial variations in incidence which are underscored by notions of endemic and hyper-endemic areas have justified *responsive* surveillance activities in those areas. An 'outreach team' operates out of KGH, responding to confirmed cases by tracing their contacts. These surveillance activities work by defining and then covering areas where it is usual to expect Lassa fever. Yet ideas of prevalence in these areas may be an artefact of the increased surveillance in those areas. Nevertheless, distinctions based on these divisions between normal and unusual have important consequences: the International Health Regulation's 'decision instrument' asks, for a subset of diseases including Lassa fever, whether a case or cluster of cases is "unusual or unexpected" (WHO, 2005). Clearly, there is a degree of tolerance of Lassa fever in this framing. The PHUs in Eastern Sierra Leone still have old health promotion posters (see figure 7), from when non-governmental organisations were involved in Lassa activities, advising of the best strategies to minimise the risk of infection.

**Figure 7 Lassa fever health promotion poster**



The scientific literature has some possible explanations for the problem of Lassa in these regions. These are focused on exposure to the rodent host. However, scholars have pointed out the specific pathogen based transmission routes can easily acquire moral and cultural 'textures' (Rosenberg, 2002, Treichler, 1999). In this way local traditions and cultures are often blamed. One paper identified the following practices as problematic in Nigeria: "rat meat as a source of protein"; "traditional autopsy"; "forceful ingestion of water used in bathing a dead husband, by a widow suspected to be involved in his death"; and "corrupt practices by staple food producers which involve drying garri (cassava flour) in the open air" (Inegbenebor et al., 2010 p54).

In Sierra Leone there has been some sensationalisation of the consumption of rats. A cluster of cases in 2011 was rumoured (inaccurately) in the press as being linked to a woman running a "rat meat restaurant" (Bausch, 2010). Poor hygiene is blamed, for example Nigeria's health minister was quoted as saying: "The spread of the recent scourge of Lassa fever in a number of communities in different parts of the country was as a result of poor personal hygiene" (Okafor, 2012). Even the breakdown of sanitation since colonialism has been blamed in the Nigerian press (Joseph, 2011). In the scientific literature 'poor housing quality', 'rodent infestation', 'poor external hygiene' (Bonner et al., 2007) and the sanitation of communities (Yalley-Ogunro et al., 1984) were assessed and found to be associated with rodent presence and of Lassa virus prevalence.

Accordingly, understandings of Lassa susceptibility on the narrow terms of rat consumption or poor personal and community hygiene mean that accompanying health promotion activities are narrow. In a top-down approach to public health, both the CDC and WHO suggest rodent control as the main prevention method. From the WHO the message is:

*"Prevention of Lassa fever in the community centers on promoting good "community hygiene" to discourage rodents from entering homes. Effective measures include storing grain and other foodstuffs in rodent-proof containers, disposing of garbage far from the home, maintaining clean households and keeping cats. Because Mastomys are so abundant in endemic areas, it is not possible to completely eliminate them from the environment" (WHO, 2012a).*

Advice from the CDC is similar:

*"Putting food away in rodent-proof containers and keeping the home clean help to discourage rodents from entering homes. Using these rodents as a food source is not recommended. Trapping in and around homes can help reduce rodent populations. However, the wide*

*distribution of Mastomys in Africa makes complete control of this rodent reservoir impractical” (CDC, 2012b).*

The fact that both admit that complete rodent control is unfeasible is telling in itself (although figure 8 shows keeping a cat can be effective). The disease prevention recommendations effectively individualise the risk of infection and responsibility for avoiding Lassa fever. However, truly effective rodent control is likely to require a community effort, if some households do not implement rodent control, or the rubbish tip is not moved further from the houses, then rodents will continue to be attracted to a village. Furthermore, what these recommendations do not address is that there may be external factors influencing rodent populations nearby which communities cannot control such as commercial farming or diamond mining. Aside from behaviour change, the response strategy in this narrative hinges on local surveillance and prompt diagnosis. As before, this approach to disease control hinges on technology and protocols which can monitor, and hopefully contain, the disease in areas where it is expected. It also relies on an individual’s assumed agency to protect themselves and seek treatment appropriately if sick.

**Figure 8 Cat eating a captured rodent, probably not *M. natalensis***



### 4.2.3 A neglected zoonotic disease ready for a scientific solution

This last narrative about Lassa fever has emerged more recently. It blends a critical assessment of the global politics of disease, namely that diseases which affect poorer countries in the South are neglected as they do not affect populations in the North who control most resources, with the perception that if investments are made in particular technologies then such diseases can be quickly subjugated. As such it follows a logic which has proved successful in securing funding and action on neglected tropical diseases (NTD) elsewhere (Allen and Parker, 2011), although there are some key differences as I point out below.

The story line in this narrative is that despite the hype that surrounds Lassa fever and other VHF, Lassa fever has actually been the subject of little research, particularly in relation to treatment (Khan et al., 2008) and there have been almost no public health or prevention interventions. Indeed, it has been described as an “unheralded problem” (Birmingham and Kenyon, 2001) and the “poster child of neglected diseases” (Donaldson, 2009). The continued but overlooked scourge of Lassa fever is a popular theme in the press especially when an outbreak occurs. Within Sierra Leone, the blame is put at the Government’s feet. After the death of Dr Conteh one journalist wrote:

*“Would it not have been timely and appropriate for the Minister of Health for instance to cry out loud for the world to hear that heavily indebted poor country Sierra Leone also has Lassa Fever which is killing her children with reckless abandon? Would it not have been wise for some smart parliamentarians to capture the world's attention that while HIV/AIDS takes years to sentence somebody to death, the Lassa Fever virus is ruthlessly doing so in just few weeks? Or is it that Lassa fever does not matter? Or are we waiting for more people to die?”* (Momodu, 2004, no page).

This narrative finds evidence from the patchy history of Lassa fever operations in Sierra Leone. After the 1972 outbreaks in Sierra Leone, the CDC set up research stations in Segbwema, Kenema and Panguma (shown in figure 9). The main treatment program was based in Segbwema at the Nixon Memorial mission hospital (Bausch et al., 2004, McCormick et al., 1999). In 1991, due to the outbreak of war which spilled over the Liberian border not far from Segbwema, Lassa activities moved from Segbwema to Kenema where they remain, despite it being outside of the hyper-endemic ‘Lassa belt’. However, due to civil instability the CDC programme pulled out of Sierra Leone in 1993, and it was not until 1996, in the wake of a steep rise in Lassa cases, that the British aid organisation Merlin took the reins by providing



limited public health and treatment but not laboratory support (Khan et al., 2008). Merlin departed in 2004 and for a period there was no dedicated Lassa fever programme. This history is one of dependency on external actors who are liable to exit when priorities change, or when circumstance such as war make work too difficult

**Figure 9 The hospital at Panguma**



As with other NTDs, this narrative has promoted technological solutions. But what is particular about Lassa fever is that the neglect is now being framed largely in terms of lack of research, and the discourse about poverty which has been persuasive elsewhere is less visible (Allen and Parker, 2011, Parker et al., 2008). Lack of basic research, due to long term programmes being stymied by war and instability, means that not enough progress has been made with diagnostics, drugs and vaccines (Khan et al., 2008). Here the three narratives converge around a scientific approach to disease control which hinges on establishing reliable diagnostics. In particular, the convergence with the global threat narrative means that resources can be made available to address the neglect. As I will now describe, the potential

biosecurity threat posed by Lassa fever has meant that particular actors have come to control the disease control agenda by being able to leverage resources most effectively.

In 2004, heavy Lassa outbreaks drew renewed attention. With stability seemingly returned to Sierra Leone and Liberia, international partners came to together in recognition of the need to direct resources towards Lassa fever. The Mano River Union Lassa Fever Network (MRU-LFN) was formed including Mano River Union (MRU) country governments<sup>34</sup>, WHO, Tulane University, the United Nations, the United States' Office of Foreign Disaster Assistance (OFDA) and the US Army Medical Research Institute of Infectious Diseases (USAMRIID) (Khan et al., 2008). The WHO's BioRisk Reduction for Dangerous Pathogens team, part of the Department of Epidemic and Pandemic Alert and Response coordinated the network and Tulane University were, and still are, the main implementing partner. The network was formed to enhance laboratory diagnostics and to develop national and regional disease control strategies, primarily for Lassa fever but also for other infectious diseases. Local disease burden was an important factor but as the list of stakeholders makes clear, the concern with Lassa fever was not simply about health in West Africa. The 'global threat' narrative and category A status gives it a leverage which other neglected diseases do not have. Yet those extra resources come on certain conditions. Techno-scientific approaches to disease control are favoured in biosecurity paradigms, where the need to develop 'counter threats' is paramount (Vogel, 2008b, Vogel, 2008a). The actors and funding sources, described more in chapter six, diagnose a lack of technology to be the problem and promote lab-based research to be the solution.

Once narrowly problematised as a lack of effective biotechnology, what matters most within this narrative are the biomedical mechanisms that will become the target of the control efforts. Understanding these mechanisms provides the roadmap for reducing the risks posed by Lassa: either by stopping infections (e.g. vaccines) or limiting deaths from infections (e.g. rapid, reliable diagnostics that enable fast treatment). In the vacuum of technology there is also a vacuum of certainty. The subtext is that improved diagnostics will reduce this uncertainty and pave the way for science and wide ranging capacity building (Khan et al., 2008). As chapter six shall explore, much of the work in the laboratory is influenced by these ideas, and the global threat narrative has proved very useful in terms of securing research

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<sup>34</sup> Sierra Leone, Liberia and Guinea

funding for diagnostics. Significantly, some of the Tulane team reported that Lassa was actually seen as well funded and organisations which would usually fund neglected diseases were not interested. The problem, they suggested, was that the funding for Lassa fever only covered laboratory research which fitted with the security agendas of funders and nothing was being spent on wider health promotion. In that sense the socio-economic dynamics which mean West African populations are vulnerable to Lassa fever were still neglected.

In summary, the three narratives about Lassa fever that I have identified above, converge into a narrative of diagnostic revolution like the one identified in chapter two. Lassa fever is presented as controllable through science. The narrative is one of moving from ignorance to risk. The first step in a scientific approach to controlling the disease is establishing diagnostics which will produce reliable knowledge and make treatment evidence based. Out of this will come wider capacity development, but what is meant by capacity remains vague. As following sections indicate, there has been some disagreement about how capacity can and should be developed.

#### **4.2.4 The Lassa fever diagnostic system: an official version**

Here I shall set out the diagnostic system as it is envisaged in the healthcare policy (and scientific) literature. As I describe this version of the system I highlight how certain dynamics within it have been framed, as a point of departure for subsequent chapters where I explore practice in different contexts within the system. Below, I trace how this formal depiction of the diagnostic system is part and parcel of the technological fix narratives in which diagnostics are envisaged as the cornerstone of rational health care, effective surveillance, national and international disease control, and, increasingly of wider capacity building projects. This version of the diagnostic system situates Lassa fever firmly in the grip of institutions of global health governance. The procedures and regulations described in the documents examined here represent an idealised version of how infectious disease control and surveillance should work. As later chapters show, they leave out much of the complexity of practice and experiential knowledge that a broader survey of the diagnostic system suggests is important.

The Sierra Leonean Ministry of Health and Sanitation (MOHS) adopted the WHO's Integrated Disease Surveillance and Response<sup>35</sup> (IDSR) which gives instructions on dealing with 'Priority Diseases' which includes Lassa fever. The June 2008 IDSR manual for Sierra Leone reads:

*"The general overall objective of the IDSR strategy is to provide a rational basis for decision-making and implementing public health interventions that are efficacious in responding to priority communicable and non-communicable diseases". (MOHS, 2008, p3)*

It goes on to explain that the International Health Regulations (IHR) are to be implemented through the IDSR, and explains their relevance to each other:

*"The successful implementation of the IHR requires the proper functioning of core surveillance, risk assessment and response capacities at country level. In Sierra Leone, IHR will be implemented within the context of the Integrated Disease Surveillance and Response (IDSR) strategy. Through IDSR Sierra Leone is developing capacities for surveillance, laboratory confirmation, notification and response to outbreak. This infrastructure could be applied for IHR implementation. On the other hand, the legal and policy backing of IHR and the additional resources that may be mobilized for supporting its implementation could be used to build national core capacities thus consolidating IDSR implementation". (p4)*

This framework advises the promotion of simplified case definitions in communities and peripheral health units to assist in disease notification and referral. As such the case definitions are a critical first step in effective surveillance systems. Table 2 shows the simplified definitions for Lassa fever and viral haemorrhagic fevers (VHFs).

Cases identified as suspect using the case definitions must then be confirmed by a laboratory test. The IDSR manual specifies that this can be with Polymerase Chain Reaction (PCR) or Enzyme Linked Immunosorbent Assay (ELISA)<sup>36</sup>, noting that it will "depend on standards established by the lassa lab (sic) in Kenema" (MOHS, 2008, p38). As I will describe in chapter five, the standard practice is that Lassa fever can be diagnosed by the detection of antibodies or antigen (Bausch et al., 2000) and the favoured technique in Kenema is an ELISA. Once confirmed, a number of actions should then follow: the case should be isolated according to infection control guidelines and treated with Ribavirin by staff using full personal protective

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<sup>35</sup> IDSR was developed by WHO African region as a cross-cutting way of health system strengthening and global surveillance

<sup>36</sup> These are laboratory diagnostic techniques, details of which will be provided in chapter six.



equipment (PPE).<sup>37</sup> Contacts should be traced and the health authorities notified. Kenema Government Hospital, as the site of the Lassa laboratory and ward is at the centre of the formal diagnostic system: it is the only place in Sierra Leone (and many of the surrounding countries) where Lassa fever can be laboratory confirmed and treated with Ribavirin.

**Table 2 Case definitions for VHF and Lassa fever used in the IDSR (MOHS, 2008)**

Simplified community definition for a VHF	Any person who has an unexplained illness with fever and bleeding or who died after an unexplained severe illness with fever and bleeding (p28)
Simplified clinical definition for reporting a VHF to district health authorities	Any person with severe illness, fever and at least one of the following signs: bloody stools, vomiting blood, or unexplained bleeding from gums, nose, vagina, skin or eyes” (p26)
Clinical case definition for Lassa fever	Any person in or travelling from an endemic area for Lassa fever with fever >38°C less than 3 weeks duration not responding to at least 48 hours of appropriate anti-malarial and anti-biotic treatment, typically with chest pain, vomiting, sore throat, and muscle aches” (p179)

There is a hierarchy of evidence and flow of information in this version of the system: disease reports and case definitions must be reported upwards and then confirmed by a laboratory, after which the diagnostic case is considered closed. This formulation of the diagnostic system puts the laboratory at the centre of disease control and healthcare. It paints a linear flow of people and information from communities up to regional hospitals, via the laboratory, and on to governments and WHO representatives. The model of Lassa fever is biomedical, in a particularly ideal type (Rosenberg, 2002) mode: the disease is characterised as identifiable on the basis of some key symptoms which become increasingly clear as the disease progresses. The problems with the system are framed as being to do with inadequate information systems and limited diagnostic capacity, as flagged up in the National Health Sector Strategic Plan 2010-2015. The health strategy states the Government’s intention to improve these areas (amongst others), and in doing so to establish building blocks to the provision of ‘rational’

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<sup>37</sup> The WHO (2008) recommends that patients should be isolated (from at least a 15m distance) and all entrants to the isolation area should use PPE. Infection control precautions include: avoiding unprotected direct contact with blood and body fluids; perform hand hygiene before and after direct patient care and after removal of PPE; disposing of/de-contaminating PPE after contact; assign specific staff to patients and limit their other work and movements; limit used of needles; if needles are used they should never be reused or recapped; and make dedicated disposal boxes for ‘sharps’ such as needles and scalpels available at point of care. PPE for VHF include: gloves (non-sterile examination gloves or surgical gloves); a gown to cover clothing and exposed skin (and a waterproof apron if gown is not impermeable); facial protection in form of a medical mask and eye protection (eye visor or goggles) or a face shield; and closed, resistant shoes (e.g. boots). These are from the WHO’s guidelines on the control of filovirus (Ebola, Marburg) haemorrhagic fever, but they are also recommended for Lassa fever.

healthcare (MOHS, 2009). In that vein, plans were made (supported by the CDC and WHO) for a National Reference Laboratory and a National Laboratory Strategic Plan and Policy were developed in 2010 (MOHS, 2010a, MOHS, 2010b). Likewise, for the international partners behind the MRU-LFN the shoring up of laboratory capacity was an obvious first step in improving surveillance and disease control:

*“The cornerstone of the MRU LFN is enhancement of laboratory capacity. The emphasis on the laboratory was a conscious decision taking into account the very non-specific clinical presentation of Lassa fever that continually undermines efforts to establish surveillance and control programs”* (Khan et al., 2008).

This call for enhanced laboratory capacity as a response to the non-specific nature of Lassa fever symptoms is evidence of the superior value attached to laboratory results by these institutions. It also gives a glimpse of tensions between ways of defining Lassa; in this example between clinical and laboratory definitions of the virus. It is expected that enhanced laboratory capacity would then provide the basis not only for better surveillance, but for wider capacity development in Sierra Leone and within global public health security (Khan et al., 2008). Figure 10 shows the Lassa Laboratory at KGH. Those in the WHO’s GAR programme, Geneva, have discussed plans to make the Lassa Laboratory a ‘centre of excellence’ to strengthen diagnostic capacity in the region and deal with disquiet that Lassa fever is getting disproportionate attention and resources.<sup>38</sup> Taking these developments into account the diagnostic system, and the Mano River Union Lassa Fever Project, might be viewed as part of a broader project to shore up regional relationships which have historically been very difficult.

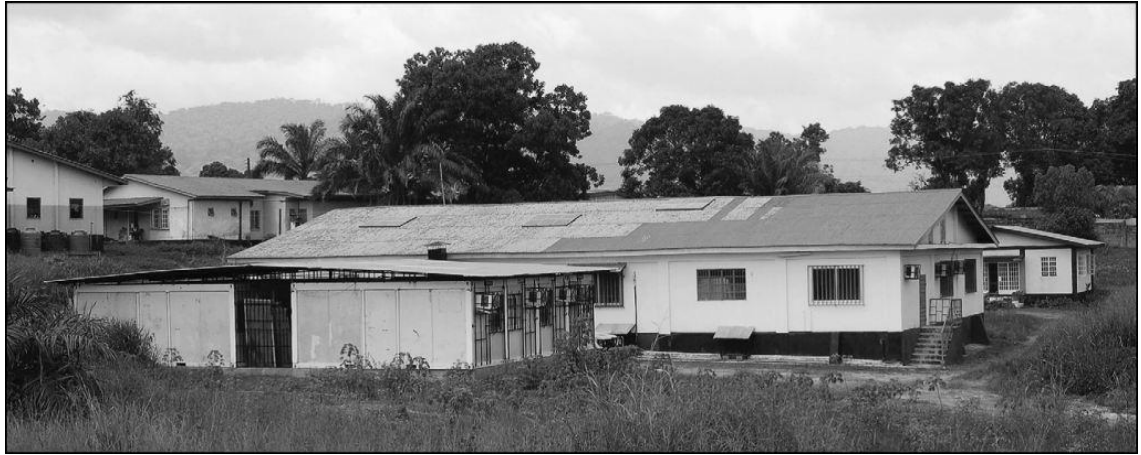
In all of these formulations of the Lassa laboratory’s role, and its connections to wider capacity development, the ‘technological revolution’ narrative which I identified in chapter two can be detected. Developments in the laboratory are depicted as the driver of change. In this policy discourse, problems within the diagnostic system are framed in terms of technical issues (cold chain, sample storage, reagent supply, sensitivity) or the weakness of the health service (e.g. poor referral). There is also a hint that other disease control options are dismissed. As a senior researcher at one of the biotech firms involved in developing the diagnostics for Lassa put it in an interview: “You’re never going to eradicate the virus,” he said. “What we want to do for the next 10 years is just get into a system where we can

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<sup>38</sup> WHO representative, Geneva, 14/12/2012

diagnose them quickly, treat them quickly and reduce the mortality rate" (Wallace, 2011). Such statements focus on medical countermeasures and play down the role of prevention activities unless they are based on vaccines. This approach contains assumptions about the controllability of Lassa fever through technology, where the presumed linearity of diagnostic processes is central to expectations of controllability.

**Figure 10 The Lassa laboratory at KGH (from Khan et al., 2008)**



### **4.3 Alternative perspectives on Lassa fever**

By nature, framings and narratives put some factors sharply into focus at the expense of others. In all of the above conceptualisations there are some questions and alternative dynamics which receive less attention or which are concealed. A feature of the three policy narratives discussed earlier is a dependence on, and high expectations of, technology. In contrast, very little research has been conducted on the disease's ecology or on simple community based preventions. Indeed this parallels much research on emerging viral diseases where efforts have focused on technology (diagnostics, surveillance, vaccines or treatments), and less on the underlying causes of this emergence (Farmer, 1999, Kuiken et al., 2003). For Lassa specifically it seems that there are at least two areas of research which need to be elaborated. First, the long term socio-ecological and political dynamics of the virus and second, its place as a longstanding and constant part of healthcare practice in Sierra Leone.

#### **4.3.1 Long-term dynamics of Lassa fever**

This is not the subject of this research but it should be mentioned briefly. Other than noting the war in Sierra Leone, broad societal stresses and changes receive scant attention in the

literature. Longer term shifts in agriculture, ecology, economics or technology are not explored in current research or policy debate. Even in articles which collect data from refugee camps, there is little mention of the social economic conditions and civil wars which may be driving those conditions, except to say that they make conditions for research unfavourable (Bonner et al., 2007). The focus on local practices or hygiene only highlights a limited range of potential risk factors and as such they should be viewed as partial stories. The “conflation of structural violence and cultural difference” or with problematic individuals, obscures underlying inequalities which drive disease susceptibility within and between communities (Farmer, 1999, p9). The Dynamic Drivers of Disease in Africa Consortium (DDDAC) is looking into aspects such as this in relation to Lassa fever. Others are working on the genetic evolution of the virus and populations across West Africa to put ideas about its ‘emergence’ to the test (Gire et al., 2012).

#### **4.3.2 Lassa fever in practice**

There has been very little research, like that which proved so fruitful for Ebola (Hewlett and Hewlett, 2008), on local understandings and management of Lassa fever.<sup>39</sup> Thus, a research agenda which addresses ‘Lassa fever in practice’ would fill a substantial gap. It would show how disease control approaches, and the policy narratives identified earlier which they are informed by, interact with longstanding healthcare practices. In practice Lassa fever is full of complexities and contradiction; this perspective echoes that of Kelly and Beisel (2011), whose descriptions of the multiple guises of malaria I described in chapter two. Their focus on the arduous, everyday ‘backstreet’ management of the disease is similar to what I have tried to achieve with Lassa fever. This is the Lassa fever which cannot be framed singularly because it is so diverse. This Lassa has multiple strains, various dosages, past infections, mild or severe symptoms and unknown prevalence and the point is to understand how that presents conundrums in everyday diagnosis and management.

Thus the considerable gap in social research on Lassa fever is my starting point. Research focused on lay understandings of Lassa fever and practices surrounding its management. It also looked at the perspectives and work of health workers and laboratory technicians as they experience the disease on the ‘frontline’.

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<sup>39</sup> Except a knowledge, attitudes and practice study by Merlin (Richmond and Baglole, 2003)

A 'Lassa in practice' perspective draws attention to divergences and clashes between the framings and narratives identified in this chapter, and others explored in the following ones. Evidence of conflicting framings of Lassa are visible in the instructions which govern the idealised official system. Under the IDSR framework Lassa fever is included as both a 'priority' and an 'Epidemic Prone Disease'. Instructions for priority diseases state that "a single suspected case is a suspected outbreak" and must be reported immediately to district level. Yet elsewhere a measured judgement is advised. The 'decision instrument' I mentioned earlier separates expected disease incidents from 'unusual' ones (MOHS, 2008). As such it distinguished infections in people and places not normally vulnerable to Lassa fever. This tangled set of instructions demonstrates Bowker and Star's point that classification systems are never coherent and in practice are always in need of tweaks to make them workable (Bowker and Star, 2000). Such tangles become very clear though, say, when a South African civil engineer dies from Lassa in a Northern province, or when a Swedish expat is suspected of contracting it, both of which happened in 2011. These cases both caused an unusual stir. The people who are infected and the places they were infected, made these cases more visible (and in terms of reporting, more significant). These are some of the tensions between the global epidemic threat and local endemic disease as they are represented in the diagnostic system.

The diagnostic system in Sierra Leone cross-sects and includes a diverse range of settings, tools, regulations, countries, disciplines, communities and individuals. The system assembles: biosafety regulations; global surveillance networks; international organisations; governments; the international research and funding infrastructures; academic, private and military research institutions; official health practitioners; unofficial health providers; local communities and patients. Basic infrastructure, such as roads, cars, planes, the internet, even paper, are needed to transport the material and technological aspects of Lassa fever diagnostics within the system. The processes and equipment needed for laboratory tests includes: the collection of serum samples by health workers in Sierra Leone; diagnostic reagents which are grown and supplied by USAMRIID (and by Tulane's consortium partners) and flown to Sierra Leone; solar powered freezers are supplied by the WHO so that reagents and samples can be stored appropriately; equipment to draw and store blood, including PPE for the laboratory and ward is sent in shipments to KGH by Tulane; denatured samples are sent back to the US for further analysis. In contrast to all of this timed and coordinated

organisation, Lassa virus presents itself unpredictably. Input of supplies and personnel can be managed to an extent but influx of people suffering from Lassa cannot and neither can the differential impacts it will have in some bodies as opposed to others.

With all these actors, and in all these settings, the likelihood that the stakeholders want and expect different things from the system is high. This might be publishable research, a product to market, training for locals, simply to find out what is wrong with them and to survive it, or even to not get sick in the first place. Related to this is the possibility that all of these groups have their own understandings of health, their own norms, institutions and modes of authority, as well as power dynamics within and between them, which influence their actions. In these respects, different actors may frame the diagnostic system very differently. In formal versions of the system, the apparatus hinges on accurate, ideally laboratory confirmed, diagnosis: early identification, contact tracing, and appropriate disease control responses. As such, it represents and forms part of the general biomedical approach to epidemic disease control. But it remains to be seen whether all actors agree with those objectives, or their valuation of scientific knowledge systems, and whether the system ‘works’ in this manner. These aspects are the focus of the next three chapters; in order to render this doable I split the system up into distinct settings where I could explore the differential knowledge production contexts. However, this separation, as I also noted in chapter three, is not complete: processes run through them, flows of people and blood cross-cut them, and framings also travel between them.

#### **4.4 Health care dynamics in Sierra Leone**

Population health presents a huge challenge in Sierra Leone, and Lassa fever is only one of many problems. In 2008, when this research began, Sierra Leone was ranked bottom (177 of 177) of the Human Development Index (UNDP, 2007). Average life expectancy was 41, infant mortality was 165 per 100,000 live births and the country also suffered some of the highest child and maternal mortality rates in the world. There were only 3 doctors per 100,000 people (compared to 200-400 in more developed countries) and government spending on healthcare was the equivalent of 1.9% of GDP (UNDP, 2007). Thus, then and now, the healthcare system operates under extreme strain and with very low capacity.

That picture is further complicated by the range of formal and informal providers that provide healthcare alongside the state, including mission and NGO health services, traditional healers and drug peddlers. As with many low resource settings where formal health care is stretched (Peters and Bloom, 2012) informal providers flourish but are not well regulated by the government. Even in the formal sector there is great variation as a range of providers have different approaches to price and manner of payment; for instance the *Médecins Sans Frontières* (MSF) hospital in Bo is free, the mission hospital in Panguma charges a flat-rate fee (50,000 Leones, £9), while government health posts provide services on a 'cost-recovery' basis. In April 2010 the Government introduced the Free Health Care Initiative (FHCI) which provided free healthcare to children under five, pregnant women and nursing mothers. For these groups, the cost-recovery policy was removed and their healthcare was provided free of charge.<sup>40</sup> Health centres overflowed initially and there has been a rise in those priority groups accessing services (Donnelly, 2011). For those not covered by the FHCI there are various vertical programmes, such as those for HIV, TB and also Lassa fever, where treatment is provided free. However, in most government health posts consultation and admission fees apply (in KGH it was upwards of 30,000 Leones, £5.40 in 2010, to be admitted to an inpatient ward). Any tests or treatments must be paid for by the patient. Extreme poverty means that the cost of government healthcare is extremely high and many are excluded as they are unable to afford even modest charges (MOHS, 2009). This is the backdrop for Lassa fever, a context crowded with many other diseases and programmes, and with very limited resources.

In Sierra Leone's tiered healthcare system, outlined in the previous chapter, ascending from Peripheral Health Units (PHUs), to District Hospitals onto Regional Hospitals, challenging cases are supposed to be referred from the PHUs upwards to the hospitals, however referral systems are not functional in some districts (MOHS, 2009). Much of the health expertise and facilities are concentrated in Freetown while there are few doctors 'up-country' in the 'provinces'.<sup>41</sup>

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<sup>40</sup> The view of some NGO and development staff was that this was rushed through. Sierra Leonean healthcare workers I spoke with agreed with the policy in principle but worried about adequacy of provisions. There have been reports that some drugs have not been getting through.

<sup>41</sup> 'Ghost' workers on payroll is a particular issue in the health and education systems, particularly in rural areas; there are many 'ghost' staff on payrolls who are no longer/or never were working but whose salaries are still paid and collected and with the effect of preventing others from being employed. There are also many staff who provide services but who are not on the payroll. This has created bottlenecks as the Government will now only put 'trained and qualified' staff on payroll but it is

## 4.5 Sites in the diagnostic system

Three sites were selected to explore framings and practices within the diagnostic system in Sierra Leone. Below I introduce each site as a preamble to the ethnographic descriptions of diagnosis in the next three chapters. I introduce these in the order they appear in the following chapters: the village of Tokenga located in the hyper-endemic zone, the laboratory at KGH, and the hospital wards at KGH. As I have argued that there is an upwards flow of information in the official version of the system from community to laboratory, this order may seem counterintuitive. I have two reasons for presenting the ethnography in this way. First, the flow of people and samples does not always follow that upwards flow. Indeed, blood samples can be sent directly from communities to the laboratory. Second, this order is intended to convey the brokerage role that the clinic plays both before and after a laboratory diagnosis.

### 4.5.1 Community

Tokenga is a Muslim<sup>42</sup> village with an estimated population of 400,<sup>43</sup> is found in Dodo chiefdom in Eastern Sierra Leone. Chiefdoms, of which there are 149 in Sierra Leone, are headed by a paramount chief, in Mende the **ndolo maha**.<sup>44</sup> Their territory is then divided into sections each with its own 'section headquarter town' and a 'section chief' (**pati maha**), who supports the paramount chief. Tokenga is the 'section headquarter town' of one of Dodo's seven sections. Individual villages also have their own 'village chief' (**ta maha**), so both a section chief and a village chief reside in Tokenga: both are elderly men. The Mende do allow women to occupy the position (Hoffer, 1972). Chiefs are elected but only candidates from chiefly lineages are allowed to stand, although the notion of pre-colonial hereditary estates is questionable (Abraham 1978 and Barrows 1976 cited in Fanthorpe, 1998, p559). A chief's responsibilities include settling disputes, presiding over the chiefdom courts and organising labour for various community enterprises. In doing so, they are supported by a 'speaker', 'headman' and 'women's leader' amongst others. Whereas once their role was to be a broker

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also these staff who are less willing to go to rural areas. As a result, rural areas have a low coverage and lots of untrained service provision.

<sup>42</sup> Muslim in a West African model, teachings of Islam overlay and interact with existing local traditions (which are also constantly changing). The result is one where Allah is worshiped alongside bush spirits and devils.

<sup>43</sup> This was the result of a census conducted by the head teacher of the school in 2009

<sup>44</sup> Chiefdoms were institutionalised by the British during colonialism, they did not exist before (Hoffer, 1972)



between the British colonial administration and 'provincial'<sup>45</sup> populations, paramount chiefs are now the point of contact between the post-independence national government and their citizens.

Sierra Leone has a parliamentary system and during my fieldwork Tokenga's constituency was represented by a female member of parliament from the opposition Sierra Leone People's Party (SLPP) party. Despite a post-war decentralisation effort from national government, which donors hoped would diminish chief's power (Fanthorpe, 2006), the authority villagers encounter on a day to day level is that of the chiefs. In Tokenga, chiefdom elections had just been held and they were in the middle of a controversial election contest in a neighbouring village when I left. Even in matters where the chief may not have any influence, villagers will work through them to get to the relevant authorities. For instance, in Tokenga residents were lobbying to have a health clinic set up in the village; it was a 'grassroots' demand which required the attention, and resources, of central government officials. However, at every stage of organising and carrying out their campaign, for instance in sending a delegation to see the district medical officer in Kenema, the villagers would meet and consult with the town and section chief.

Tokenga is 6 miles from Dodo Town, the chiefdom headquarter. Panguma, the headquarter town of neighbouring Lower Bambara chiefdom is 9 miles away, and is better served for commercial, transport and health needs. The road to Tokenga is a dirt track, and is rough and hilly. During my visit, which was in the dry season, motorbikes would very occasionally ride it and once a truck arrived to collect a crop harvest, but otherwise journeys were made on foot. In the rains the mud and log bridges would be impassable for vehicles. There is a small primary school staffed by four teachers, only one of whom is on government payroll.<sup>46</sup> If children are to continue schooling after primary level they would be sent to live elsewhere in order to attend secondary school.

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<sup>45</sup> 'Up country' or outside of the British protectorate which consisted of Freetown peninsular

<sup>46</sup> The teachers (1 head teacher, 2 tutors, and 1 Islamic teacher) had tried numerous times to get on payroll which would mean they were official government employees and would receive a regular state salary. However, the current Government's reform of payroll from public services like health and education is attempting to cleanse not only 'ghost workers' (who do not exist but whose salaries are picked up by someone), but also the 'untrained and unqualified' who currently occupy positions on the payroll. The teachers at Tokenga would fall into this latter category: despite the school being officially recognised no teachers had been sent to take up work there (filling rural positions is a common problem) and so the community requested some of their own people to fill the gap, but not being trained teachers these men have little chance of making it on to the payroll.

There is no government health clinic in Tokenga and so people travel to either Dodo or Guala (5.5 miles) where there are clinics. There is also a hospital in Panguma. There had once been maternal health nurse who visited Tokenga every few weeks, but that had ceased. Residents of the village are in the process of lobbying the district health officer for a Government nurse and clinic to be instated in the village. They had collected money between themselves to send delegates to Kenema to argue their case and, on my second trip, had also started construction on the clinic themselves. As far as I know, there is still no resident nurse. The nurse at Dodo clinic was described as frequently absent, or the clinic empty of medicine.

Compounds consist of different kinds of housing structures. **Mawæ** (household) heads traditionally built either 'multiple houses' or 'big houses' to house dependents (Leach, 1994). 'Multiple houses' are divided into private rooms where individuals or couples (and their young children) will sleep. The 'big houses' are undivided shared sleeping quarters, usually for women, and as polygamy is common often for co-wives when it is not their turn spend the night with their husband. Tokenga has a number of large 'multiple houses', but it does not have any 'big houses', though it does also have smaller individual houses built by men for themselves and their immediate family. Such 'small houses' are increasingly popular (Leach, 1994). They are the newest structures in Tokenga, and there are more being built. Houses are built from a mud mix. At their most basic (and cheapest) this is packed into a wooden frame. Others are made from mud bricks which can be left bare, or if there are funds the bricks get covered with a plaster (figure 11 shows a plastered 'big' house, erosion is visible at ground level). Floors are mostly packed earth, though some are plastered. Roofs are thatched with palm or covered with corrugated iron. Houses with packed earth floors and no cement are more hospitable environments for burrowing rodents, including the *M. natalensis*.

Tokenga is relatively well equipped, certainly more so than smaller villages, in that it had latrines, a water tank and pumps. It had retained more of the larger, older, plaster covered houses than many other villages. During the civil war the rebels had not entered the village, so these fine old buildings which had often been a target of the rebels elsewhere, are still standing; in other towns and villages in that area it is more common to see their burnt out remains. I was told the rebels had surrounded Tokenga but it had been protected by **Kamajo** men. **Kamajo** is the term for a male hunter who uses medicines. During the war many of them

acted as a civil defence force giving the word a new meaning<sup>47</sup>; they are now often referred to in an Anglicised way as Kamajors. In Tokenga, during the war the **Kamajo** leader was the section chief's son; the chief showed me photos of his son posing with bullets and guns and told me how he had died just before the war was over, of Lassa fever.

**Figure 11 The water supply and houses in Tokenga**



Kitchens are separate buildings which are primarily used for storage as all cooking is done outside over a wood fire, though they are used for shelter during rain. Kitchens are generally on the periphery of the village, behind houses, and are always made of mud with thatched roofs, but with lockable doors to keep equipment and food safe. Figure 12 shows how kitchens and houses are arranged. Women cook, usually rice and a sauce of 'greens' such as cassava leaf or potato leaf. Left over rice is kept, usually in cooking pots or bowls with a plate balanced on top, to be eaten as *kol ris* (cold rice) the next morning. Stored food which rodents can gain access to is a possible transmission route for Lassa fever. The outreach team advise people to cover their food well to protect from Lassa fever. There is little food waste, but that and any

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<sup>47</sup> As well as protecting communities there have also been accusations that they committed brutality too. Despite this, in Tokenga they are talked of positively.

other rubbish is put on a dump just on the edge of the village. Some villages have hygiene officers, but apparently not in Tokenga.

**Figure 12 Houses (left) and kitchens (right) in Tokenga**



#### **4.5.2 Laboratory**

The 'Lassa Lab' at KGH became operational in 2006 (with testing routine in 2008) as a result of the Mano River Union Lassa Fever Network which was formed in 2004. The "cornerstone" of the network was to improve laboratory capacity for diagnosis of Lassa fever (Khan et al., 2008). Previously diagnostics had only been performed intermittently in Mano River Union (MRU) countries, or samples had to be sent to the US or Europe for testing which, with the increasingly strict regulatory environment for 'Select Agents' such as Lassa, meant they could take months to get a result rendering them of little use for clinical or case investigation purposes (Khan et al., 2008). The 'Lassa lab' is located within KGH hospital grounds, it shares a building with the KGH general laboratory which was built with support from Merlin, the United Nations Mission in Sierra Leone, OFDA, WHO, Tulane University, and the Sierra Leone Ministry of Health and Sanitation (Khan et al., 2008). The laboratory was built to operate at a BSL-3 level, though in practice it operates somewhere in between BSL 2 and BSL 3. Entrance to the laboratory is through a lockable door leading to small area for donning PPE: gowns, gloves, goggles, masks and wellington boots. There is a second door which leads to the main laboratory. Exit from the laboratory is via a different door, to an area where protective gear is

discarded or disinfected. In this way the flow of people through the laboratory is controlled, however not all staff and visitors to the laboratory follow these procedures to the letter. As the local electricity supply, known as ‘town power’, is not reliable (or even available at all during most of the dry season), electricity for the laboratory is supplied from a generator. Tulane and the WHO have installed solar panels to ensure that freezers maintain their temperature,

At the time of fieldwork, the laboratory employed three permanent Sierra Leonean technicians who provided Lassa fever diagnosis using the ELISA technique which I explain in chapter five. The laboratory is regularly visited by Tulane University researchers and other affiliated researchers who are involved in developing new diagnostics for Lassa fever. The laboratory is seen as the engine of research, a building block which removed ‘bottlenecks’ and opened up new research avenues. Representatives of the MRU LFN described its potential thus:

*“The enhanced physical and organizational infrastructure provided by the MRU LFN and KGH Lassa Laboratory, and especially the implementation of real-time laboratory diagnostics, offer tremendous potential for research on LF (Lassa fever). Key areas of investigation include the development and testing of new diagnostic techniques (such as the aforementioned recombinant based assays); a more complete understanding of the clinical presentation, pathogenesis, correlates of immunity, and natural history of LASV (Lassa virus) transmission; and the development and testing of new treatments and vaccines”. (Khan et al., 2008, p109)*

As well as providing routine diagnostics the laboratory periodically hosts researchers from Tulane University and other institutions. In 2010 there were about a dozen research projects being run by Tulane University and collaborators through KGH. Two main projects were ongoing in the laboratory. The first was a project on the ‘Preclinical development of recombinant antigens for the diagnosis of Lassa fever’. This was a collaboration between Tulane University, Boston University, USAMRIID, and three biotech companies (Autoimmune Inc., Corgenix Inc., and Vybion Inc.). The second was investigating ‘Roles of protective or pathogenic B cell epitopes in human Lassa fever’ This was a collaboration between Tulane, Boston and Harvard Universities, USAMRIID, the Broad Institute, Scripps Institute, and Autoimmune Inc., Corgenix Inc., and Vybion Inc.. Both were funded by the National Institutes for Health (NIH) and led by senior laboratory scientists from Tulane University. Chapter five will describe progress made on the diagnostic grant.

### 4.5.3 Clinic

The KGH hospital provides secondary care for the Kenema district. Inpatient care is offered in the male, female, maternity and children's ward. There is also the 'annex ward' where patients can pay a higher admission fee for a private room or a room that is shared with fewer people. There are 4-5 doctors who cover these wards assisted by nurses and students. A converted shipping container houses the outpatient clinic which is simply known as 'the container'. The hospital is supported by a blood bank and a general laboratory although the range of tests available is limited. There are also a handful of specialist clinics and wards such as the HIV clinic, TB clinic and, of course, there is the Lassa ward. The Lassa ward is looked after by the same doctor who is responsible for the male, female and annex ward. KGH is run as per the government health financing policies operating on a cost recovery basis, until the introduction of the Free Health Care Initiative in 2010 described earlier. Until that, and still for some people, nothing is free at the hospital; for example, as well as the admission fee patients have to bring their own bed sheets. Many purchase school exercise books as a cheaper alternative to the official patient charts. Some wards, such as the maternity ward, can be very busy but many others appeared frequently only half full, most probably because of cost. The environment is very basic, hot and dark. In 2011 the maternity ward burnt down, reportedly the result of faulty electrical wiring.

Lassa fever presents a particular threat of nosocomial outbreaks and it has a long history of affecting health workers, including many at KGH. Nurses can remember outbreaks and colleagues who were affected. The provision of basic protective equipment such as gloves was not routine on KGH's general wards, let alone anything like the PPE described in section 4.2.4. Confirmed cases of Lassa fever are treated in a separate isolation ward. I have already described the centralised diagnostic and treatment system but it should be pointed out that KGH is located outside of the traditionally hyper-endemic zone. It was not always this way, as well as the previous base in Segbwema some early outbreaks were dealt with on site. McCormick describes setting up isolation procedures at other hospitals in the 'Lassa belt' (McCormick et al., 1999), and it is conceivable that if proper PPE was provided this would be feasible again. However, as of now, everything is directed towards KGH, both resources and patients.



The 'Lassa Ward' is located on the grounds of KGH. It is shown in figure 13. It has 25 beds, divided between rooms which contain 1-3 beds each. The building was not originally designed to be an isolation ward and so it has been adapted; the red line which cuts the reception area in half should only be crossed by patients or those in full PPE and a disinfection station stands just behind it. PPE on the wards consists of a gown, wellington boots, gloves, goggles and a mask. New supplies of PPE arrived whilst I was there, but in the early stages some nurses had been making use of what looked like a ski-mask. The availability of PPE and adherence to isolation procedures can be a matter of life and death for healthcare workers in the region. Unfortunately many health workers have died after contracting Lassa fever from patients, including Dr Conteh. It is hard to recruit staff for the Lassa ward and the staff who do work there are particularly dedicated. A number of them have worked there for decades. I was told by nurses in other parts of the country that they had avoided working in the Eastern district just so they could avoid Lassa fever. The head nurse of the Lassa fever ward had herself been recruited after surviving Lassa. She and other nursing staff sometimes laughed that they were recruited because they were immune.

**Figure 13 The entrance to the Lassa ward**



The ward is extremely basic and dilapidated in parts. There is no reliable source of electricity, consequently it is dark and hot; I saw patients lying on the tiled floor in attempts to keep cool. Small scale repairs have been made recently; for instance the construction of a visitor's reception area in the fenced off entrance area, and a replacement morgue which was built when the original one had become run down and, with tragic irony, so infested with rats that bodies could not be stored in there. There had been plans for a new ward (Khan et al., 2008). Foundations had even been laid but this had run out of funding and ground to a halt. It was a source of some tension between the WHO and Tulane, although I was informed new plans were being made, this time funded by the US Department of Defense.

For now the old ward carries on with very limited medical equipment (Khan et al., 2008) and for drugs it suffers the same shortages and supply problems as the rest of Sierra Leone. Tulane University and the MRU-LFN do supply some supportive drugs and Ribavirin is offered free to patients after a donation by the Chinese government. The provision of free Ribavirin is critical as it would be far too expensive for most Sierra Leoneans to afford at approximately \$1000USD per patient (Khan et al., 2008).

## **4.6 Conclusion**

This chapter discussed three narratives about Lassa fever's emergence and control which are evident in policy and popular discourses. The first narrative, about global threat, emphasised the need for disease identification and containment to stop the virus flowing across borders. The second concerned ideas of local endemicity and emphasised the need for local public health promotion and surveillance. The third described a neglected disease, which was in need of more technology and research. All three narratives converge on the promise of technology and greater investment in science. In an approach which exhibits signs of technology and science 'silver bullet' solutions, the establishment of diagnostics and surveillance is portrayed as the building blocks of effective disease control. The importance of these technologies cannot be denied, and they are certainly pivotal to dealing with the disease both locally and internationally. However, the troublesome feature of these narratives about the promise of science and technology for disease control is their tendency to overshadow, or even dismiss, alternative approaches and understandings of disease ecology and management. Moreover, I suggested they overlook the complexity of the disease and the process of diagnosis in the Sierra Leonean context. An illustration of this can be found in the



official version of the diagnostic system, as formulated in Government and WHO policy documents. This version of the diagnostic system frames Lassa fever and the process of diagnosis in an idealised way: case definitions are used to identify typical symptoms and the disease must be laboratory confirmed. Information flows upwards through healthcare tiers and patients and samples are centralised around the KGH. Two additional areas of research which were not adequately represented in these narratives, or in the idealised descriptions of the diagnostic system, were highlighted: the first acknowledged the longer term dynamics of Lassa fever and the second emphasised the everyday nature of Lassa fever in practice. The next three chapters aim to address the latter of those research deficits. By exploring Lassa fever in practice a more nuanced understanding of the role of new technologies for the diagnosis and control of Lassa fever is gained.

Finally, at the end of this chapter I introduced the sites in which I examine Lassa fever in practice. As the previous chapter set out, the sites are settings where aspects, or framings, of Lassa fever are enacted. They are not the only places where diagnostic activity goes on; nor are they discrete places. They do not in themselves constitute the diagnostic system, rather they are locales where facets of the system interact. The following three chapters will examine the multiple processes, pathways, framings and enactments which make up the diagnostic system.

## **5 ‘We are just learning that name’: diagnosis in community settings**

Following on from the introduction to Tokenga in the previous chapter, I will now explore healthcare practice and Lassa diagnosis in the village as well as through the experiences of a group of ex-Lassa patients. In chapter two it was asserted that diverse framings and practices emerge out of social contexts, so instead of focusing on Lassa in isolation, here it is approached through the wider social and cultural framework of health and disease in a Mende village setting. The dominant narratives I identified in the previous chapter are largely unfamiliar here. On the world stage Lassa fever is a threat, an emerging or neglected disease whose presence in the region requires specialised healthcare measures. At the village level it is experienced alongside many other health problems, where what happens to someone infected with Lassa and how this is identified (or not) depends on established patterns of therapeutic practice, and how they relate to the social and material context of the village rather than the virus’s Category A or biosafety level 4 (BSL-4) status. But just as Lassa fever is the subject of nightmarish narratives on the global stage, the sudden and grisly end which it can cause has, at times, been associated with local stories of an equally alarming kind. People would often say they would rather have HIV than Lassa fever, as Lassa fever kills so quickly. Witchcraft too is implicated: I once heard Lassa fever referred to as a ‘witch fight’ with the injuries sustained in the fight manifesting themselves in the bleeding that is sometimes seen. More importantly, pregnant women, already vulnerable, are the subject of witchcraft rumours. Then there are stories of lethal injections administered at the hospital to people suffering the disease. I will come to all of these. Lastly, there are also respects in which village experiences of Lassa are influenced by those prominent international narratives, say by a visit from the outreach team; as a result new associations of Lassa are emerging in Tokenga as a range of outside meanings become associated with longstanding ideas of sickness and health. In this chapter I examine the negotiation of these framings and narratives, looking at how they intersect with the process and practice of disease recognition and healing.

### **5.1 Social life and livelihoods**

Tokenga’s residents are subsistence farmers. A few families had larger plantations of cash crops like cocoa, oil palm and coffee, though a number of these larger plantations were not being harvested due to labour shortages. Others had smaller scale ventures growing crops

such as pineapples or even marijuana for sale. Rice is the staple food. People say if they have not eaten rice they have not eaten. It is a hugely significant part of social life and is often gifted. Not having rice, perhaps as a result of not being able to farm, is restrictive and a strain; people have to work hard to 'buy' or 'find' rice by other means. Households or individuals cultivate their own shifting areas of upland rice, or sometimes swamp rice. There are also some communal farm areas where 'town rice' is produced (which women are threshing in figure 14). Rice is supplemented by intercropping vegetables (i.e. maize, aubergine, chilli pepper) on designated farm areas, or with 'greens' (i.e. cassava leaf, potato leaf) grown in separate 'gardens', mostly by women. Livestock is limited in Sierra Leone particularly after the civil war. In Tokenga there were a few hens and goats but most meat was 'bush meat' which is hunted by men using dogs or traps (**mani**). This included cane rat (known in Krio as *cottin grass*); rodents (known as *arata*, and translated back to English as rats); and also monkey (referred to as *baboon*). Fish is widely eaten both dried and fresh. Fishing is done by women with nets in shallow waters, or by men with traps left on river beds.

**Figure 14 Women threshing communal 'town rice'**



At the village edge the buildings stop and the bush begins with only small footpaths leading off to farms or neighbouring villages. Older Mende villages, like Tokenga, tend to be composed of descent groups who trace their lineage to village founders. Descendants of these original settlers are usually the dominant landholders and chiefs are drawn from their lineages (Little, 1967, Murphy and Bledsoe, 1987). There are five main descent groups in Tokenga and each claimed to occupy an area of the village. These sections contained one or more compounds for each lineage where people under a **mawɛɛ** (household) head lived, linked to them through kinship or patronage. The meaning of **mawɛɛ** has shifted as farming practices have changed; whereas once a **mawɛɛ** would have consisted of up to 50 people who farmed rice together (Little 1948), now it is commonly used to mean the smaller sub-units who farm together (Leach, 1994). Figure 15 shows one family's farm, and farm hut (**kpowa**). To clear the farm in the picture after it had been burnt the family enlisted a group of adolescents and provided them a meal for their work. I was told by a member of the outreach team that the shift in farming as smaller units had particular relevance to Lassa fever. Where rice used to be stored in large rice barns (**kpuwu**) it was now common for these smaller family units to keep rice in their houses which attracts rodents. People do complain of rodents eating their rice both on the farm and in town. There is one *arata*, the one with the *long mot* (long mouth) who is said to be the 'Lassa rat'. According to villagers this rodent smells bad and 'loves rice', which may be part of the reason why it has been (wrongly) designated the 'Lassa rat'. By description, this rodent is more likely to be a shrew but it is relevant because it forms part of this community's framings of Lassa fever and its transmission.

As in much of Sierra Leone, the promise of finding diamonds provides a constant backdrop. Men in the village periodically go off for a few days or weeks to nearby villages thought to have diamonds, or to well-established mining towns like Tongo Fields which was a few hours walk. Much of this is done at their own expense, though occasionally they might receive sponsorship to dig, perhaps through a contact in the mining town Tongo or Kenema. For a contract they agree to give up most of the value of anything they find in return for a stipend. The constant presence of mining and its impact on the environment and social life has been noted elsewhere (Ferme, 2001, Leach, 1994, Richards, 1996). Tokenga is linked into Sierra Leone's powerful informal sector, characterised by William Reno as the 'shadow state' (1995), as equally as any other village.

**Figure 15 Cleared and burnt upland farm, with farm hut**



Another much noted presence in Mende communities is that of the ‘secret societies’.<sup>48</sup> Most rural adolescents will be initiated into either the local **Pɔɔ** (Poro, the male society) or **Sande** (Sande, female society). In the on-going Sande initiations during my visit, the initiates were segregated off into the Sande ‘society bush’, an area outside of the village in the forest. In these ‘bush schools’ initiates undergo processes, training, and ordeals (controversially the clitoridectomy for girls) which turns them into gendered beings (Bledsoe, 1984). The bush schools of the secret societies have been described as being places of education, teaching young girls and boys essential life skills to be women or men (Little, 1967). This is certainly the ‘public face’ of the societies and their initiations. In a neighbouring village when the Sande initiates had completed their initiation and were ‘pulled’ from their ‘society bush’, they performed songs which they had learnt during initiation about, amongst other things, how to live in a polygamous marriage. The influence of secret societies in health domains will be described later in this chapter.

The mosque in Tokenga is well attended. In addition to this there are a range of spirits and devils who inhabit the surrounding landscape. Others have described these matters in more detail (Ferme, 2001, Jędrej, 1974, Little, 1967), here I will outline only the main aspects.

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<sup>48</sup> Links between secret societies, the ‘shadow state’ and Government officials should also be acknowledged

Secret societies have their own society devils and spirits. There are ancestral spirits who need to be respected but are generally kindly towards their descendants. Bush spirits inhabiting the surrounding areas can be mischievous and cause damage or accidents (Ferme, 2001, Leach, 1994). Another non-ancestral spirit, in Mende **Jina** and known as 'Jins' in English<sup>49</sup>, are described as having a human form, white skin and living near rivers. Jins can bring luck and wealth, but they are sometimes said to send sickness or madness.

A **hona** (witch spirit) is located in the belly of a **honomo** (a witch). Witches are believed to have their own secret society; fellow witches can recognise one of their own but those who are not witches themselves cannot detect them. They are said to go about **hona hinda** (witchcraft), or 'witchcraft business', at night. This includes eating children, poisoning victim's food or shooting them with a 'witch gun'. There are two kinds of 'witch': 'born witch' and 'bought witch'. Born witch is passed through 'witch families'. One man estimated that witch families equalled non-witch families in number. Bought witch can be purchased from an appropriate medicine man (sometimes referred to as a witchdoctor though this is an anglicised term). Bought witch is stronger than born witch; bought witch is used to do good and to fight the bad 'born witch'. **Honomo** are likely to attack children or people who are successful. A particular kind of post colonial discourse is evident when villagers attribute witchcraft to 'African' or 'black' desire to destroy each other because of their tendency for hatred and jealousy. The witchcraft in Tokenga is contrasted to the assumed witchcraft that **puublaa** (white people) have but which they use to do wonderful things such as invent mobile phones and planes. One of Tokenga's neighbouring villages is said to have many witches.

## 5.2 Impressions of 'Lassa'

There are certainly hints in Tokenga of Lassa fever's global and regional importance. There are not many diseases which cause so many visits from outsiders, including myself. Only a few months before my first stint in Tokenga a local woman had fallen sick and died from Lassa. Following up this case, the outreach team had visited to do contact-tracing and health promotion as per protocol. Despite the sad occasion, the arrival of these 'strangers', along with a projector to show films was remembered with excitement. Perhaps because this visit was still fresh in people's minds, at the time of my research the word 'Lassa' was recognisable

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<sup>49</sup> Jins are mentioned in other Islamic areas so are likely to have been incorporated by the Mende

to almost everyone I spoke to; most people could list a few key symptoms and children took pride in reeling them off to me. Of course, there were those who were still unsure of how to recognise a case of Lassa or what should be done about one, but the dominant message contained in a phrase I heard repeatedly was clear: ‘that person should be taken straight to hospital’, and there should be no delay. Even the resident healers and imams agreed that there are no remedies to be found in traditional medicine and the only treatment for Lassa is biomedical, more specifically it should be administered only at a hospital. In terms of prevention, the village authorities had passed a new law that forbade the consumption of *arata*<sup>50</sup>, a strategy emphasised in the outreach team’s prevention efforts. This law stated that if anyone was found eating *arata* then they would be fined. On top of which, if that person subsequently fell sick they would not be taken to hospital.

These statements should be considered against the backdrop of fevers in general. Fever is a common complaint in Mende villages. In Mende **kɔɛ** is used to mean fever and cold. A person would say they were attacked by **kɔɛ** to mean they “feel cold” or that they had a temperature, in Krio: *de bodi wam* (the body is warm). **Kɔɛ** was frequently accompanied by sweats or shivers. In Mende, **kɔɛ** is also used to mean deception (Innes, 1969), underlining the ambiguous nature of fever with its fluctuations from hot to cold. Ethnographic texts of the region emphasise the pervasiveness of ambiguity in social life (Bledsoe and Robey, 1986, Ferme, 2001) and it appears that the Mende experience of fevers is no different. People distinguish two types of fever: **kɔɛ wee** (small fever/cold) and **kɔɛ wa** (big fever/cold). The first, **kɔɛ wee** passes in a few hours, “**kɔɛ wee** attacks people, they tremble, their body gets warm, then later it goes away”.<sup>51</sup> It ‘attacks’ people frequently I was told “every time you do hard work you will feel that one”.<sup>52</sup> It is attributed to everyday causes such as hard work in the bush, eating *kol ris*. One man told me, “sometimes when you eat *kol ris*, **kɔɛ wee** will attack. You will tremble. You set fire to warm your body, but then you get hot and sweat”.<sup>53</sup> In contrast **kɔɛ wa** was characterised by a more intense and longer lasting fever and was associated with other symptoms, “when that cold attacks the person and goes up into the head, they will see that persons mouth will be red and have some wounds, so straight off they

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<sup>50</sup> Although *Mastomys natalensis* is actually a species of mouse it is usually referred to as a rat. Health promotion on Lassa in Sierra Leone warns people against eating rats in general.

<sup>51</sup> Female, Amara family, Tokenga, 13/03/2012

<sup>52</sup> Male, Sonnoh family, Tokenga, 12/03/2010

<sup>53</sup> Male, Turay family, Tokenga, 13/03/2010



will say that is **kole wa**".<sup>54</sup> I was frequently told that **kole wa** is Lassa: "**kole wa** used to kill people, (we) used to hear of it from Panguma. (we) heard of it from Panguma before it arrived here. Whenever people are attacked by such cold when they go to hospital they call it Lassa".<sup>55</sup>

A number of issues are raised above. The location of these fever categories in real experience is a critical part of exploring Lassa diagnosis; the classifications above appear straightforward but what do patient's and community member's accounts show? Fevers, big and small, are key to the general healthcare context in Tokenga and the processes by which Lassa is diagnosed, including the association between Lassa and **kole wa**. As experienced medical staff will testify, and chapter seven will demonstrate, Lassa is extremely hard to recognise based on symptoms alone; therefore what happens in village settings does not hinge on disease-specific knowledge of Lassa, but on wider concerns and approaches to health. In the village context the application of the label Lassa to someone's symptoms is both the result of, and results in, varied treatment pathways which are rather different to the single pathway assumed in the formal framing of diagnosis which is represented above. The difficulty of recognising Lassa symptomatically means its response (or the lack of it) to treatments targeting other diseases becomes a critical element in the diagnostic process. Another part of the story is that the range of health interventions which get tried and tested as a Lassa diagnosis begins to take shape are negotiated using locally experienced categories; this opens the process up to the possibility of a range of different outcomes, many of which may not echo expert advice. There are also questions about how, in this process, a diagnosis of Lassa comes to be accepted as valid.

One dimension of these locally experienced categories that is particularly relevant and potentially challenging is witchcraft; four out of the six cases of Lassa in the village were attributed at some point to me as having involved witchcraft. Some of these explanations were well developed and widely known. What is interesting is the way that these witchcraft stories overlap with local disease categories and the epidemiology of Lassa fever. The sudden death of someone powerful is cause for suspecting the involvement of a **honamo**; this was the case with the chief's son, the **Kamajo** who was described as a war hero. Yet it is the particular vulnerability of pregnant women from Lassa fever which cross-sects these witchcraft beliefs so strikingly. There is a widely held belief that pregnant women who have difficulties or die in

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<sup>54</sup> Male, Turay family, Tokenga, 13/03/2010

<sup>55</sup> Female, Amara family, Tokenga, 13/03/2012



pregnancy or childbirth are witches themselves.<sup>56</sup> Three pregnant women have died of Lassa fever in Tokenga in almost as many years. Here, I explore how these explanations of disease causation and outcomes intersect with diagnostic practices, and in particular, how they challenge the validity of biomedical knowledge by dealing with the limitations of the government healthcare system.

To recognise the plurality of experience and meaning so important in the diagnostic process, I will now set out the ‘therapeutic landscape’ (Leach et al 2008). In doing so I look not only at which treatments are available, but also how they are used, and how meanings are constructed in relation to experiences of them and the people associated with them. This acknowledges the defining influence such relationships have on healthcare practice. Through these practice-based categories I build up a picture of Lassa diagnosis, of how meanings surrounding Lassa are negotiated and how they might be changing. For all the talk of witches and Lassa fever there were people, in Tokenga and surrounding villages, who did not recognise the disease’s name, however these people would almost certainly know of **kole**. Did **kole wa** previously mean something broader, for example, and if so how has it narrowed to mean ‘only’ Lassa? Is Lassa integrated into normal routines or does it contrast to other healthcare practices? Are there, or have there ever been, local methods of treatment and diagnosis for Lassa? None of these questions have been addressed before yet all of them are essential for understanding and improving Lassa fever diagnosis.

### 5.3 Lassa within Tokenga’s Therapeutic Landscape

Despite not having a government health clinic there is certainly no void of therapeutics or local technologies for diagnosis and treatment in Tokenga. As is common throughout low income countries (Peters and Bloom, 2012, Standing and Bloom, 2002) the informal sector is the source of much, if not most, of the treatments consumed; private suppliers of healing products and advice outweigh any formal government or accredited distribution. The relationship between new kinds of health technologies, such as ‘English medicine’ and old ones, such as ‘herbs’, is complex and residents described conflicted and uncertain relationships with aspects of both regimes.

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<sup>56</sup> Similar ideas have been reported elsewhere (Ferme, 2001) and in relation to Lassa fever (Richmond and Baglole, 2003)

### 5.3.1 Mende hale and Pu hale

The Mende word for medicine is **hale**. In Tokenga residents talk about two kinds of medicine: **Mende hale** (this covers traditional medicine, sometimes referred to as ‘native herbs’) and **Pu hale** (**pu** meaning white, indicating ‘white people’s medicine’, also known as *English mersin* in Krio; in practice this meant all ‘Western’ pharmaceuticals, which in reality were often Chinese, Nigerian or Indian made). Periodically external health workers for the Government or NGOs arrive to distribute vaccines or drugs as part of ‘priority disease’ programmes. But mostly **pu hale** is obtained informally. Individual tablets are sold alongside cigarettes on the village’s petty trade stall both priced at ‘2 for 2 block’, two cigarettes or two tablets for 200 Leones (the equivalent of £0.036 at 2010 exchange rates); a drug pedlar visits once a month with a suitcase of pharmaceuticals (but also some traditional medicine). Some residents have personal supplies, either bought outside of Tokenga, or sent from friends and relatives. There is one resident working with **pu hale**, a man called Mohammed who prior to marrying a local woman had worked in an urban pharmacy; though he has no formal training he has effectively become doctor to Tokenga and the surrounding villages. Mohammed makes house calls, supplies drugs, injections and, he told me, even fixing up and administering intravenous fluids. He is referred to as a nurse by residents.

**Mende hale** includes tree barks, leaves, or any object which when processed – and used in the correct way – will have curative or protective powers. Importantly **Mende hale** is not used only for health matters, it is a broad category of medicines which can be used to assist in all sorts of practical or ritual tasks including hunting, farming, fishing as well as healing. As later sections will explore, the skills and knowledge needed to practice with **Mende hale** often comes with membership of a secret society or runs in families; in the domain of health there are some well-known remedies which can be prepared by anyone, but there are others which must be obtained from specialist **halemɔ**. Tokenga has two **halemɔ**, both elderly women, who are consulted for health concerns ranging from the minor to serious. Others who deploy specialist knowledge of **Mende hale** are the three traditional birth attendants (TBAs). The work of the TBAs in taking care of pregnant and nursing women is fundamentally tied to their position as Sande officials and their use of specific society **hale** (Ferme, 2001, MacCormack, 1984). The TBAs also illustrate the way in which traditional and biomedical medicines are not rigidly separate: the TBAs have been trained by NGOs (and government) in elements of western medical midwifery as well as to ‘refer on’ to government health facilities (this is a

well-established strategy and has been documented previously in Sierra Leone for example in MacCormack, 1984).

The blend of traditional and biomedical activities carried out by the TBAs suggests that although the distinction between **pu hale** and **Mende hale** is locally used, it is more nuanced than it first appears. As noted previously, African medical systems have been characterised as open and plural (Janzen, 1981, Reynolds Whyte, 1982). Furthermore, within those plural systems, pervasive dichotomies such as those between ‘public’ and ‘private’, ‘formal’ and ‘informal’, or ‘traditional’ and ‘biomedical’ have been shown to be artificial (Cross and MacGregor, 2010, Leach et al., 2008, Standing and Bloom, 2002).

Instead they are better understood as hybrid. However, hybrid should not be taken to mean that there are no differences in how therapeutics are used. In Tokenga, despite an often stated preference for **pu hale** it is clear that, as people negotiate their way through the multiple providers of healthcare, their choices are not simply determined by a play-off between biomedical and traditional options. Instead they make use of alternative categories which are more salient to their own experiences and which are rooted in broader social and historical concerns. As the following sections attempt to document, the categories mediating healthcare practice and the diagnosis of Lassa are more likely to revolve around: the way medicine is thought to work; forms of expertise; types of illness; and payment methods. Some are more relevant than others but it is through these elements that a diagnosis of Lassa develops, and thorough which it takes on meaning.

### 5.3.2 How hale works: regimes of medicine use

Although **hale** can be roughly translated as ‘medicine’, in its broadest terms it equates to ‘power’. Thus, in Mende usage **hale** covers a much broader concept than the western biomedical notion of medicine. Mende understanding of **hale** encompasses powerful substances, chemical or supernatural, able to do both good and bad. As well as curative compounds **hale** can refer to objects or mixtures which have supernatural powers enabling them to achieve particular objectives, including the non-medical, for instance to detect lies or thieves (Little, 1948). **Mende hale** is distinctive, along with other West African regions (Leach et al., 2008), for having both protective and curative effects. Amulets are worn by children to ward off a range of things including thunder, witches, convulsions or malaria. The concept of

**hale** extends to the secret knowledge of the Sande and Poro societies, as the word **hale** also refers to the societies themselves: **Sande hale** for the Sande or **polɛi hale** for the Poro (Jedrej, 1976b).

Yet although **hale** comes in many shapes and sizes and performs multiple roles with great effect, **hale** does not have innate power; it needs particular conditions or actions to make it work. It is owned and given by specific people for specific purposes. The social distinctions that **hale** represents either in its possession or use (in the form of knowledge or remedies), are critical not only to how it works but also to how society works: differentiation and distinctions in **hale** use echo distinctions in life. For instance gender crosscuts **hale**; activities such as palm climbing or hunting are gendered, men and women have differing roles and there are specific medicines to assist in these roles (Leach, 1994). Thus rules about medicines are also codes about gender and moral order, a point also illustrated by the secret societies control of **hale** and their maintenance of hierarchy.

The conditions which must be ensured to bestow **hale** with its power are at the root of some striking features of medicinal socio-technical practice in Tokenga. On the one hand, numerous rules surround the use of **Mende hale** but on the other, the use of **pu hale** is characterised by an absence of rules. First, the controlled conditions which are so fundamental to the preparation of **Mende hale** also extends to how they are consumed and various restrictions are imposed. For instance a **halemɔ** will pray on a medicine or ‘call the name’ of the person they are preparing medicine for, after which that medicine belongs only to that person and may do harm if used wrongly or by anyone else. There are distinct instructions about how to use **Mende hale**. Ropes made from special leaves twisted and tied around the waist is a common treatment, particularly for malaria, yet not anyone can do this. A **halemɔ** is employed to make them and it will only work if tied on to the patient while they stand in a doorway. Another medicine for healing wounds cannot be passed from person to person but instead has to be placed on the ground before being picked up by another person. Other traditional remedies cannot be used with injections or **pu hale**. Even some of the self-administered treatments have certain prescriptions. For example, putting babies to lie in the rice fan is a method of curing convulsions, but it will only work if the word for rice fan, **fɛɛ** in Mende, is not said aloud when preparing to treat the infant in this way. The socially embedded and prescriptive nature of **Mende hale** underlines how healing is not just a technical process

but a thoroughly social one. The efficacy of the medicine depends on the quality of social relations; the rules of its use, which determine its effectiveness, are to a large extent concerned with upholding the authority of healers and other moral codes.

In contrast, Western medicines are sold without instructions and there is little guidance on administering them, except what people may know themselves, or what their (untrained) vendors may suggest. Old stocks of medicine from previous trips to health providers can also be re-used inappropriately, for instance the offer made by a grandmother of her typhoid medicine to treat the sore on her granddaughter's foot. Sometimes **pu hale** is used in unconventional ways, as in the practice of sprinkling the contents on an antibiotic capsule on to wounds to heal and prevent infection. Yet, although there may be an absence of biomedical guidance this does not mean there is a blank slate; when people are left to self-medicate they will build their actions on other precedents. Bledsoe and Goubaud (1985) observed that Western pharmaceuticals are subject to "reinterpretation" in line with Mende concepts of **hale**; the transformation of pharmaceuticals, such as injections, as they are incorporated into established healthcare systems has been observed elsewhere (Geest et al., 1996, Reynolds Whyte, 1992) There are suggestions of this in Tokenga, for example the practice of taking paracetamol daily to *protect* from fevers and colds echoing the protective qualities of some **Mende hale**.

It should be noted that not all **Mende hale** are subject to strict rules, and not all **pu hale** are unfamiliar. Indeed, there are traditional and biomedical medicines which are not subject to special controls, can be prepared independently and which villagers use regularly with equal familiarity. These are largely for those 'everyday' familiar diseases. Indeed it is these medicines that interviewees described using in their initial attempts to treat unknown cases of Lassa: ginger, pineapple skin tea, bitter leaves and bark, paracetamol. However aside from these common remedies, on the whole there are fewer restrictions governing the use of **pu hale** (at least that which is available in Tokenga), than on **Mende hale**.

Healthcare systems and the use of medicine within them are co-produced with moral and social order, as such they are historically situated and path dependant (Bloom and Standing, 2006, Janzen, 1981, Leach et al., 2008, Reynolds Whyte, 1982). In the Mende case, the rules and beliefs concerning how **Mende hale** works are embedded in wider configurations of a

social order based on secrecy and hierarchy. Mende society is made up of people belonging or excluded from different societies<sup>57</sup> and levels of hierarchy within these, each with their own areas of specialist knowledge, including health. There are both vertical (e.g. between all females in the Sande and between all males in the Poro) and horizontal (e.g. between senior society officials over younger initiates) manifestations of sodality and power (Bledsoe, 1984, Ferme, 1994, Hoffer, 1974). It is of particular relevance that **hale** also refers to secret societies (**Sande hale** and **polɛi hale**), as it underlines how **hale** is not just a material remedy but also the hierarchical knowledge around which social relations are organised. In terms of health, the restricted possession of **hale** (as knowledge or as material medicines) is precisely what makes it so powerful (Bledsoe and Robey, 1986, Jedrej, 1976a). These are the historical and social foundations which Mende therapeutic practice is embedded in, and which create highly structured domains of wellbeing and access to healthcare. The situation is somewhat different for **pu hale**.

Access to **pu hale** and biomedical treatment is, of course, restricted in important respects, both financially and through its own hierarchy of expertise, with community nurses at PHUs referring up to doctors at district hospitals. However, thinking of medicines as technology, it is significant that the production and use of **Mende hale** is set within locally meaningful 'techniques' and 'regimes' (Hopkins, 2004). Conversely when **pu hale** is imported into the village by drug peddlers and the like, it is done so independently of the techniques and regimes which were designed to support its use. While some biomedical therapies are incorporated into existing Mende regimes, partly collapsing distinctions between traditional and Western, the limited technical know-how of **pu hale** within the biomedical regime has serious ramifications for drug resistance, where the informal and un-regulated supply of western medicine is so prevalent. The issue has additional relevance to processes of Lassa diagnosis because, as will be reiterated in chapter seven, clinical diagnosis depends on an accurate history of previous treatments and responses to them, and if drugs have not been taken properly this becomes difficult.

### 5.3.3 Differential access to medicine and knowledge

The proceeding discussion of **hale** is closely linked to the issue of power as practiced by certain people drawing on distinct claims to knowledge. Biomedical health systems can be

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<sup>57</sup> Just as men and women have societies, so do witches and spirits

conceptualised as systems of organised access to expert knowledge (Bloom and Standing, 2006), and the ability to make a diagnosis is one of the main reasons for consulting a specialist health worker. As the preceding discussion of **hale** has alluded to, access to expert healing knowledge is equally structured. In this section I outline the various domains of power, knowledge and practice and reveal how they assist in finding out what is the cause of a sickness.

First there is Tokenga's residents own expertise to consider. They have considerable experience in recognising and treating common ailments, from rashes and sores to malaria, they are able to recognise the symptoms and respond effectively in many cases. When a sickness cannot be dealt with independently at home, the choice of village based **halemo** includes: the 'drug peddlers', herbalists, the TBAs, or the resident 'nurse'. In all of Tokenga's Lassa cases the advice of one of these people was sought initially; being located in the village they are an obvious first step when hospitals are so far away but the reasons one is chosen over another are more complex. The stated preference for **pu hale** is cross-cut by other considerations to do with payment, kinds of disease, as well as the regimes surrounding medicine use touched upon earlier. I found, in those who had knowledge of Lassa fever, a consensus view that there were no traditional remedies for Lassa fever and that going to the hospital was best. However, the difficulty in recognising Lassa means this can be largely irrelevant.

The herbalists and the 'nurse' have few diagnostic tools in the biomedical sense. Instead they rely on their accumulated specialist knowledge of disease and symptoms. The herbalists see signs relating to treatment outcome as they prepare **hale**, such as the colour of medicinal leaves when they collect them or whether the ropes fray and break as they twist them for malaria. The resident 'nurse' relies on his experience in pharmacies and has a medical text book he consults about symptoms. Interestingly the herbalists' signs concern prognosis rather than diagnosis indicating whether a patient will survive or die. The potential that sickness is due to supernatural causes calls for other forms of investigation, based the capacities of a limited number of people who have the powers to "see what is behind" a problem and then to deal with it appropriately.

When supernatural causes are suspected a 'witch doctor'<sup>58</sup>, *lookin gron*<sup>59</sup> or *kamoh*<sup>60</sup> are amongst those who can confirm whether it is so and assist if it is. Certain kinds of sickness are more strongly associated with witchcraft or 'bad medicine'. Sudden deaths and pregnancy have already been noted, but it can also be behind longstanding illnesses which are not cured by normal methods. For instance an elderly woman treated for months with **pu hale** and admitted to a hospital was eventually taken to a *kamoh*. A *kamoh* uses verses of the Quran to pursue outcomes as instructed by a client, this might include matters of love, work, school, telling the past or future, court cases, dealing with enemies, madness, or protection (Bledsoe and Robey, 1986). Because their privileged knowledge of Islamic texts is at the root of their abilities, the *kamoh* is regarded as good for dealing with devils and jins. In performing their work they may make a show of using Islamic writing; in Tokenga the *kamoh* wrote out a series of letters and symbols when I consulted him and made it clear his words of advice were based on messages derived from them. In general, they will not enter in to explanations in order to maintain secrecy and the respect which comes with it. Jins are said to have sodalities and the skill of the *kamoh* or *moriman* is to act as a broker (Bledsoe and Robey, 1986). Likewise, witches are always explained as having 'their own society', and that a 'witchdoctors' ability to defeat witches comes from their knowledge of 'witch business'. The *kamoh* in Tokenga, who was the Imam, said he could 'try' with witches but generally such things are left to witchdoctors. In Tokenga this is either the town chief who is a respected 'witch doctor', or a second man who visits Tokenga and has powers to 'fight witch' and 'drive it away'. The involvement of witches can be detected in a number of ways: by soothsayers and witchdoctors but also in dreams or by certain people who are deemed to have the power to 'see things', such as twins. The herbalists in Tokenga also claimed to be able to tell 'straight away' if a witch was behind an illness though they were not able to treat it.

In terms of authority and belief in healing potential there are some interesting shifts taking place around **hale**. Before the war, Carol MacCormack (1984) argued that the centralised, top-down, bureaucratic health system in Sierra Leone was dislocated from rural modes of authority. She pointed out that the limited manpower and resources which did reach those

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<sup>58</sup> 'Witch doctor' is someone who was able to 'fight witch', a somewhat ambiguously acquired skill

<sup>59</sup> '*lookin gron*' Krio for 'looking ground', someone who can see the past/future, similar to a soothsayer

<sup>60</sup> I use *kamoh* to mean someone who practices Islamic magic. Another Mende name for this was *moriman*. In Tokenga *kamoh* was interchangeable with *moriman* and soothsayer. This usage is slightly different from Bledsoe and Robey (1986, p223) who draw a distinction between a *moriman* as a practitioner of Islamic magic and a *kamoh* (also known as a *karamoko*) primarily as an Islamic teacher-scholar.



areas was often alienated from recognisable forms of health care expertise and delivery, such as the TBAs who are also secret society officials, and so lacked legitimacy. During my fieldwork people frequently told me they preferred **pu hale**. The campaign by Tokenga's residents to get a government clinic and nurse in the village was a good indicator of that preference, as well as some degree of approval for government healthcare. But the relationship with **pu hale** is complicated; villagers are aware and strongly disapprove of the counterfeit and expired drugs they are sold by *pepper doctors* (a negative term for drug peddlers or untrained providers). Equally they are not convinced by the integrity or quality of 'official' healthcare where prices are high and where, it is said, the nurses 'do not care' for patients. The negotiation of medicine and treatment is also a negotiation of the people and the systems providing it.

Some Tokenga residents expressed views which suggest MacCormack's argument still holds:

*"He didn't take the right medicine for that sickness, and even tests were delayed. The treatment should have been free, according to what we know. They didn't ask for money, money was there, our brothers were there... the government hospital mostly are not busy for patients, this is the main problem, they do not care for patients".<sup>61</sup>*

The pre-paid model that Sierra Leonean government hospitals work on is disapprovingly interpreted as hospital staff being more interested in money than treating patients. The lack of resources at these points of care leads to a further eroding of confidence. The nearest government clinic is often bypassed in favour of Panguma hospital because, residents told me, the nurse was often absent or had no medicines. The legitimacy of formal healthcare institutions is further undermined by incidents where holes in their claims to biomedical expertise are exposed. Lassa has a way of making the 'experts' appear incompetent, and stories like that of Mariama, who was misdiagnosed, are testament to this. This was what her husband recounted:

*"the doctors told us that they are trying. I asked them whether they would be able to cure my wife, and to know what really is affecting her. It is just at the later point that they told me it was Lassa, They didn't mention about Lassa when we were there for all the 14 days, except on the 15<sup>th</sup> day they reported that it was Lassa. We went to Kenema, we were there for only 4 days, then she died".<sup>62</sup>*

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<sup>61</sup> Patient's brother, Lassa history 2, Tokenga, 19/02/2010

<sup>62</sup> Husband of patient, Lassa history 3, Tokenga, 19/02/2010

Her husband described the hospital's initial diagnosis of Typhoid as "their first sin". Significantly, as I will come to, this is one of the cases which was widely reported as being witchcraft. Here the failure of biomedicine and common beliefs about pregnant women converge to challenge biomedical expertise and diagnosis, and keep alternative forms of authority alive.

The awful story of one family from a village which experienced an outbreak of Lassa fever in 2010 exemplifies the high costs of being on the very end of a poorly resourced health system where staff are not well trained. Four members of the same family contracted Lassa, and despite visits to the local government health centre, two children died before Lassa was queried, and a third child died later in Kenema, while their mother was left with severe deafness. When the first child got sick he was taken to the local clinic who said it was malaria. Medicines and injections were bought, but crucially the nurses did not transfer them on to a hospital until it was too late. As the boy's father put it in Krio: "*time don pass....no transfer we*"<sup>63</sup> (time passed...we were not transferred). The boy was not able to eat, stand, sleep, talk. His father told me that they did not make the trip to Panguma hospital because in his mind "he has died already". The second child fell sick a couple of days later and they returned to the clinic. This time there was no medicine and so the father took the child to a clinic in a neighbouring village. Lassa fever was not mentioned at either clinic, and that child also died. On his return to his village the man found his wife and another child sick, at this point the nurses finally called Kenema. The failure to pick up these cases early enough led to a request by village residents that the nurses be removed and replaced, who were fed up with the lack of attention and care which left them so vulnerable. In this case their wish was granted, with some additional advocacy help from the Lassa outreach team, however the under-resourcing and lack of proper training in Sierra Leonean health settings means that non-specific diseases such as Lassa will continue to present problems for claims to legitimacy and expertise; in such circumstances, the dynamics of such relationships could be shaken up if diagnostic technologies, such as RDTs, were to be made available outside of KGH.

Despite the tensions evident above, in cases of escalating severity a visit to a biomedical practitioner is usually regarded as the necessary next step for fever. But there are other factors at play in the decisions people make about where to go. It is striking that out of the

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<sup>63</sup> Father of patients, Lassa history 8, Foindu, 12/05/2010

accounts of Lassa fever I collected from Kenema Town, one from a nurse at the hospital, the majority of them went initially to private hospitals and pharmacies rather than KGH. One exasperated nurse put it down to “personal relationships”. Established trust and connections are understandably likely to be a significant in decision-making: out of Tokenga’s six known Lassa cases, spanning a period from the civil war until 2010, five of them were treated by ‘private’ pharmacists and ‘dispensers’; two of these saw no government representative and were never treated at Kenema. The first case fell sick during the civil war (1991-2002), he was treated for 3 days by a private pharmacist who gave him injections and tablets “but they never knew it was Lassa”.<sup>64</sup> After two days his brother came and took him to Blama (a town near to Kenema) to a private dispenser “who had a relationship with my [his] brother”. This dispenser recognised the signs immediately: “straight away he said it is Lassa”. He was treated by this man for a period of 40 days until he got better, though he did not recall with what as he had been too unwell to know what was happening. Though it was wartime and circumstances were strained, it is a striking example of Lassa being treated informally, especially given that the Lassa ward was so nearby. This case illustrates that there is a practice of treating Lassa informally, despite the attempts to centralise care in Kenema. While some private dispensers do refer suspect cases to hospitals, there are clearly those who actively discourage people and it is left to the outreach team to dissuade them from treating suspect Lassa patients, which would mean a loss of revenue for them.

A second of Tokenga’s residents was actually on his way to Panguma hospital when he encountered a private dispenser in Dodo who recognised he had Lassa telling him “this is not just an ordinary cold, this is Lassa”.<sup>65</sup> Both the sick man and the dispenser had heard of the lethal injection rumours and the dispenser advised him not to go to Kenema, telling him to go to Tongo where there were dispensers who could treat Lassa. He went straight to Tongo where another dispenser agreed it was Lassa because of his symptoms: sore throat, red eyes, and headaches. After at least a week of treatment and injections, at a cost of 40,000 Leones (£7.20 in 2010 exchange rates), he began to recover. It may be accepted that Lassa is not treatable with ‘herbs’, but there are apparently some informal providers of **pu hale** who will try to treat it.

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<sup>64</sup> Lassa history 6, Tokenga, 11/03/2010

<sup>65</sup> Lassa history 1, Tokenga, 18/02/2010

The TBAs are a good example of how health systems and healing practices cross-sect patterns of authority in other social and cultural domains. They are also of particular relevance here as Tokenga has seen three pregnant women die from Lassa and all of them were seen by the TBAs initially. This indicates that there are certain domains of expertise whose linkages to official aspects of the Lassa diagnostic system are of considerable importance. The linkages are complex. On one level, they have long been cultivated: TBAs have been encouraged to 'refer on' and feed into the government system for a long time (MacCormack, 1984). Some free health care has been provided to pregnant women historically too, but the dynamics changed entirely with the announcement of the Free Health Care Initiative in 2010. Even before that, I was told that pregnant women prefer to go straight to clinics if they are in the later stages of pregnancy. However, the walk from Tokenga to any of the nearest clinics was at least a few hours, able bodied; as such TBAs are an important source of general and emergency local care. A recent development is that TBAs have been banned from assisting in healthcare (Whitaker, 2012) making the links more precarious, though during my fieldwork they were still working and it is hard to imagine they would not continue to do so in the near future. The impact such developments have on how forms of expertise are accessed, and the consequences it has on therapeutic landscape and diagnosis have yet to become clear.

In the next section I outline how concepts of kinds of disease are implicated in healthcare practice. Diseases are defined not down traditional or biomedical lines as much as by practical concerns. The disease categories are practice orientated and as such they cut across the relationships and social dimensions of healings described so far. After that I discuss the way therapeutic options are also influenced by money, or *moni business* as it is known in Krio.

#### **5.3.4 Kinds of disease**

Taken as a whole, healthcare and disease in Tokenga is multiple and complex. Here I build on well-established studies of African pluralistic treatment environments (Janzen, 1978, Reynolds Whyte, 1982) by focusing on an overlooked factor which is variation in disease categories (Leach et al., 2008). The reason for this is that the scope for understanding 'natural' diseases is huge. In Tokenga diseases present themselves in many shapes and sizes. Some have clear symptoms or causes while others remain mysterious. Some are serious, others are less so. They can have biomedical names and definitions or descriptions which depart significantly from Western medical principles. At no point does sorcery have to be involved in

causing or treating any of them. There are multiple other classifications which determine how people respond first. Explanations of disease involve shifts between kinds of sickness which reveals a fluid understanding of illnesses. I suggest that these fluid perspectives on disease are able to accommodate and deal with the inevitable ambiguity.

Some diseases exist only as their symptoms, they include **joijoi** (hiccups), **hewei** (convulsions), **blaiblai** (cracked heels) **ngeloe** (when a child cries like goat). These are maintained to be distinct diseases. Descriptions of them reveal understandings of disease which contrast to Western biomedical ones. For instance, **joijoi** is thought to be a serious disease; it can 'come inside' other diseases and last for up to a week, leaving a person unable to speak or breathe, even causing sudden death. Other diseases have well known causes attached to their symptoms such as **kplee** (worms), **kraw kraw** (heat rash) or **bel wei** (malaria). Biomedical disease labels are used, such as pneumonia, dysentery, or gonorrhoea. Some biomedical names have been incorporated into Mende: **malari**, **typhoidi**, even **lassi**. But not everyone is at ease with this biomedical language, replying that they 'don't know about that' when asked. At times they seem to exist in little more than their abstract English name, as labels which are diagnosed and treated by unfamiliar people and in unfamiliar surroundings outside of the village.

There are some distinctions between diseases which are known locally and are part of a longer history of health knowledge and those newer diseases which have been learnt about through new (biomedical) forms of healthcare. For a long time I was confused by talk of a dramatic sounding disease called 'split head' which seemed fairly common. I established that it affects mostly women and children and causes a dip in the middle of the skull from the front to the back of the head<sup>66</sup>. Even on fully developed adults this can feel soft and fleshy instead of hard like bone. I was assured that this is a Mende disease treatable only with **Mende hale**. Western medicines are not believed to be effective, it is not something they have the power to deal with. Indeed every Western doctor I asked working in Sierra Leone had never heard of such a disease. Sierra Leonean health workers knew what it was but said that there were no treatments for it, except the 'native herbs'. I saw at least three cases during my fieldwork. It was also common to see evidence of it. To treat it a paste of herbs was applied to the soft

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<sup>66</sup> Down the sagittal suture in between the two parietal bones, or the fontanelles in children.

section of the skull and women who had been treated for it would have a characteristic bald patch down the middle of their heads.

Lassa is the opposite to 'split head'; as the villagers told me initially "[we] don't have the medicine in Mende for that."<sup>67</sup> it is a biomedical disease label which needs biomedical care in a biomedical setting. Yet this framing and course of action depends on Lassa being identified early which does not happen. The cause of many illness episodes, including Lassa, remain unknown. As such the disease classification system which has most relevance and impact on people's actions is the differentiation between an *ordinary sick* and *hospital sick*. Ordinary sicknesses can be treated with known remedies, traditional or biomedical, which do not require the patient to leave the village. Hospital sicknesses on the other hand need specialist attention which can only be found outside the village. Lassa is described as a 'hospital sick' because of its severity. All of Tokenga's healthcare providers agreed that it cannot be treated in the village, with either **pu-hale** or **Mende hale**. In contrast **kɔle wee** is seen as an 'ordinary sick', for which sufferers described taking different concoctions of pills, herbs and just waiting it out. An ex-Lassa patient's description of the beginning of his symptoms was typical: "*ah bin de feel say no more na ordinary cold, na mersin no more ah bin de drink, paracetamol*" (I thought it was just an ordinary cold, I just took some medicine, paracetamol).<sup>68</sup>

The boundaries between a 'hospital sick' and a 'ordinary sick' are not drawn around particular diseases, symptoms, or causes, but on levels of seriousness. Boundaries are, and must be, flexible as an 'ordinary sick' can quickly shift to 'hospital sick'; in rural contexts there is little alternative than a system based on waiting it out. As the accounts of Lassa in Tokenga make clear initially at least distinctions are not easily made: "We were thinking it was an ordinary cold or Malaria. This was our thinking, it's malaria. Because [the cold] was frequent, it attacked him frequently"<sup>69</sup>. The mention of malaria is pertinent as it is another disease which crosses boundaries, chronic as it is in Sierra Leone it is usually a routine 'ordinary sick' but it can also flare up into a fatal episode of 'hospital sick'.

In addition to severity, there are other implicit dimensions to 'hospital sick'. Lassa was described to me as having a 'big name' or as one man put it "*Dat sick, e nam big!*" (that disease,

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<sup>67</sup> Male, Sonnoh family, Tokenga, 12/03/2010

<sup>68</sup> Lassa history 9, Tongo, 24/04/2010

<sup>69</sup> Mother of patient, Lassa history 2, Tokenga, 19/02/2010

it has a big name).<sup>70</sup> This man described how he had been afraid when the doctor diagnosed Lassa: “*wae de doctor don prove say na Lassa, mi heart be worry, mi heart e be spoil*” (When the doctor proved it was Lassa my heart was worried, it ‘spoiled’; meaning it was heavy). Another expression in Mende was a **hiegbɛ wa** (a big disease), in Krio a ‘*big sick*’. As a renowned and fearful **hiegbɛ wah**, Lassa is an archetypal hospital sick. But with bigness and hospitals come implications: being away from work and farms, travelling long distances and, critically, paying potentially large sums of money. As such, routine life is severely disrupted, and can spiral out of control, once hospital care is sought. During a conversation with a man in another village he explained to me the fundamentals of treatment options for fever: “If you get money then if you have **kɔlɛ** you will go (to the hospital), if not you don’t go anywhere”. The same man who referred to Lassa as a ‘big sick’ (above) emphasised that people only survive if they have money and family: “*Wae dey no get moni, dey die*” (when they do not have money they die). He added later, “*dat sick, wae e move sombodi, if dey no get fambul, dey die. Becos, for carry n go any hospital, na big distance*” (that disease, when it infects somebody, if they do not have family they will die because to take them to a hospital is a big distance). These are the social relations of sickness (Young, 1982). Lassa is not just experienced through these money and relationship dimensions, it is fundamentally diagnosed through them, perhaps constituted too: with money, and family, a sickness can make the transition to become a ‘hospital sick’. Without money, it is more difficult. I will be relating this to the mangle of practice in more detail later, but I want to emphasise how the dimensions of diagnosis covered here can be interpreted as being forms of resistance which are encountered as a diagnosis emerges. The way these resistances are responded to, be they fear of going to hospital or inability to get to the hospital, shapes how, and if, a diagnosis of Lassa fever emerges with some very different consequences. Negotiating the cost implications of sicknesses and of various treatment options is the theme of the next section.

The transition from ‘ordinary sick’ to ‘hospital sick’ is a key step along the pathway towards the formal diagnostic system. However, when the label Lassa fever is applied to a ‘big sick’ it can, paradoxically, be a step in the wrong direction. In the lethal injection rumours the notion of a ‘hospital sick’ mutates in a way which has the potential to influence diagnostic pathways in a completely opposite way as the hospital becomes the one place to avoid. The rumour that Lassa patients are given lethal injections at Kenema was widespread. Ex-Lassa patients whom

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<sup>70</sup> Lassa history 10, Tongo, 27/04/2010

I interviewed from areas across the Kenema district recalled they had been scared to go to Kenema because of it. In fact the Tokenga resident who decided not to go to Kenema hospital after the dispenser told him he likely had Lassa gave it as his primary reason:

*“People were dying whenever they took them to Kenema hospital. If they are having Lassa most of them will not survive. So really that was my fears!.....By then Lassa had broken out around here, so any patient which they discovered had Lassa they took to Kenema hospital, if they see that you are not going to survive they will inject you to die”.<sup>71</sup>*

There are signs that belief in the rumour is diminishing; in Tokenga people usually said it was something they used to believe and (as expected) surviving ex-Lassa patients could all confirm that was not true. However, one woman in Tokenga maintained that hospital staff still do it (in the case of HIV too) in order to minimise harm to others. The infected person is killed, she said, to “let it no scatter” (so it does not spread). The supposed rationale therefore, is not evil health care workers but a fatalistic response to a situation where it is thought nothing can be done. Problematic beliefs such as these are most likely borne out of rumours (and experience) of high mortality rates combined with specialised and centralised treatment facilities which exclude those not with Lassa fever. Similar concerns about the distrust of health workers have been raised with Ebola (Hewlett and Hewlett, 2008).

### **5.3.5 Payment methods**

There are practical matters about how treatments can be obtained and how much they cost. There are significant differences in the way these treatments are paid for. As I previously noted, the tablets sold at the petty trade stall are cheap and priced like cigarettes ‘2 for 2 block’. The herbalists can be given ‘kola’<sup>72</sup>, perhaps 200 or 300 Leones, but sometimes food or other gifts. Mohammed, the informal village nurse, charged little or nothing for his services, only asking cost-recovery prices for any medicines he bought. If people did not have money he would accept rice. The visiting drug peddler’s business is based on monetary transactions which are mostly paid up front, though he allows some people to keep tabs with him. The key point here is that payments for the services of the ‘nurse’ and the herbalists (and to a lesser extent the drug peddler) are informal and can be paid after. Mustapha, the ‘nurse’, was

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<sup>71</sup> Lassa history 1, Tokenga, 18/02/2010

<sup>72</sup> This is generally a small gift or amount of money. The expression comes from the giving of Kola nuts. Kola nuts are grown in Sierra Leone but are traded throughout Africa. Within Sierra Leone they are used as offerings in key social occasions, including funerals and weddings. They break into two parts and so are often shared, which is part of their symbolic importance.



praised in particular by residents for the good he was doing for the community by providing nearly free-health care; one resident described him as “working for God”.

This is in stark contrast to the government and mission hospitals or clinics where payment must come first. People’s disapproval is expressed in the Krio phrase *‘pas you pull moni’* (not unless you pay). Admission to the nearest hospital, Panguma, was 50,000 Leones (£9.00 in 2010) which is a huge fee already but any treatment and procedures received would be charged on top of that. Operations could be hundreds of thousands of Leones, and if patients were referred on to hospitals such as KGH there would be a similar set of fees to pay again. Some suggested that in desperate times they may go to the hospital and see if someone there ‘will help you’ by lowering a price. Otherwise it was agreed that without money there would be no point in going to the hospital. People tell stories of wounded or dying people being ignored for lack of money. This would not actually be true in the case for Lassa as it is one of the few diseases in Sierra Leone where treatment is free. However although some people were aware of this, it was not common knowledge. Furthermore, given that Lassa is usually not diagnosed until a trip to the hospital is made it remains the case that people with non-specific febrile symptoms will perceive the monetary barriers as they would any other sickness.<sup>73</sup> And the histories of Lassa in Tokenga reveal that substantial amounts of money get spent in hospitals before the free care is reached on the Lassa ward.

The story of Kema the most recent case of Lassa from Tokenga demonstrates this all too well: Kema was 7 months pregnant, feeling feverish, with pain all over her body and especially in her sides. She was taken by her husband’s family to see Mohammed and the TBAs who both treated and monitored her. Onlookers speculated she had a sickness called **kotubee** which causes pain in the sides and so she was given the traditional remedy for that. After two days her condition worsened and she was taken to the clinic at Dodo in a hammock. There, the nurse gave her “an IV” (intravenous therapy) and for a while she seemed better. She was able to stand up and wash. Her husband went back to Tokenga to fetch 50,000 (£9.00 in 2010) Leones to pay for the drip while his mother stayed with Kema. Overnight she went into labour but there were complications, she was unable to deliver and the child died. When Kema’s

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<sup>73</sup> As the FHCI was only introduced in April 2010, after the bulk of my data collection, it remains to be seen how this will impact on health care seeking and Lassa diagnosis. Significantly, the months immediately after it was introduced the clinics and hospitals did see a noticeable increase in the number of women and children coming for care which should result in more Lassa fever diagnosis.

husband returned with the money in the morning he was told the news. At that point he remembers the nurse saying that she suspected Lassa: “she told us it is Lassa, she wore hand gloves”.<sup>74</sup> An ambulance was called to take them to Kenema, where after paying 20,000 Leones (£3.60 in 2010) for admission Kema was put on to the maternity ward. For a drip they had to pay another 15,000 Leones (£2.70 in 2010). During the night her condition worsened and the nurses told them to buy another injection. The doctor examined her the next morning and said he suspected Lassa. He asked them all to leave and arranged for her to be transferred to the Lassa ward. In all this time Kema had still not delivered her still born baby. Her relatives were told that the operation to remove the child would cost a further 200,000 Leones. As they did not have that amount of money with them Kema’s husband had to travel back to Tokenga to ‘find’ it. Kema died while he was gone. The money, which he had succeeded in getting together, was used instead to pay for chemicals to spray and wash the body, and to buy a shroud for burial. During Kema’s ordeal her husband had had to travel back to Tokenga to ‘find money’ twice. Neither the distances or the sums are insignificant but both were futile. Kema’s husband reflected on his wife’s illness:

*“at Dodo health centre they did their best, they tried, it is only god that did not allow her to live....at Kenema they tried but their problem is unless you buy whatever they need for treatment, if you don’t buy it they will not treat....I came back for money.”<sup>75</sup>*

Though treatments at Dodo and Kenema have to be paid for, the nurse at Dodo, who was known to them, could be paid later. Whereas at Kenema, Kema’s husband said, “if you don’t pay money they won’t do anything”.

Enlisting the help of a witchdoctor can rival hospitals in price. An initial consultation to a *moriman*, *witchdoctor* or *kamoh* could be as little as ‘2 block’ (200 Leones). However, receiving protection (often in the form of herbs and materials sewn into bundles to be worn or carried, usually in a concealed place) can cost as much as the hospital bills. The healers and witchdoctors do take on patients for long term treatment and usually the fee is paid as they go along or afterwards. In that way it is more flexible than a pre-paid hospital bill. One family had employed Tokenga’s *kamoh* to cure their grandmother who had been sick for a long time. He asked them for 300,000 (£54 in 2010) Leones and began treating her. The family had paid him 200,000 (£36 in 2010) for the initial stages of her treatment when the lady died. Angered by

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<sup>74</sup> Husband of patient, Lassa history 4, Tokenga, 09/03/2010

<sup>75</sup> Husband of patient, Lassa history 4, Tokenga, 09/03/2010

this, particularly because he had failed to warn them that she would die, the family had refused to pay the rest of the sum.

Evidently, the different sources of care bring with them very different payment arrangements. Many of the informal healthcare workers, including private pharmacists, village dispensers or herbalists, can be paid informally, perhaps after the treatment, in instalments or by other means such as rice. These transactions serve to build up, and on, personal relationships and are often interpreted as the healer 'caring' and 'trying' for a patient which is looked on favourably; on the whole, these are the elements considered as lacking in the formal healthcare settings. In terms of Lassa the free treatment is welcomed once people arrive on the ward but it does little to affect the perceived monetary barriers, as many people either do not know about it, or more likely do not know they have Lassa. This leaves the pathway towards a diagnosis of Lassa in a hospital setting as riddled with risks and costs. As the case of Kema shows, it is possible to pay a huge amount and still lose everything. For some the risk is too much. As the father whose story I told previously, who lost three of his children to Lassa fever, explained in the barest sense: when the clinic staff finally referred his first son to Panguma hospital the boy had deteriorated to the point that he could no longer walk, sleep, eat or talk. Doubtful that he would even survive the journey to the hospital he refused to take him, reasoning that his son would die anyway and he would not pay money for him to die: *"Ah say no, e don don, na die e dae die so, so ah no go pay no moni"* (I said no, he is finished, it's over, he has died already so I am not going to pay money).<sup>76</sup> This underlines the point made earlier about big sicknesses; payment is a cruel mediator in the way 'hospital sick' are, or can be, dealt with. Health and healing, with both **Mende hale** and **pu hale** is a social process; relationships, local categories and meanings are all important but frequently the final decisions are boiled down to access and finances.

## 5.4 How Lassa emerges

The activity to improve diagnostics being conducted in the Kenema lab is already having an effect, little by little; as diagnostics and surveillance improve village settings such as Tokenga are brought, unknowingly, into a global research machine. The trips to Kenema, 'pulling' of blood samples and visits from outreach and strange researchers like me are all impacting on how individual cases of Lassa fever come to be recognised.

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<sup>76</sup> Lassa history 8, Foindu, 12/05/2010

### 5.4.1 The process of diagnosis

The preceding pages have given an insight into aspects of therapeutic practice. I have tried to bring out the way they all have a part in shaping the Lassa diagnostic process. The process is not defined by testing instruments but instead it is a bricolage system which entails, to varying degrees: symptom recognition, the classification of severity, the use of different remedies, and visits to various authorities. The diagnostic label of Lassa is not usually applied until a trip to one of these authorities and usually to one located outside of the village. At most stages a diagnosis 'relies' on the failure of treatments as this provokes a trip to the next tier of healthcare. Most signs in this system point towards a hospital, for example there are not concerted attempts to treat it within village settings. Yet the process is still characterised by uncertainty combined with vulnerability because, on top of the risks that a trip to the hospital brings (whether it is fears of fatal injections, or cost), once there the uncertainty does not end. As the story of Mariama who spent 14 days in hospital before Lassa was queried shows, the stories of Lassa diagnosis are full of images of patients and their family being at the receiving end of clinical ambiguity. There is a sense among some families that it could have been avoided:

*"if they could have called or mentioned that it was Lassa maybe everybody would have been busy enough to contribute and to cure the man.....sometimes they [his relatives] called them [the doctors and nurses] to come to the bed but they never"<sup>77</sup>.*

Indeed sometimes the uncertainty appears to be increased by circumstances in health settings. Kema's husband reported that the nurse at Dodo referred them to Kenema, wearing gloves and telling them it was Lassa. The apparent failure to communicate the message of Lassa fever is a story echoed by a doctor in chapter seven who describes his misgivings about the delay in the case definitions and the poor communication between tiers in the health care system. Kema was not transferred directly to the Lassa ward where she could have started treatment earlier.

Until a patient's blood sample gets to the Lassa laboratory in Kenema no reliable or formal diagnosis of Lassa is possible. Even so, it is sometimes tentatively applied before that point. This no-man's-land of the illness/sickness experience is left largely to the peripheral and informal health care providers where there are contrasting approaches. Though there are

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<sup>77</sup> Brother of patient, Lassa history 2, Tokenga, 19/02/2010

times when cases suspected of Lassa are referred to appropriate government clinics but there were also cases where patients were referred *away* from Kenema. Then there were the times where Lassa went undiagnosed in hospital for many days. Before a patient reaches Kenema, and more specifically the Lassa Ward, there are many opportunities for cases of Lassa to slip away from the more formal parts of the diagnostic system. Significantly it is not beliefs or practices surrounding traditional medicine which seem to cause the most disruption to the workings of the formal diagnostic system; instead disruption is more likely to be caused by avoidance and distrust of Government providers, in particular due to cost and rumours about lethal injections.

Although the diagnostic system draws patients, and their blood, to a hospital, the test result which is so concrete for the scientists and doctors is open to different interpretations back in the village. Just because uncertainty is closed down in some people's eyes, it may not be universal; ambiguity can be pervasive if there are other things which can be 'behind' a sickness. The application of a Lassa positive label to a patient by experts, thorough laboratory or clinic based knowledge production contexts, may encounter alternative explanations once away from those contexts, as appears to happen with witchcraft. This shifting and uncertain terrain is a feature of Mende social life, and is often cultivated. As Ferme (2001) has pointed out, there are a multitude of everyday ways in which Mende culture is ambiguous, and that much of the ambiguity is deliberate and actively maintained. There is a resistance to static definitions, or simple dichotomies, which Ferme highlights by pointing to the position of the *mabole*, a gender ambiguous female member of the male Poro society, whose gender shifts across contexts; or to the inclusion of the child born after a set of twins in the category of twins, and their links with the spirit world which blurs the lines between supernatural and natural. Family histories, and ties to land are also concealed in different ways, being re-worked orally, which can obscure lineages of 'stranger', 'founder' 'newcomer' or 'slave' (Ferme, 2001) and can be used to political advantage (Murphy, 1980).

These ethnographies which identify a 'cultural idiom of ambiguity' (Ferme, 2001, p8) point out that this unpredictability has long been a part of Mende life; the 'sobels' during the war (soldiers by day, rebels at night) and the sudden wealth of diamonds are just modern manifestations of it. What is more, on a daily level 'practices of concealment' (Ferme, 2001, p8) serve to manage unpredictability, instability, and ambiguity, and even to add to it. The

Mende world is one where meanings are actively contested and it is of particular relevance to consider how this may disrupt biomedical diagnosis, which seeks to identify a cause by closing down the possibility of alternative meanings. It presents a challenge to the authority of doctor, or biomedical care in general, and is a reminder of the importance of other sources of **hale**, and the people or rules which channel its power. The meaning of a test result finds itself open to alternative meanings when one considers the Mende logic of witchcraft. Biomedical diagnosis and its practice in healthcare settings which are frequently found wanting in their level of care and expertise, may simply be more modern manifestations of uncertainty and unpredictability to add to the list.

As I have alluded to already, sickness in certain kinds of people is associated with being witches (pregnant women) or being targets of witches (children, successful people). Now I would like to turn to the ways those categories of vulnerable people cross-sect with Lassa fever, for which I draw on examples of actual cases in Tokenga. In doing so I return to the question I opened with about how local narratives surrounding Lassa, here witchcraft, impact on practices. What is clear from the accounts I was given, if they are to be trusted, is that there are not examples of people consulting witchdoctors or *kamohs* during the acute stages of sickness. This is important as at least two of the cases are widely linked to witchcraft, others occasionally, but those stories were less well developed. These accounts show that if front line everyday treatments in the village did not work, then biomedical treatment at a clinic, hospital or private dispenser was next. People's health seeking practices tend to lead them out of the village where the name Lassa is applied but there is sometimes ambiguity about these labels once back in the village setting. Mambu, the **Kamajo** son of the chief, was always said to have died of Lassa fever. Some doubts were raised about what had made him sick. For instance, in relation to rodents his mother expressed her reservations: "that is what the medical people tell us, but by then he was not eating rats".<sup>78</sup> Privately, an alternative explanation was offered. Another Tokenga resident, Sao<sup>79</sup>, had had a dream in which he saw Mambu being beaten with sticks by a group of people. He told Mambu's brother about this dream and the next day Mambu fell sick. The conclusion was that Mambu had been witched.

The second witch related death was pregnant Mariama whose story I have already told part of. She was in Panguma hospital for 14 days before the doctor queried Lassa. Another part of

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<sup>78</sup> Mother of patient, Lassa history 2, Tokenga, 19/02/2010

<sup>79</sup> Sao is a twin name. Twins have particular powers to 'see things'

her story, widely known in Tokenga, was this: the 'Joboi' devil<sup>80</sup> had visited Tokenga during the day where it had danced and entertained. Afterwards all the women had beaten Joiboi to the ground and tried unsuccessfully to drag him from the village. This was all done in plain sight for all to see (and will have been performed by a masked dancer). However when the devil finally left the village it was said that pregnant Mariama had continued to torment the devil and 'sat' or 'danced on the devil's head'.<sup>81</sup> This reported incident led people to the conclusion that her subsequent death was because she 'had witch' and had brought the misfortune on herself. According to Mende beliefs about pregnancy and witchcraft, if a female witch becomes pregnant then she must desist from all 'witchcraft business' for the duration of her pregnancy. If she does not, then she will bring harm either to herself or to her unborn child (or both). 'Dancing on the devils head' was interpreted as engaging in 'witchcraft business'. A good friend of Mariama's husband told me that when Mariama was taken to the hospital even though the doctors said it was Lassa, actually it was 'witch'.

These examples illustrate the instability resulting from a diagnostic category which is applied externally and then grafted on to local knowledge and experiences, where it can take on alternative meanings. A popular explanation is that if a witch is 'behind' a sickness it will either mean the hospital tests find nothing, or what they find will not be real. The witches play tricks on the doctors. It is important to note that these accusations of witchcraft do not appear to interfere with biomedical treatments or deter people from going to hospitals. In Mariama's case it was an 'after the event' explanation, and with Mambu, though the dream was reported to his brother before he fell sick, he was still taken to hospital. Indeed, some of these explanations provide interpretations of disease events which bounce off biomedical ones as opposed to being entirely separate and 'traditional'. The fact that Mariama's husband did not contract Lassa despite its apparent contagiousness was offered as another sign that her sickness was caused by her witchcraft. This is the plural model of disease causation described elsewhere in which biomedical or natural causes can co-exist with non-natural ones (Janzen, 1981, Reynolds Whyte, 1982). The day I left Tokenga I heard the following story which encapsulates this: a girl had woken up with a pain in her arm. She had had a dream in which she had been shot in the arm and so the consensus was that she had been shot with a witch gun. To deal with the 'witch bullet' she had been taken to a witchdoctor who removed it; to

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<sup>80</sup> Joboi was a devil from the neighbouring village. This village was said to have a lot of witches and strong spirits, Joboi was one of their most powerful devils.

<sup>81</sup> Versions of this story were told to me on three occasions by unrelated people.

deal with the pain she was taken to a clinic for painkillers. For health promotion and interventions to be successful the integration of biomedical and alternative beliefs about causation needs to be considered.

I was initially troubled by the implications these stories had, as 'to have witch' is hereditary the surviving family of Mariama or the chief's son would surely be cast in doubt too, but these paths did not seem to be pursued. It strikes me now that this is a continuation of the strategies of concealment and deliberate ambiguity which Ferme has shown are so pervasive and useful culturally. In terms of links between Lassa and witchcraft, pregnant women are more vulnerable to the stigma and ambiguity of what is believed (by others) to be causing their sickness. Even when a Lassa positive result can be received from the laboratory in Kenema, the diagnosis can still be questioned according to the cultural norm that things are not always as they seem. Improving the diagnostic tools which apply biomedical disease labels does little to suppress the instability and unpredictability of Mende life. The certainty that laboratory confirmation should bring is not recognised everywhere. This does not amount to reliable knowledge about disease causation in a village context.

Given the central importance that getting to a hospital has for Lassa diagnosis, it would be incomplete to end this discussion without mentioning the wider social factors which facilitate, or hinder this journey. Young has defined sickness as the "process through which worrisome behavioural and biological signs, particularly ones originating in disease, are given socially recognizable meanings" (Young, 1982, p270). The process of getting to the hospital, or a clinic, or a private dispenser is encompassed in his use of 'sickness' and which I equate to the diagnostic system and navigation of therapeutic landscape. What I have shown is that it depends on more than just how symptoms present and are interpreted. All healthcare options are not equally possible. Depending on whom you are and where you are, the process is an unequal one characterised by the quality of your social relations.

If you have a **hiegbɛ wa** then the trip to a hospital which would transform it into a 'hospital sick' is not a free move. First, there is the 'money business'; as the saying goes '*pass you pull moni*' (unless you give money): you must have money to go to a hospital. Second, to get to hospital also requires resources of a more social kind. People might need to be literally carried there. Sometimes these dependencies are made explicit, as in (the perhaps empty)



threat in Tokenga that if a person known to have eaten rats gets sick they will not be carried to hospital. The reality is that some people have more of these resources than others. This would apply to 'finding' or borrowing money to pay for emergency healthcare too. The phrase 'wealth in people' (Bledsoe, 1980) has been used to describe the patron-client relations that pervade social and political life in the region. 'Health in people' could be a fitting adaptation to describe one of the key elements needed to attain some degree of security over wellbeing in rural villages. The same inequalities are present in death; on my last trip to Tokenga the chief's son died. One the same day another woman also died but she was a 'stranger' and her death was barely noted, contrasting with the steady stream of guests arriving from as far as Kenema and Freetown to pay tribute to the dead man.

The social relations of sickness were evident in similar ways for Lassa and influenced the experience of being diagnosed with Lassa and what Lassa comes to symbolise for them. The Lassa ward's clinical staff play a pivotal role; some ex-patients speak of them as if family, they credit them with bringing them back from the brink of death and for their kindness during recovery. Also important is how they are treated by friends and family. Though the ward operates an isolation policy there are spaces for visitors, which is often so crowded with guests you could forget it was the dreaded Lassa ward; but the flip side to this was the patients who spoke of no visitors and of people 'running from them'. Being avoided by companions was usually only mentioned after diagnosis, for a limited period during and after recovery, as fear of the name Lassa set in. A nurse, who contracted Lassa while working at KGH in 2008, cried as she remembered how people avoided her, refusing her food or any contact with her, she said, "that made the sick aggravated. Really, because there was nobody around me. The neighbours were there, but no assistance".<sup>82</sup> She said when she was in the hospital she had few visitors; when some friends from the hospital did come she was so glad and took it as a sign that she was going to survive.

These issues are cross cut by the macro dynamics of the Sierra Leonean health system. The health service landscape is filled by different programmes and policies which give preference to particular groups (i.e. those covered by the FHCI) or particular diseases (i.e. HIV, TB, and also Lassa), for which treatment is provided free. In these it is inscribed that who you are makes a difference to the barriers you will encounter. However, even though Lassa treatment

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<sup>82</sup> Lassa history 11, Kenema, 14/04/2012

is provided free, as most people are unaware they have Lassa until they go to a hospital, the economic barriers remain.

#### 5.4.2 “We are just learning that name”

There are signs that the biomedical disease Lassa fever is converging with local framings of fever. The name Lassa is relatively new to Tokenga’s inhabitants. Time and again I was told that Lassa was something they were only hearing of recently: “I never knew of Lassa before...it is just recently now we are hearing about Lassa”.<sup>83</sup> This does not mean that the sickness is new to them, some people described how they have suffered from it in the past but they have only just learnt the name Lassa: “People used to get this cold, then later people would talk about Lassa, normally they will not survive, only occasionally”.<sup>84</sup> Another man told me: “it has killed people here, a lot. It is just now the people have discovered it is Lassa. Formally it attacked people here, they were just treating people with native medicine until that person either survives or dies”<sup>85</sup>. In this way, Lassa fever is framed as a longstanding sickness. It is increasingly associated with, and described as, **kɔɛ wa**. The merging of Lassa fever simultaneously presents Lassa as a disease which is not new while also narrowing down what **kɔɛ wa** signifies.

During my fieldwork **kɔɛ wa** was frequently translated as Lassa, and Lassa as **kɔɛ wa**. It appeared that **kɔɛ wa** has become Lassa. One man summarised it thus: “formerly [we] did not know that name Lassa, [we] were just calling it **kɔɛ wa**. Just now [we] have known that **kɔɛ wa** is Lassa”<sup>86</sup>. However, another man ridiculed such statements, “people have been saying that **kɔɛ wa** is Lassa, but there are many others, we Mende just box them all together under **kɔɛ wa**”. When I asked whether other diseases with fever such as malaria, pneumonia, or typhoid could be **kɔɛ wa** the answer was mostly no. In practice when someone falls ill there is little way of distinguishing kinds of fevers based on symptoms alone. Though it is interesting if the significance of **kɔɛ wa** is changing from meaning something more general to something much more specific, in practice the same diagnostic processes apply.

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<sup>83</sup> Mother of patient, Lassa history 2, Tokenga, 19/02/2010

<sup>84</sup> Male, Turay family, Tokenga, 13/03/2010

<sup>85</sup> Male, Sonnoh family, Tokenga, 12/03/2010

<sup>86</sup> Male, Sonnoh family, Tokenga, 12/03/2010

As this chapter has illustrated, diagnostic practices and processes are not disease specific but instead are related to more flexible notions of 'hospital' and 'ordinary sick'. In turn, the framing of Lassa as a 'big fever' means it is relatively open and inclusive so picks up all manner of non-specific fevers. It is in contrast to the pathogen specific diagnosis which brings the Lassa surveillance and outreach operation to the village. Arguably the link in Tokenga may have been strengthened by the outreach team's recent visit, though it was not just in Tokenga that I was told **kole wa** meant Lassa, it is common in other villages too. Sensitisation to Lassa is not a new thing, the remnants of old Lassa fever awareness public health campaigns can be found in faded posters or on old t-shirts worn in villages across the region. Although awareness is still a long way off 100% it appears that, for many, **kole wa** and Lassa fever have come to mean a distinct disease, at least in Lassa heavy regions.

There are two dominant issues emerging out of the Lassa sensitisation by outreach teams so far. The first is to do with hygiene and the second concerns the rodent hosts. Both topics are associated with stigma. This is not directly the result of the outreach team but of the health promotion efforts more widely, and historically. To begin, Lassa has become negatively associated with poor hygiene. People in Tokenga will criticise those in their own community for not being clean enough, comparing it to other villages which they said were cleaner and pointing to that as the reason for Lassa in Tokenga. It seems the outreach team's advice about keeping the environment clean can be re-interpreted as a criticism of poor hygiene which labels certain towns, places and even people as dirty. One measure promoted by the outreach team to fight Lassa was to keep a cat. Once on a meeting with the paramount chief of Lower Bambara chiefdom (headquarter Panguma), I naively asked if he would be getting a cat to which he replied, stiffened and seemingly offended, that he did not need one because his house was clean.

Knowledge of the *Mastomys*' role as the reservoir for Lassa was patchy. Some would venture that *arata* were the source of Lassa but this is usually couched in uncertainty, for example I was told: "We don't really know what causes it, it is just recently they are saying it is caused by rats"<sup>87</sup>. Dig deeper and people's perspectives on the origins of Lassa are more complicated as the public health message meshes with local knowledge. People often focused the connection on the link between eating rats and getting Lassa which provoked some doubt:

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<sup>87</sup> Male, Turay family, Tokenga, 13/03/2010

“the doctor used to come here and they advised people not to eat rats because they said the rat causes that. Those people who that cold attacked they are not eating this rat. Most of them, because I can’t talk for them all”.<sup>88</sup>

The link with rodents is complicated by their dietary and social significance. Eating rodents is common in Sierra Leone. Though it is hard to collect data on this as most people say they no longer eat *arata*. When probed they would also tell me they tasted ‘sweet’. Some young boys said they didn’t believe it was the cause of Lassa fever because they had eaten *arata* and they did not get sick. This line of argument, whether rodents had or hadn’t been eaten and what the consequences were, shows an appreciation of biomedical causal explanations for Lassa fever infection. At the same time it also challenges them. Mostly, at least when talking to a white female researcher people would deny it and use it as an insult against others. After interviewing the family who had lost three children to Lassa fever their neighbour told me, disapprovingly, that he had seen the family eating rats.

The stigma of eating rats is fed by the public health messages<sup>89</sup> and subsequent laws against rat consumption. Those messages are in stark contrast to a ceremony called ‘feeding the palm’ which was to be performed in a nearby village. The ceremony is carried out exclusively by men with the intention of protecting the men who climb the tall ‘native’ palm trees to harvest their kernels for palm oil (as shown in figure 16). It takes place around March and April before the harvest. All the men who intend to climb for that year’s harvest are required to catch between 10-30 *arata* as a contribution. The preparations, involving catching, roasting and drying the rodents can start up to 2 months before the ceremony takes place. All kinds of *arata* are acceptable, except the ‘one with the long mouth’ (**tuile**<sup>90</sup>) which is said to have a bad smell and be the ‘Lassa rat’. The rodents are caught using a type of trap called **torlei**<sup>91</sup> (see figure 17) which I was told is made especially for small rodents and ‘no other beef’ (no other meat). The trap is left overnight with bait to tempt the rodents. The men then cook rice and a stew with salt, hot pepper and the ubiquitous MSG laden ‘Maggi’ flavourings. An offering of this food is given to spirits in a ‘secret place’ and one man will climb a designated palm to

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<sup>88</sup> Male, Amara family, Tokenga, 13/03/2012

<sup>89</sup> Apparently NGOs in the 1980s devised health promotion songs for Lassa fever

<sup>90</sup> My spelling

<sup>91</sup> My spelling

scatter food over the top saying “here is your own food, be generous with us, have a cold heart<sup>92</sup>”.

**Figure 16 A man climbing a palm tree to collect kernels for oil**



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<sup>92</sup> Cold heart is used to mean kind and peaceful, the opposite of a warm heart which means angry, fiery or vengeful.



The link between the palm and the 'rat' is that there is one 'rat' species in particular, known as **segei**<sup>93</sup>, who 'loves the palm' and is always found amongst the fronds at the top eating the palm kernels. By feeding the palm tree with rodents, the hope is that the **segei** will then stop feeding on the palm. During my first visit the men in this village had begun preparations for the ceremony and it was to be the first time they performed the ceremony for years, having stopped during the war. They were bringing it back because a number of men had fallen while cutting palm kernels. However, on this occasion the ceremony did not take place. On my second trip I was told that the election of a new village chief had disrupted their plans, so they had had to cancel it, but had eaten the rats anyway. In Tokenga, I was told the ceremony had not been performed since before the war. Their reason for stopping was that eating 'rats' was against the teachings of Islam.

**Figure 17 Rodent trap, with mock 'rat' on right**



A final point about the convergence of local and scientific health messages is that the new biomedical explanations of **kole wah** and its transmission, accepted or not, are strongly couched as coming from outside sources. Usually this is described as from 'the whites', though sometimes 'the doctors': "I don't really know where to get it but the white people are saying

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<sup>93</sup> My spelling

from the river or rats. [but we] do not yet know how really it attacks”.<sup>94</sup> Lassa is portrayed as something which they are told about, and as a topic about which they lack the expertise to ‘really know ourselves’. There was considerable use of the phrase “we are told” accompanied by an apparent reluctance to question it: “I will not deny the doctor. I will not doubt what they say”.<sup>95</sup> The disenfranchisement from medical knowledge about Lassa is striking, though perhaps less so considering the highly controlled and hierarchical system of specialist knowledge and power traditionally found in Mende communities. Medical knowledge surrounding Lassa may seem as off limits as certain aspects of secret societies. However although on one level there is acceptance of biomedical accounts, this chapter has also shown how, away from doctors, there is space for doubt and ambiguity where alternative explanations can flourish.

### 5.4.3 Uncertainty after diagnosis

The ambiguity experienced throughout the process of Lassa diagnosis is great and brings with it significant risks and vulnerability. I have discussed the uncertainties during the run up to a diagnosis and the ways these are negotiated, and also the subsequent underlying ambiguities over the ‘proof’ of a test result. There are further uncertainties which arise after a case of Lassa which are to some degree an outcome of the global research apparatus, which is driving the effort for improved diagnostics.

The arrival of the team and their surveillance activities make a big impact. Some have their fears calmed. A woman who was caring for a patient before they went to hospital told me:

*“We were tested for Lassa, it proved negative. She ate food and gave me the balance, or drank water from the same cup, but my result was negative. I was worried that I could have it, because they said it was transferable, but they tested my blood and it proved negative. I was so worried”.<sup>96</sup>*

For others it raises new questions and uncertainties to confront. One man expressed how the ambiguity over how you get Lassa, and who has it, pervades all areas of social life: “Here we don’t know, we just live together, we don’t know who has Lassa. According to what you hear, you cannot eat with a Lassa person, but we eat together....we share jokes, this is what has

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<sup>94</sup> Male, Sonnoh family, Tokenga, 12/03/2010

<sup>95</sup> Male, Turay family, Tokenga, 13/03/2010

<sup>96</sup> Carer of patient, Lassa history 4, Tokenga, 09/03/2010

given us doubt....we don't know".<sup>97</sup> The plastic yellow tape which is attached to houses sampled for trapping and inspection by the outreach team is often left attached, a lingering reminder of these doubts and unanswered questions.

It is interesting to consider this in the context of international biomedical research, where interpretations of research projects and institutions have been shown to be shaped by broad historical and social perspectives, for instance, of blood stealing white people (Fairhead et al., 2006, Geissler and Pool, 2006). Although the injection rumours are clearly an example of distrust of both national and foreign providers of healthcare, the international research efforts surrounding it were less obviously negatively perceived. Partly this must be to do with limited awareness of the research machinery that patients and villages were now part of. However, in subtle ways they did see and feel its impacts. On both surveillance and research calls, the outreach and ecology team will take blood samples from case-contacts or from old follow up cases (for research purposes) as well as conducting overnight rodent trapping in selected houses. After such visits a number of Tokenga's residents and ex-Lassa interviewees vocalised their ambivalence. One resident explained:

*"They only tested relatives that were around the people who passed away. According to our experience we are in the circle of Lassa (points around him) here, here, and here. But they only tested people in this area, where the last case was"*<sup>98</sup>.

The arrival of the team can be welcomed, but equally it can deepen uncertainty as to what is happening and why. The health promotion video and talks explain where Lassa comes from and what should be done to avoid it, but why some people get tested and others do not, or why some houses were selected for rat trapping and others aren't, is less well communicated. A number of the ex-patients I interviewed enquired about follow up activities when the outreach team had come to take further samples from them. One man described: *"dey cam investigate how de sick he don do well with me.... dey cam pull de blood back. Dem say dey de go test am but from dat time we no bin de yeri abot de results yet"* (They came to investigate how I had recovered from the sickness, they took a blood sample. They said they would go and test it but from that time we haven't heard about the results). He told me he wanted the results: *"Ah wan get di information"*.<sup>99</sup>

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<sup>97</sup> Brother of patient, Lassa history 5, Tokenga, 11/03/2010

<sup>98</sup> Brother, Lassa history 6, Tokenga, 11/03/2010

<sup>99</sup> Lassa history 9, Tongo, 24/04/2010



Many others asked me similar questions about if I knew why the team had come for follow up samples of their blood. They wanted to know if I knew what their results were and what it meant, could it mean that they could still have or catch Lassa? Lastly, some villagers in Tokenga are under the impression that they will be given the results of these tests, which is not the case. One of Tokenga's residents, the headmaster at the neighbouring village's school, informed me that the outreach team had come to catch rats on which they would perform tests to prove whether Lassa was in the village. He said for now they were still awaiting the results, but they would soon be returning with the results. His take on the outreach and surveillance activities shows how the rationale behind the case-contacting, trapping and sample collection are not differentiated at the village level. As a result, they can be the cause of concern as villagers are left in doubt and waiting for answers.<sup>100</sup>

## 5.5 Conclusions

The formal diagnostic system and the main institutional narratives which surround it are both conceptually and spatially distant from life in Tokenga and places like it. Aspects of them, such as the outreach team's visit and the 'pulling' of blood, can nevertheless be felt. The mangle of practice's back and forth starts within the village's therapeutic landscape. Routine healing approaches are twinned with routine symptoms: for small fevers there are 'tabs' of 'panadol' or bitter barks. This is familiar territory and usually 'ordinary sick' and can be dealt with: it is a stable relationship. Uncertainty does creep in through and there are doubts about the quality of some medicines. The stability can be disrupted if the sickness proves not to be dampened by ordinary treatments. The virus exerts its agency and resistance is manifested as un-dampened fever or other unexplained pains and symptoms. In response, other therapeutic avenues are considered. For example a local healer may be sought, perhaps a practitioner of **pu hale** or **Mende hale**, or both. Kinds of sickness can mediate the decision, but most of all it depends on social relationships and money, as the categories of sickness themselves are generally flexible. Money and relationships become more important as symptoms get worse and can themselves count as resistances: 'big sick' and 'big fevers' require big money and support to get to hospitals. At hospitals there is perceived to be less care and the risks and costs are higher, in such contexts, healing has to be negotiated differently. At various turns the sick, or their carers, can choose alternative routes, for example, by not going to hospital and

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<sup>100</sup> The Tulane team considered it unethical to give results to villagers of invalidated diagnostics. However they were used for clinical and contact tracing purposes.

choosing a private dispenser. The diagnostic pathway for Lassa fever emerges in this mangle of practice. The name 'Lassa' has its own local associations which influence decisions: lethal injections and witchcraft are used to make sense of the progress and treatment of the disease. Overall, local framings of disease and Lassa fever, such as 'big fevers' and 'hospital sick', reveal a fluid understanding of sickness and therapeutic practice. It is an approach which appears to acknowledge that certain aspects of health cannot be pinned down and as such it provides a way to live with uncertainty and the limited options available.

## 6 'An emerging paradigm': diagnosis in the laboratory

In contrast with the previous chapter, here I explore the framings, narratives and practices of Lassa fever diagnosis in the laboratory at Kenema Government Hospital (KGH). As noted in chapter four, the 'Lassa lab' is indispensable in the formal diagnostic system and the foundation on which surveillance, response and capacity development efforts are built. The laboratory is the place where officially a case of Lassa fever is confirmed and as such is the link between proven and unproven, countable and not countable. Modified versions of the global threat and neglected disease narratives are most obvious in this setting, which is unsurprising as they both conclude with the assertion that more science and research is needed to address the problem of Lassa fever. This chapter describes how the resulting investments in diagnostics have influenced activities in the laboratory and the diagnostic system.

In this chapter I will show that the developments in the laboratory are reshaping the knowledge base for Lassa fever not only in terms of *what* is known about the disease but also *how* it is known. There was an opinion among some laboratory researchers that the core body of knowledge about Lassa fever was based on unreliable clinical observations. As a senior laboratory scientist once put it to me, "doctors speak for what we know about Lassa". However during the course of my fieldwork 'the lab' increasingly asserted its own claim of authority regarding Lassa. Laboratory scientists talk of the existing body of knowledge (i.e. information contained in scientific papers) as 'dogma'. They view this canon of received wisdoms about the disease sceptically and see their work, sometimes zealously, as correcting it. An aspect of 'dogma' that I focus on in particular is the interpretation of Enzyme Linked Immunosorbent Assays (ELISAs) which test for Immunoglobulin M (IgM, an antibody). An article published in 2011 claimed that the "current diagnostic paradigm for acute LF (Lassa fever) should be reconsidered" (Branco et al., 2011b p1) in light of emerging knowledge about the disease gleaned from laboratory developments. It argued that the role of IgM needed to be redefined and specifically, that an IgM positive result in West African populations should not be considered a diagnostic marker. This chapter explains the conditions under which this revised view of Lassa fever diagnosis was achieved. The 'emerging' diagnostic paradigm should be seen as setting into motion a reframing of Lassa fever and a re-orientation of disease and diagnostic systems, which is part of a wider process which I am describing as

'laboritization' after Knorr Cetina (1999). I explore the dynamics and narratives of laboritization, looking to see how it is upheld in practice, but also where there are limits to it.

## 6.1 Laboritization

In *Epistemic Cultures*, Karin Knorr Cetina uses the term 'laboritization' to indicate the process by which a 'field science' becomes a 'laboratory science' (Knorr Cetina, 1999). Knorr Cetina argues that movement of objects into new environments in order to study them reconfigures them, and in the process, it also reconfigures the people studying them. In her words, they are 'enhanced' (Knorr Cetina, 1999). I argue that Lassa fever diagnosis is undergoing its own process of 'laboritization': blood and other bodily fluids are taken out of their natural habitat, the patient's body, and reconfigured by placing them in a laboratory and subjecting them to laboratory processes.<sup>101</sup>

In Knorr Cetina's original conceptualisation Laboritization is a social process through which both natural and social orders are renegotiated as a result of procedural and technical manipulations in the laboratory. The term is helpful because it conveys the sense in which the resulting transformations are the result of a very particular framing of Lassa fever, which is context specific: the 'emerging diagnostic paradigm' is a *laboratory* narrative and in many ways it is limited to laboratories. Thus, laboritization should be understood as a trajectory which is in keeping with the narratives surrounding Lassa fever which call for more control of the disease through improved and increased research on diagnostics (Gire et al., 2012, Khan et al., 2008). In these narratives, complete laboritization is a desired endpoint which will make diagnosis and health systems stronger and more scientific.

The social dimensions of laboratories and laboritization must not be underestimated. Knorr Cetina's term applies to the organisation and transformation of people in the laboratory as well as specimens. Laboratories have distinct social structures; they are spoken of as 'belonging' to the senior scientist who is in charge of them. When Tulane were in Kenema they transported their hierarchy from the US to the Kenema laboratory. The hierarchy went from the senior researcher, through the doctoral students in order of experience and down to any assistants accompanying them. By and large, the senior members of the team directed the

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<sup>101</sup> A potentially important dynamic in this process would be the influence of rapid diagnostic tests which imply the reverse by taking the laboratory back into the field. These tests are in development for Lassa fever but they were not being used widely during my fieldwork.

research activities which took place within the laboratory. The 'Lassa lab' was sometimes referred to as the 'Tulane lab' by people in Sierra Leone, a point bitterly contested by the WHO, who have also invested in it<sup>102</sup>. When the Tulane researchers were not in Kenema the hierarchy in the Kenema laboratory was notably less. There is a senior technician who is in charge of the two younger male technicians but activity in the laboratory is generally routine and by rota. The senior Lassa laboratory technician has worked on Lassa fever for years but, as the Lassa lab only became operational in 2006, the other two technicians are some of the newest members of the wider Lassa team. One of them runs his own small laboratory privately on the side and the second, who joined just when I arrived, had just finished college. He replaced a previous technician who had gone to Ghana for further training. He too was eager for training and accreditation opportunities. When Tulane are in Kenema there is a noticeable split between those involved in research (the US visitors) and those performing the clinical diagnostics (the Sierra Leonean technicians). These divisions have some bearing on how risks and uncertainties are experienced and dealt with as I will come to in later sections of this chapter.

The point of a biosafety level 3 (BSL-3) laboratory, as the one in Kenema is supposed to be, is that it is distinct from the outside world. The 'Lassa lab' is located towards the back of the hospital grounds, at the bottom of an incline. The building houses the Lassa fever project office, the Lassa outreach and surveillance office, as well as the hospital's general laboratory. The ecology team, who trap rodents on outreach and research trips, are located in an adjacent building. The staff of both the general and Lassa laboratories, who are mainly male, often sit under a mango tree near the building waiting for samples to come in or for procedures to run. Inside the Lassa laboratory the atmosphere is somewhat different. Lab coats, boots, goggles and facemasks are worn, and entrance and exit are through different doors. Boots must be bathed in disinfectant and gloves discarded upon exit. Inevitably, rules get relaxed the more time people spend in there. Masks come away from faces and people pop their heads round the doors to chat. Both the laboratory cleaner and the engineer routinely came into the laboratory wearing shorts and sandals. Relaxed the rules can be, the reasons for the precaution is never too far away: while visiting the Lassa ward one day I was surprised to hear the voice of that same cleaner from inside one of its rooms. He had come down with fever and had been admitted to the ward as a precaution. After spending a few days there it was

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<sup>102</sup> WHO representative, Geneva, 14/12/2012

determined he did not have Lassa fever and he was discharged. Another time in the laboratory Tulane were running some tests on a sample which had already been confirmed positive. High levels of virus had been found in the sample and the patient had died a few days before. The senior technician warned everybody in the laboratory to “double glove” because the sample was “hot”. Both these incidents exposed the underlying threat which is easily normalised. They also expose the way human behaviour is supposed to be disciplined, part of laboritization, to limit such threats. As this chapter will show controlling both human and material agency is a difficult and often incomplete task.

## **6.2 Narratives of Lassa fever diagnosis at work in laboritization**

Knorr-Cetina’s original use of laboritization was to highlight the transformation and manipulation of objects coming into the laboratory; in this chapter I set out how these processes have occurred for Lassa fever. I show how attempts have been made to make Lassa controllable and stable, to behave reliably enough to diagnose. Two sub-narratives have driven these efforts. They are recognisable as related to the narratives in chapter four which concluded technology was the pathway out of neglect. In the first, the global threat becomes a research and commercial opportunity. In the second, high quality diagnostics are needed to unravel the ‘dogma’ of Lassa research and pave the way for a new paradigm. Both sub-narratives work with aspects of the framings introduced in chapter four. Essentially they view Lassa fever as an uncertain object but one which can be brought under control, a process in which improved diagnostics are a necessary and critical first step. Both of these framings have influenced the way diagnostics have been developed, by whom, for whom, and where and how they are used.

### **6.2.1 The global threat becomes a research and commercial opportunity**

The implications of the global threat narrative are that it has enabled Lassa, and Lassa diagnostics, to become a viable commercial research opportunity. The ‘category A’ framing has brought in investment for Lassa but these resources have been won for reasons other than the local disease burden which, in practice, has resulted in tensions over conflicting agendas. This essentially vertical investment with its emphasis on product development (and silver bullet expectations) contrasts with the humanitarian operations of past and present NGOs.

The main manifestations of the global threat narrative, namely the BSL regulations and the category A status, impinge on work in the laboratory in different ways. The biosafety levels denote risk minimisation practices and are primarily concerned with protecting people handling pathogens in medical or scientific laboratories, while bioterrorism categories denote potential biological threats, and are largely concerned with protecting specific populations. The different rationales behind each classification means their impacts are distinctive. The BSL regulations have meant that providing diagnostics for both research and diagnosis has been challenging and has contributed to the air of uncertainty. I deal with these in the next section. For this first sub-narrative the Category A framing has had the most impact.

The category A status looms large in the laboratory, indeed it is the reason the work is taking place in the first place. The first line of Tulane's successfully funded bid to the United States' National Institute of Health (NIH) to develop the recombinant ELISAs states that the project will develop "Diagnostics for Biodefense". It continues later:

*"Because of its high case fatality rate, ability to spread easily by human-human contact, and potential for aerosol release, LASV (Lassa Virus) is classified as a Biosafety Level 4 and NIAID Biodefense category A agent. The potential use of LASV as a biological weapon directed against civilian or military targets necessitates development of "effective, rapid, highly sensitive, specific, easy to use, adaptable, and cost-effective medical diagnostics for public health laboratories, hospital-based clinical laboratories, and point-of-care use" to diagnose individuals exposed to and/or infected with LASV" (Garry, 2004 p64).*

In private researchers debate the category A classification: some do not think Lassa virus is likely to be used as a bioterrorist weapon or that it would make an effective weapon if it was used. It is regarded as excited exaggeration:

*"How likely is Lassa to become a disseminated biodefense agent? I don't know, I think probably not very likely....There are people I have spoken to who really firmly believe that Lassa doesn't even belong in the category A. It is just an issue of a little bit of sensationalism".<sup>103</sup>*

You need not look far for examples of that sensationalism, the newspaper article which described the Kenema operations as a "U.S. anti-terror outpost" (Akam, 2011) is one. Yet, while at times the researchers try to distance themselves from such sensationalism, at others they are aware of its utility for funding and they actively evoke it. In the search for research

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<sup>103</sup> Tulane laboratory scientist, Kenema, 02/03/2010

funding the categorisation of Lassa as a bioterrorist threat opens up new possibilities for research into Lassa:

*"If you fell into the category A, that's where the big money was. Ok so if you wanted to do big money research you had to come up with some really good ideas, whether it was diagnostics, or vaccines or therapeutics.....if you picked a category A agent your chances of being funded probably went up significantly. Kind of, sort of, in a way, why we're in it, OK?"*<sup>104</sup>

Researchers themselves claim to be more concerned about local disease burdens than hypothetical international ones and the diagnostics funding proposal goes on to state: "The impact of Lassa fever in endemic areas of West Africa is immense, and a safe and effective diagnostic would also provide a very significant public health benefit" (Garry, 2004 p64). The ordering of the paragraph makes it clear that, in regards to funding, the West African public health benefit is of secondary significance.<sup>105</sup> This represents a 'securitization' of Lassa fever and the interventions to tackle it, a phenomenon which may increase resources but also tends to direct resources away from local priorities to international security ones (Elbe, 2006). Priorities are altered, and as biodefense eclipses local disease burdens new concerns and objectives enter the frame: counter-terrorism is one, but other security related opportunities open up. These include commercial ones: post 9/11 the US government formed the U.S. Africa Command (AFRICOM) and planned to station some, or all, of this new military outfit in Liberia, opening up a potential market for Lassa 'products':

*"so in a Lassa endemic area, what is that going to mean?..... Lassa fever is obviously going to be on the list of things to test, so having a quick rapid assay to test for Lassa fever, and a confirmatory assay, and the ability to treat this person is going to be important. So the United states government and NATO allies are going to be customers for these diagnostics at some point"*<sup>106</sup>

Therefore, through securitization Lassa becomes both a security threat and a commercially viable research interest. This framing has brought in resources which arguably would not have been available otherwise, indeed for years Lassa received very little global attention or funding. However, for some, the way in which the money gained from Lassa's securitization is being spent in Sierra Leone is a point of contention. An opinion expressed by WHO staff and Sierra Leonean officials was that operations at the Kenema laboratory have been proprietorial and to the benefit of US and Tulane's interests above local ones. Sierra Leonean government

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<sup>104</sup> Tulane laboratory scientist, Kenema, 02/03/2010

<sup>105</sup> This should not be surprising given the funding stream is for biodefense.

<sup>106</sup> Tulane laboratory scientist, Kenema, 02/03/2010



officials point to the limited number of Sierra Leonean's who have been trained compared to US citizens. There is a sentiment, albeit muted, that the capacity building could have been more wide ranging, and locally beneficial. Perpetuating these interpretations are the comparisons which are drawn between the program at Kenema and other NGOs and humanitarian organisations, past and present: the activities of 'Tulane' (as the most visible partner in the consortium) are compared to those of Merlin, the British aid organisation who were previously responsible for the Lassa ward, and of MSF who run a hospital not far from Kenema. 'Tulane' are usually judged to fall short when it comes to the trickle down of resources and operations outside of the laboratory.

Any comparison should take into account the different remits of each organisation. There are institutional reasons for these differences as they are related to different framings of the Lassa disease system. Merlin is a provider of emergency health care and it was there in a humanitarian capacity, thus their focus was not on developing diagnostics but treating people. Tulane is not a humanitarian or aid organisation and the laboratory is their focus. These different objectives were not always acknowledged, the two were just measured against each other in terms of what could be seen to be provided. While there was some frustration amongst those in the research team who felt they were bringing in a great deal of extra resources to Kenema, and Sierra Leone, there was also recognition that there was more that could be done for disease control and capacity development both inside and outside of the laboratory. However with the terms set by research grants geared towards developing 'diagnostics for biodefense' there was little room for manoeuvre. Small concessions were made as some research resources were freed up where possible, for instance improving the visitor's area in the isolation ward or providing new equipment for the nurses. In general, there appeared to be a mismatch between what the research funds allowed Tulane to do through their grants and the expectations of different stakeholders: the lack of equipment in the ward, pay levels for the team, the level of training and development received in the laboratory, and the incorporation of Kenema's facilities into national laboratory and health plans were all issues.

### **6.2.2 High quality diagnostics to unravel the "Dogma"**

In this narrative the existing body of knowledge on Lassa, and past diagnostic techniques, are characterised as unreliable. Instead Lassa is constructed as a highly uncertain object and out

of this another narrative can flourish: the reduction of uncertainty as a result of the new diagnostics, made possible by improvements in ‘sensitivity’ and ‘specificity’.

When I was spending time at the KGH laboratory Lassa was very much defined as being an unknown quantity. This framing rested on a characterisation of the existing knowledge base as unreliable. One mantra went: “throw out everything you think you know about Lassa”. Whether it was the (unreliable) methods or the (unreliable) diagnostics, a Tulane researcher put it succinctly: “they just don’t get the results we get” in reference to the years of published research on Lassa fever. The scepticism about the existing knowledge base was strong and vocal, and manifested in the use of the term “dogma” to describe the existing knowledge and what was perceived to be an unquestioning acceptance – and regurgitation - of unreliable results. They saw themselves as having to work against this “dogma” and they argued that instead of the assurances dogma would usually provide, actually there was considerable ignorance which would only be reduced by advances in diagnostics. This set of narratives, of blind faith and ignorance moving towards certainty, are interlocking; they rely on contrasts drawn between the “dogma” and the “emerging view” and between the “traditional assay” and the “recombinant assay”. Diagnostics were often referred to as “building blocks”, as the “obvious place to start”, reinforcing the idea that the existing knowledge was not reliable and did not amount to knowledge of real substance.

The improvements in diagnostics are rooted in the mechanistic biomedical disease framing, specifically the principles of immunology, which have improved the sensitivity and specificity of the tests. The traditional assay is not trusted by the Tulane team because the inputs were considered to be of poor quality, even described as “junk”: “it’s the GIGO effect, right: Garbage in Garbage Out”<sup>107</sup> was one researcher’s way of putting it. The objective was to get to a point where it was “Quality in, Quality Out”, for this the reagents and the samples needed considerable work, which I will soon describe. Framing the work in the laboratory is the idea of moving from ignorance to risk. Incertitude is expressed as the probability of classification errors expressed as improvements in assay sensitivity and specificity. As queried in chapter two, sensitivity and specificity are arguably only dealing with some aspects of uncertainty.

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<sup>107</sup> Tulane laboratory scientist, Kenema, 02/03/2010

Validity and reliability are prominent themes in any diagnostic laboratory and a great deal of laboratory activity revolves around attempts to control or codify them; sensitivity and specificity are explicit attempts to deal with the risk and uncertainty of error. It is on the back of increased sensitivity and specificity that the scientists working in the Kenema laboratory believe that the new 'recombinant assay' they have developed provides a more reliable knowledge base than the 'traditional assay'. With the new diagnostics not only is case identification more accurate, but as a result, a more robust disease profile is being built which departs significantly from the established 'dogma'.<sup>108</sup>

Traces of the BSL-4 classification are evident in the formulation of this narrative. As I noted earlier, it is a code of practice, not a legal regulation although it is often interpreted as such. It means that the live Lassa virus should not be handled in laboratories which do not have high containment facilities. In 2007 there were only 20 BSL-4 laboratories in the world (Gronvall et al., 2007) and when research on Lassa begun there were even fewer. None of these were, or are, in West Africa. BSL-4 Laboratories are hugely costly to maintain, and therefore research on Lassa fever was also extremely costly to do. This meant research could only be done by a select few players, notably the CDC and USAMRIID (US Army Medical Research Institute of Infectious Diseases), and there were significant bottlenecks in the process which was located so far from the areas of disease burden (Khan et al., 2008). A consequence was that diagnostics were not routinely available in Sierra Leone and other countries in the region which were most in need of them. This was not only to do with the absence of local laboratories equipped to diagnose Lassa, it was also due to bottlenecks in the manufacture of reagents for Lassa diagnosis in the US.

Developing reagents for the traditional assay involved the use of live Lassa virus which, due to its biohazard classification had to be done in a BSL-4 level laboratory. These reagents were "incredibly cumbersome, difficult and expensive to produce"<sup>109</sup> and after all the effort, yielded only very small amounts. Reagents had to be produced and shipped to Sierra Leone from the US military research centre, USAMRIID, which had BSL-4 facilities. This combination of factors meant that supply was limited and likely to run out. Also reagents had to be stored for long periods where they were liable to "go off". Maintaining the laboratory's service under these

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<sup>108</sup> Despite all the talk of sensitivity, as the assays haven't been fully validated yet there final sensitivity and specificity figures have not yet been calculated.

<sup>109</sup> Tulane laboratory scientist, Kenema, 02/03/2010

circumstances proved difficult. Indeed, in early 2010 the positive control that had been provided for the IgM ELISA stopped producing signal. As there was no more to replace it, it had to be substituted with real serum from previous positive cases, but this was also an unreliable supply, and there were extended periods when no IgM assays were performed. This all shapes the sense of urgency about improving the diagnostics.

The supply and quality problems were another aspect of the uncertainty and strengthened the narrative of the benefits of new diagnostics. To a large extent they also shaped the innovation pathway as we shall see in the next section: to reduce dependence on the unreliable live-virus based diagnostics Tulane and their collaborators side stepped the BSL-4 issue by cloning the proteins in the Lassa virus. A researcher told me how this enabled them to remove the dangerous proteins which were responsible for infection, described as the “engine of the virus”<sup>110</sup>. From there they could use Polymerase Chain Reaction (PCR) techniques to select, or as he said “literally fishing out”, those that were of most relevance to diagnostics. This was the nucleoprotein and glycoprotein 1 and 2 in particular. The exclusion of the infectious proteins in the recombinant reagents meant that they can be handled in BSL-2 or 3 laboratories.

### **6.3 Developing diagnostic and laboratory authority**

In the eyes of doctors, scientists, government and the WHO the laboratory is now the place where a diagnosis of Lassa is confirmed officially, following the upward flow of information in official versions of the diagnostic system. This was not always the way in Sierra Leone, indeed laboratory diagnostics for Lassa fever were not routinely available in the country until 2006 when the Mano River Union Lassa Fever Network (MRU-LFN) and Tulane began their work at KGH. Though the opinion that a case of Lassa fever should be confirmed by laboratory investigation may have been held in principle, in practice it was not possible; cases were diagnosed on clinical grounds (perhaps supported by some laboratory investigations into other clinical aspects of the disease) but unless samples were sent to overseas laboratories there was no confirmatory laboratory test on offer. The report of a WHO investigation after outbreaks in 2003, reaching further West than was usual, highlighted the need for enhanced laboratory capacity (WHO, 2003). The development and implementation of a routine test for Lassa fever is an important step because, as chapter four emphasised, this is central to the narratives of disease control which are based around identification, containment and

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<sup>110</sup> Tulane laboratory scientist, Kenema, 02/03/2010

technological solutions. All of this relies on establishing that it is the Lassa virus which is making a particular patient sick. The laboratory, with its capabilities to isolate and identify viruses is the place where this can be done with most certainty, in a biomedical sense at least. There are implications. Cunningham (1992) has shown how the laboratory fundamentally altered definitions of disease and Rosenberg (2002) highlighted that institutionalisations of diagnosis tend to obscure the multi-dimensionality of disease. In the following sections I look at the way the laboratory defines Lassa fever. This will allow me to examine whether developments in laboratory diagnostics have caused other aspects of Lassa fever to be overlooked in diagnosis.

Though there are various tests for Lassa fever they work on the same principle; due to the pathogenesis of LASV and the basics of immunology, either the virus itself or traces of it (i.e. antibodies, such as IgM) can be found in samples of bodily fluid. The confirmatory diagnostic for Lassa fever in Kenema is the ELISA. Indeed, for most of my fieldwork period this was the only test available for Lassa fever onsite.<sup>111</sup>

Alternative methods to diagnose Lassa fever include virus isolation, PCR and Indirect Fluorescent-Antibody Test (IFA) (Bausch et al., 2000, Panning et al., 2010). ELISAs are favoured by Tulane scientists because they consider them to be a more appropriate procedure for routine diagnostics than the other techniques. Virus isolation or PCR require expensive and advanced equipment, a high degree of technical skill and, in the case of PCR, are easily contaminated (See Fair, 2007, Garry, 2004). Furthermore, with PCR, which works by matching strands of genetic material, there is an additional risk that it would not be able to detect the different strains of Lassa virus and its utility has been questioned elsewhere (Panning et al., 2010). Therefore, though PCR and virus isolation are generally valued for their specificity, indeed virus isolation is considered to be the 'gold standard' for Lassa virus (Bausch et al., 2000), in practical terms they were not considered appropriate. In some ways, PCR was *too* specific. In this instance, the 'gold standard' was not the "right tool for the job" (Casper and Clarke, 1998). The optimum test would be able to diagnose patients who had cleared the virus recently as well as patients who still had virus in their blood. As a simple technique which can

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<sup>111</sup> Towards the end, a prototype rapid diagnostic test (RDT) was introduced but it was still in the early stages of validation and was only being used with any regularity in the lab to compare its results with the ELISA's results. This rapid test, a 'Lateral Flow', was being developed as front line point-of care test only, positive cases on the lateral flow would need to be confirmed using the ELISA which will remain as the confirmatory assay.

be used to detect virus and antibodies the ELISA fitted the bill and was deemed to be the most clinically useful diagnostic test (Bausch et al., 2000, Garry, 2004). On measures of *sensitivity* and *specificity* the ELISA outperformed the other alternative, the IFA (Bausch et al., 2000). The choice of ELISA represents a technological choice, a trajectory. 'Suitability of fit' for the chosen diagnostic was determined by ideas about its future place and use within a wider diagnostic system. The wider system was characterised as having limited capacity and so a simple technique was favoured. Sick people within the system were characterised as having antigen or antibodies to Lassa virus and so a technique which could detect both was favoured. At this point then, both antigen and antibodies were considered diagnostically relevant.

An ELISA is a kind of immunoassay. Immunoassays are tests which use antibodies as reagents<sup>112</sup> (Crowther, 2000). Antibodies are used to test for a reaction (for a reaction would be expected if those antibodies were mixed with the other ingredients in the assay). Enzyme immunoassays work on the same principle but involve the addition of enzymes which are used to detect, by a change of colour, if a reaction has occurred (as shown in figure 18).<sup>113</sup> Analysis of the intensity of this change in colour, which is referred to as 'signal', allows for a quantifiable result which is one of the main benefits of an ELISA. Essentially then, an ELISA is a step-wise process which works on the basic principles of immunology, antigen and antibody binding. Different reagents are added in stages to be 'captured' or 'separated' during incubation or washing respectively. This makes the ELISA flexible as different reagents can be used to test for different things.

There are three types of ELISA being developed for Lassa fever. One tests for the virus antigen proteins (AG). The two others test for antibodies to the virus: the first is for Immunoglobulin M (IgM) which is an early immune response and indicates a recent infection; the second is for Immunoglobulin G (IgG) which is a mature immune response and indicates a past infection. When fieldwork began the antigen-capture and IgM-capture ELISA were used for diagnosis and the IgG was used for surveillance (so was not a routine test). If the assay works well then the 'signal' which is observed should be the result of the specific Lassa virus and antibody proteins binding together. For the 'antigen capture' the ELISA plate is coated with Lassa virus

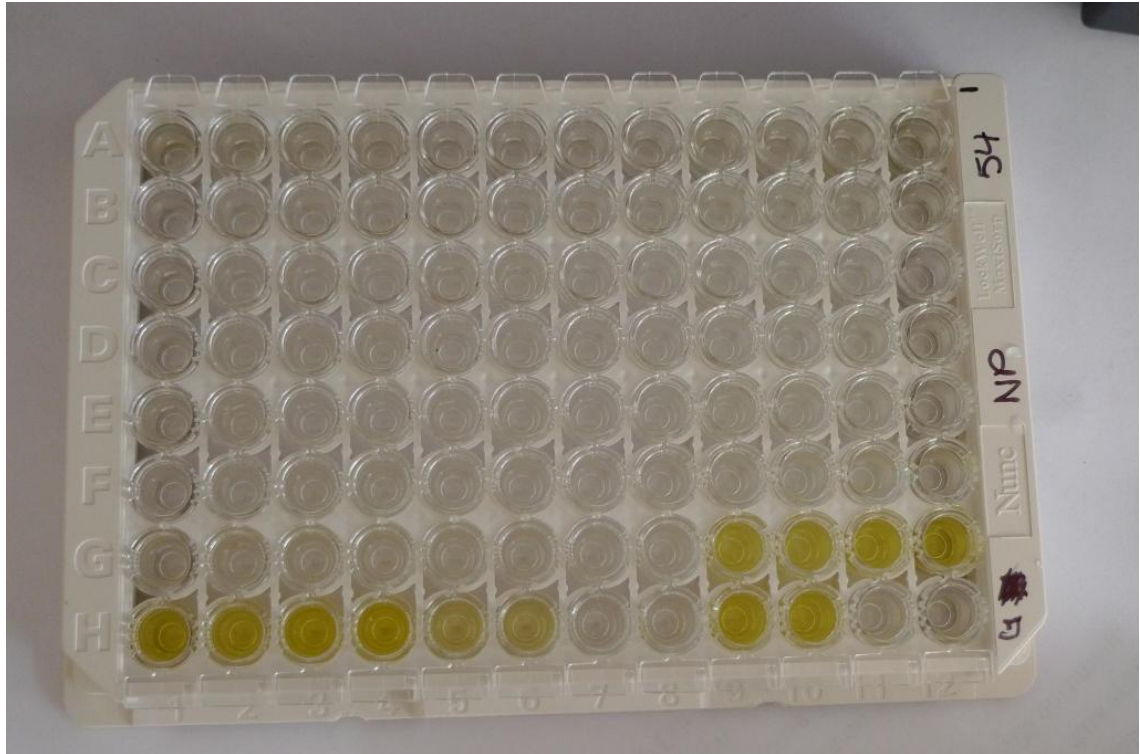
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<sup>112</sup> A reagent is a substance/compound added (to a testing system) to test for a reaction

<sup>113</sup> This is because when the enzymes are added they attach to the reactants (the ingredients which have reacted) and this can be seen when an appropriate substrate (a chemical compound which reacts with the enzyme and produces a change in colour) is added.

IgM which will capture Lassa virus AG if it is present in the test sample. For the 'IgM capture' the ELISA plate is coated with Lassa virus AG which will capture Lassa virus IgM if it is present in the test sample.

**Figure 18 A used ELISA plate (dark yellow shows a reaction)**



A problem with the test is that non-Lassa proteins which are present in the sample and the reagent can also bind, which is called 'non-specific binding'. Non-specific binding can also produce signal of varying strengths, this change in colour is often referred to as 'background' or 'noise'. A certain amount of 'background' is expected and tolerated, but non-specific binding can produce signal strong enough to appear positive, which would be a false positive.

The 'traditional assay' and Tulane's new 'recombinant assay' work on the same basic principles; the ELISA 'sandwich' theory, outlined above. However, as figure 19 shows, there are differences. This table is taken from the diagnostics grant application. The prefix 'anti' is used as a short hand to indicate what the proteins in that reagent will bind to: 'anti-human IgM' is a reagent which will capture Lassa IgM (from a human). There are more stages to the traditional assay and it takes longer (approximately 5 hours 15 minutes versus 1 hour 15 minutes). These differences are significant because of the impact they have on the assay's

clinical utility and its sensitivity and specificity. They have been achieved by adaptations to the assay's ingredients and technique which I will describe below. It is on that basis that the Tulane scientists claim to have reshaped the 'diagnostic paradigm' (Branco et al., 2011b). Figure 20 is a photograph of a poster on the laboratory wall which shows the stages of traditional assay.

**Figure 19 Comparison of 'Traditional' and 'Recombinant' IgM ELISA (Garry, 2004)**

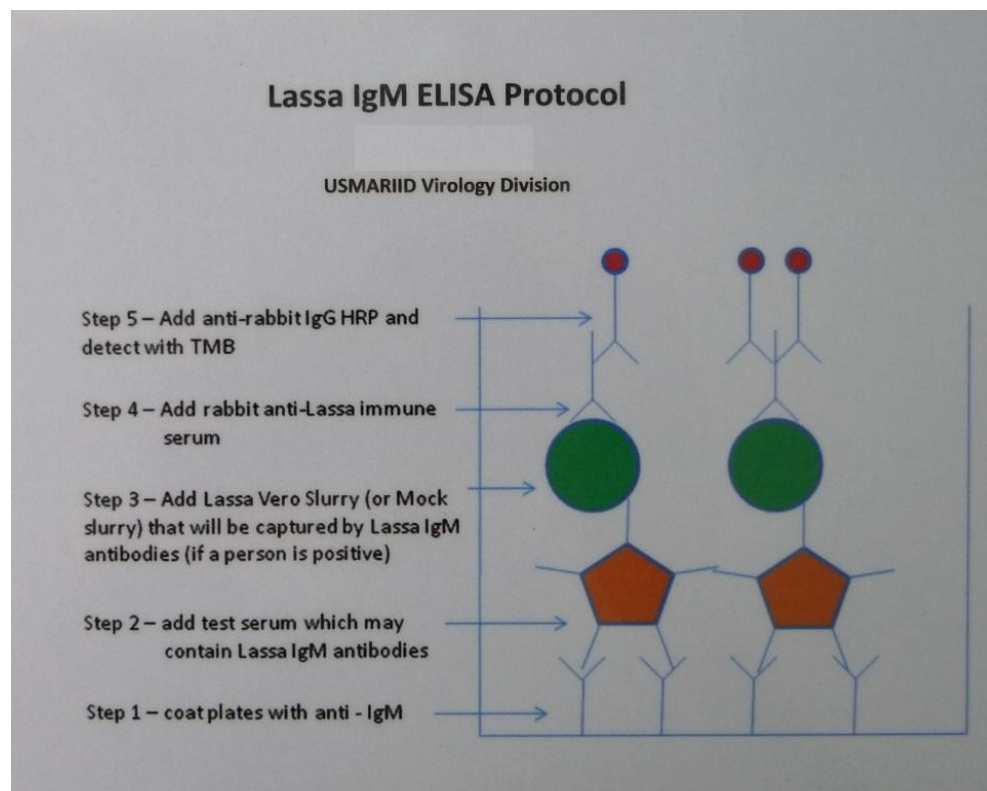
Table 4. Comparison of Traditional and Recombinant IgM-capture ELISA					
Traditional IgM capture ELISA			Recombinant IgM capture ELISA <sup>1</sup>		
Step	Component	Time	Step	Component	Time
1 <sup>1</sup>	Anti-human IgM	1 hour	-	Recombinant LASV NP, GP1 and 2	precoat
2 <sup>1</sup>	Patient serum	1 hour	1 <sup>2</sup>	Patient serum	30 min.
3 <sup>1</sup>	LASV- or mock-infected cell lysates	1 hour	-		
4 <sup>1</sup>	Rabbit anti-LASV	1 hour	-		
5 <sup>1</sup>	HRP-conj. anti-rabbit IgG	1 hour	2 <sup>2</sup>	HRP-conj. anti-human IgM <sup>3</sup>	30 min.
6	Tetramethylbenzidine (TMB); 2 N H <sub>2</sub> SO <sub>4</sub> (stop); read absorbance at 450 nm	5-15 minutes	3	Tetramethylbenzidine (TMB); 2 N H <sub>2</sub> SO <sub>4</sub> (stop); read absorbance at 450 nm	5-15 minutes

<sup>1</sup>plates are washed 5X after this step in PBS-Tween 20

<sup>2</sup>plates are washed 4X after this step in PBS-Tween 20

<sup>3</sup>HRP-conj. anti-human IgG is used in the IgG-capture ELISA.

**Figure 20 Visual representation of ELISA (IgM) protocol from the laboratory wall**





## 6.4 The emergence of a new diagnostic paradigm in practice

Returning to the theme of laboritization, I will now consider the way diagnosis of Lassa fever is practiced in the laboratory and trace any imprints of the sub-narratives just discussed on those practices. A paper published by members of the Tulane diagnostics team is a good place to start. It reads:

*“Analysis of humoral immune responses by antibody-capture ELISA and Lassa virus viremia by antigen-capture ELISA in suspected patients admitted to the Kenema Government Hospital Lassa Fever Ward in Sierra Leone over the past five years is reshaping our understanding of acute Lassa fever”* (Branco et al., 2011b, p1).

It goes on to conclude:

*“we suggest that the traditional paradigm for diagnosis of acute Lassa fever in West Africa should be reconsidered and changed”* (Branco et al., 2011b, p13).

The article above marshals evidence from the laboratory to overhaul the existing approach to Lassa fever diagnosis, both in the laboratory and in clinical settings. The new approach they suggest is based on analysis of the new recombinant assays. In the following sections I describe the changes which took place in more detail and set out the terms on which this new paradigm is based. By looking at practice in detail it becomes evident that aspects of these statements conceal some remaining uncertainties and divergent opinions. With consideration of the wider diagnostic process in this thesis’ other empirical chapters, the way in which this enhanced and reshaped diagnostic paradigm is impacting on diagnostic processes and practices is questionable. Any major paradigm shift has to be worked out and negotiated in the context of established paradigms and practices.

There are two areas in which the emerging view is strikingly different from the ‘dogma’ One concerns the interpretation of IgM serostatus and the second concerns the geographical spread of Lassa. At the start of my fieldwork a positive IgM result was considered a ‘laboratory confirmed’ case which had to be admitted to the Lassa ward; by the end of my fieldwork, patients testing positive for IgM were frequently kept on the general wards. In a short space of time, the relative importance of an IgM positive result was significantly reduced: “LASV specific IgM serostatus cannot be considered a diagnostic marker of acute disease in West Africans” (Branco et al., 2011b). This statement is made on the grounds that IgM appears to remain in patient serum longer than first appreciated. This led one senior

Tulane researcher to tell me “lots of the IgM we see are not new infections, they are sick with something else, they are dying of something else”. This new interpretation of IgM means many ‘lab confirmed’ IgM positive cases were admitted to the ward, and treated, which he said, “was probably not the right thing to have done”.

The new paradigm represents significant departures from the existing knowledge and practice of Lassa fever diagnosis. It is important to understand how such revisions could be suggested with the certainty they were. Much of this revolves around the reductions in uncertainty made possible by the new diagnostics. Much of the laboratory work involved in developing and using the diagnostics is about dealing with uncertainty: the recombinants altered the balance uncertainty in three ways: ingredients, technique and interpretation.

#### **6.4.1 Ingredients**

I noted earlier that much of the uncertainty surrounding Lassa, and the dogma, was to do with the ingredients used in the traditional assay. The traditional assay’s reagents are considered inferior because the way they are produced means they are impure and there is more chance of non-specific binding. Making the reagents requires growing more of the virus, which is done by infecting monkey cells in a laboratory and allowing the virus to replicate. The cells are from Green Monkey Kidney Cells, also known as Vero cells. The result is a sort of melting pot described by one scientist as containing “every protein in that cell which is tens of thousands if not hundreds of thousands” including the viral proteins in addition to the original cell proteins. To deal with this he said “they have got to figure out a way of actually pulling the specific Lassa proteins out of that gamish”.<sup>114</sup> This process is very important because if any of the non-Lassa proteins get into the reagent they can cause cross-reactivity with non-Lassa proteins in the patient’s sample. The resulting reagents are called ‘Lassa virus slurry’ or ‘Lassa Vero slurry’.

The purpose of the Lassa Vero slurry is that when added to the traditional ELISA, if there is Lassa specific IgM present in the test sample, it will bind to the Lassa virus in the slurry. However, if monkeys have been eaten or have simply had close contact with people (both of which can be true in Sierra Leone) then there is a chance they will have non-Lassa IgM in their blood which reacts to proteins in the Vero slurry. Such a reaction would have nothing to do

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<sup>114</sup> Tulane laboratory scientist, Kenema, 02/03/2010. Gamish is a Yiddish word used to mean a mix or ‘mis-mash’

with Lassa virus and so would cause a false positive. For the laboratory it represents impurity; a complexity of the outside world which needs to be removed. In a setting like Sierra Leone where some of the common cell culture hosts are also food sources, it means that it is difficult to avoid running into chains of non-LASV specific reactions, like “anti-monkey, anti-virus, anti-rat”.<sup>115</sup>

Step three in figure 20 calls for ‘Lassa mock slurry’ or ‘Lassa Vero slurry’ to be added as part of the traditional IgM assay. This represents the extra stage (stage three) shown in the comparison between the traditional IgM assay and the recombinant assay in figure 19. This additional step is an attempt to deal with the cross-reactivity problems described above and is one of the reasons that the traditional assay takes longer. In addition to the Lassa Vero slurry, a mock slurry is also produced. This is the same as the Vero cell slurry but it has not had the Lassa virus grown in it, therefore it has all the proteins from the ‘gamish’ but no traces of Lassa virus. It acts as a control to counter the cross-reactions which may stem from “anti-monkey, anti-virus, anti-rat” interactions. Thus in the traditional assay two samples are run: one with ‘mock slurry’ and one with ‘real’ Lassa Vero slurry. Once the assay is completed and optical density readings (measuring the intensity of colour change) have been obtained, the reading from the ‘mock slurry’ is subtracted from that of the ‘Lassa Vero slurry’. This is supposed to limit the influence of non-specific binding caused by proteins from the ‘gamish’ which have not been adequately removed from the ‘Lassa Vero slurry’. This step in analysis cannot remove the possibility of non-specific binding it is simply an attempt to control for the fact that it may occur. There is no clear way of knowing what is binding with what in both the mock and the Vero slurry assays, meaning results should still be interpreted with caution.

The traditional assay’s laboritization processes are not sufficient to fully remove traces of varying food systems and immunity responses which interfere with its validity, such as if monkey are food sources. The result of this failure is a higher risk of false positives. As discussed the production of reagents for the traditional assay is also more expensive and dangerous because it involves working with a BSL-4 pathogen. Purer, cleaner and less dangerous reagents can be produced by re-engineering the virus to produce the ‘recombinant proteins’ to use as the reagents. In simple terms, this is done by cloning the viruses’ proteins and recombining them. Cloning the virus enables scientists to produce reagent in higher

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<sup>115</sup> Tulane laboratory scientist, Kenema, 02/03/2010

quantities and free from the impurities of the gamish. Cloning also allows the researchers to manipulate the virus, to recombine it; the infectious ‘engine’ proteins are removed to side-step the BSL-4 issue and specific proteins, or combination of proteins, are selected and are tested to see which are consistently useful in diagnosis, to be used as reagents in the final diagnostic kits. The resulting assay has more specificity because not only are non-Lassa proteins in the ‘gamish’ removed, but so are less relevant proteins in the virus. The assay achieves its specificity by narrowing the reactions down to specific parts of the virus; in the process the virus is spliced and recombined, and the result is increased certainty that a reaction is a valid one.

Blood is another ingredient where assay validity can be affected. The process of extraction and storage of blood determines the quality of the sample and therefore the quality of the test result. This was not a weakness of the ‘traditional assay’ per se but work on the recombinants instigated work to improve the ‘cold chain’. By the time the recombinant assay was ready the ‘cold chain’ was also stable enough to produce samples which could be described as “that nice little straw yellow serum”.<sup>116</sup> The improvements made here did not involve the same level of re-engineering that developing the recombinant proteins did. However the changes made to the system of sample collection and storage altered the constitution of the sample in such a fundamental way that results from them were finally considered trustworthy. One researcher told me that the results obtained from samples collected before the cold chain was improved were judged not to be of publishable quality.

Improving the cold chain required equipment and processes which reached far wider than just the laboratory, for instance the outreach team is also involved in collecting samples. Both the laboratory and the outreach team were given centrifuges in order to separate the serum from blood samples as soon as possible. Figure 21 shows a member of the outreach team using the centrifuge in the field. Samples were separated into smaller vials so they would not be subjected to being taken in and out of the freezer multiple times. Solar power had been installed to make power to the freezers more reliable. All of these changes were to streamline the transition of serum from the arm to the point that it was needed for testing, enabling the laboratory to “produce good samples” as one senior Tulane researcher put it. The impact of improving sample collection and storage illustrates Knorr Cetina’s point about the re-shaping

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<sup>116</sup> Tulane laboratory scientist, Kenema, 02/03/2010

(and improvement) of objects as they are subjected to the ‘internal processing environments’ of the laboratory (Knorr Cetina, 1999, p38). As such, the work of the diagnostic laboratory can be understood as *producing* as much as *detecting*.

### 6.4.2 Technique

As well as the innovations in ingredients the other key difference between the traditional and the recombinant assay was how they were performed. Time was dramatically reduced: the traditional assay used to take approximately five hours, with the ELISA plates needing to be coated overnight. Therefore in practice a diagnosis could take nearly 24 hours. The recombinant assay shortened the wait to just under two hours in total. The implications of this on patient survival are great because the earlier a diagnosis can be made the higher the chances that the treatment will be successful. Two hours as opposed to 24 hours could be critical.

**Figure 21 A member of the outreach team using the centrifuge in the field**



A discussion of the research process which went into developing the diagnostics is enlightening here. In order for the diagnostic to be considered reliable, and in particular reliable enough for others to use, the technique had to be stabilised. Stability and standardisation is also important for the commercialisation of the assay and for approval by the Food and Drug Administration (FDA). The eventual method of performing the

recombinant assay was the result of tinkering with different parameters during field testing. This process is akin to the tuning which Pickering (1995) described in the mangle's pursuit of stabilisation. The adjustments were aimed at settling on an optimum reaction process which encouraged specific binding and minimised 'background' binding which can make results hard to read. These included:

- Plate washing cycles (minimising non-specific binding)
- The addition of blocking solution (minimising non-specific binding)
- Levels of enzyme in the substrate (can speed up or slow down a reaction)
- Temperature of incubation (pace of reaction)
- Movement i.e. vibrating plates or stationary (pace of reaction)
- Time i.e. of blocking, reacting, incubation (levels of reaction)
- Concentration of soap in plate wash (affecting levels of binding)

The exploration of different combinations of these appeared unplanned. Many of the tweaks were based on trial and error or personal preference. When field tests were being run on the assays there was debate over how long they should be left to develop colour in the final stage. Tacit knowledge seemed to be important as researchers would judge by eye when to stop the reaction. Standing over the ELISA plates as the colour in the wells darkened, researchers would discuss when to add the stop solution to halt the reaction. Different team members had different preferences for the depth of colour in the positive samples and for tolerance of 'background' colour. One of the more senior members of the team preferred to have a low background. When some of the other researchers were running tests in his absence, one decided to see what would happen if they left the reaction for longer than was usual. They joked that the senior colleague would 'flip out' when he saw them.

Although the development stage may have looked haphazard, the data was always kept for analysis. The objective was to manufacture commercial diagnostic kits which would work anywhere in the world. As such the procedures would have to be as standardised as the hardware. When it came to introducing the new diagnostics into routine practice at KGH each step of the new assay was spelled out in revised Standard Operating Procedures (SOPs). In fact, new versions of SOPs would arrive with each Tulane research trip. All the equipment, the pipettes, ELISA plates, mixing plates are all standardised. The standardised equipment and techniques can be seen as the establishment of order to create scientific facts which STS

scholars have commented on (Cambrosio and Keating, 1995, Latour and Woolgar, 1979, O'Connell, 1993).

The need to standardise the technique for performing the assay was highlighted by the problems other people had had in using the new recombinant assays in different settings. The team had given their reagents to teams in Nigeria and Gabon to trial. Results had not been consistent, causing some anxiety. Discussing this one night, one team member expressed his confusion: “We are the only ones who have run our assays and got them to work, it’s a bit of a worry”. He reasoned that this could be explained by failure to follow the given instructions properly but there were instances which could not be explained. Referring to previous team members who had tested early versions of the recombinant assays at KGH he remembered: “I don’t know what is going on. It was the same story here until recently. They used to come back really frustrated. All background. Then we would look at it and say there were positives”. Clearly there is resistance which needs to be accommodated but it is unclear where the resistance is coming from. It could be to do with the way the tests were performed, the environments they were performed in, or the tests themselves.

Performing the assay successfully was a complicated affair even with the instructions. As a technique, there are many variables which can influence it. For a while the high background in samples processed in the Kenema laboratory were puzzling researchers. Background colour was higher than when the same tests were run in the US. It was initially explained to me as caused by a difference in the temperature between Sierra Leone and the site in the US. Later someone realised that the machine which washes the plates had not been cleaned properly which meant that the unbound reagents were not being washed away as effectively as they should have been. This could also cause high background. A clinician involved in the development of these new assays conceded that there is always an “inherent variability”<sup>117</sup> to an ELISA test. The same clinician noted that he saw a lot of variation in the data coming out of the KGH laboratory. There could be any number of reasons: the temperature in the Kenema laboratory could fluctuate; the air-conditioning was not reliable and its use depended on the availability of ‘town power’<sup>118</sup>; electricity in general is not reliable and even the solar panels

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<sup>117</sup> Tulane medical clinician, telephone interview, 27/07/2012

<sup>118</sup> Kenema’s electricity supply is known as ‘town power’ for at least 6 months of the year, during the dry season, it is patchy to non-existent. The laboratory has solar power for the freezers but air conditioning is rationed as that would come from the generator.

can occasionally become depleted; sometimes the sun pours into the window onto the laboratory workbench where plates were prepared. In sum, there are many potential sources of variability which can interfere with the smooth and standardised running of the assay. SOPs are an attempt to control for these kinds of events but they cannot rid all variability from the process. Finally despite training and the use of SOPs people cannot be homogenised. There are peculiarities to people and to moments in time and the simplest factors can make a difference. For instance, at what point the reagents are taken out of the fridge makes a difference to their temperature (and potentially the reaction) when they are added to the assay.

The drive to see the product through to market was evident in many aspects of the work in the Kenema laboratory. In addition to the desired FDA approval, the success of the diagnostics were often discussed in terms of whether they could be mass produced, standardised and sold in kits which would work anywhere. As one senior Tulane researcher told me:

*"I hope with some of our partners in the private sector biotech companies, the goal, we may not get there right on time but we are not that far away, is to by the end of the year actually have a commercially available product where someone can say ok, for the first time in history, you can say 'let me call up and order a Lassa kit,' from a company that has been produced and validated and you can use that anywhere in the world for your research or your public health or diagnosing patients of whatever".<sup>119</sup>*

A major concern of the team was to develop tests which would work in laboratories with limited capacity. They have to be simple but reliable, considered as 'appropriate' in Mabey's definition (Mabey et al., 2004). But how these products would be of benefit to Sierra Leone once they were no longer provided free during research was not clear. One suggestion was that arrangements could be made whereby they could be donated or sold cheaply to West African governments or aid organisations, compensated by more expensive prices from US based markets.

### **6.4.3 (Re)Interpretation**

Interpreting the ELISA results is another area which underwent significant change. It is possible to make a guess at the results of an ELISA test by judging the colour the sample and reagent have turned in the plate wells with the naked eye. However, though this may be the end of the reaction, it is not the end of the diagnostic test. A binary result is the aim. The plate

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<sup>119</sup> Tulane medical clinician, Kenema, 27/03/2010



is put through a light density reader which quantifies the density of light in each well, these readings can then be analysed.

The way this subsequent analysis was done changed a number of times during my data collection period. Each time a new method was introduced it was supposed to be a more reliable way of interpreting the result. The changes provided some interesting examples of how uncertainty in interpretation was present, if not formally acknowledged and only really acknowledged once there was something better to replace it.

Reading result by eye can be difficult, particularly if there is a lot of background noise, or weak signal. Allowing the test to develop longer will produce a higher signal on positives, but also a higher background. The tolerance level for these 'optical densities' differed between the team. It is the ratio of background noise to signal that matters, but can be hard to gauge. When the tests were in the early stages of field testing, this could be an uncertain and subjective decision:

Researcher 1: *"So you've got an overwhelming number of positives?"*

Researcher 2: *"Depends on what you call positive"*

Researcher 1: 1 *"Well there are lots of very dark results"*

Researcher 2: *"Very dark", raises eyebrows.*

Later, Researcher 1 adds: *"none of that means a damn thing until we know what's negative.....and what is statistically different.....and then it's the math talking, it's not just you pushing the ruler back and forth"*

Working out the parameters of what is positive and what is negative went through different stages and became increasingly quantified. As the method changed, what made someone positive for Lassa fever also changed. Mol (1994) noted something similar in a study of anaemia where depending on the diagnostic method being used the object being defined changed. With the traditional assay the procedure had been to draw a bar graph in Microsoft Excel using the sample's optical density values. If the column for the test sample looked about the same height as the positive then it was recorded as a positive. Figure 22 shows the bar charts I refer to on the computer screen. Differences in the scale on the vertical axis (used for the optical density reading) meant that there was variation in how big the differences looked and interpretation was not consistent across tests.

**Figure 22 Laboratory technician examining results, showing bar charts**



A test of statistical significance (an ANOVA) was introduced which provided an ‘improved’ way of distinguishing between the test sample and the positive and negative controls. The two younger Sierra Leonean clinicians were particularly enthusiastic about this new test. Frequently, the test proved a result to be different to what had been judged by eye. In one case, one of these technicians and a member of the clinical team who had seen the bar chart disagreed about how to interpret the levels in the IgM result. The technician went to run the statistical test on the results. It was negative as he had suspected. He was vindicated and so were the new statistical diagnostic techniques. In reference to this case he told me plainly: “if it is not positive, it’s not positive”. This was a huge change from only a few weeks earlier when there was no clear way to settle a disagreement like he and the nurse had had. Only a few months later the statistical test was discarded in favour of another method. Suddenly the statistics were the unreliable method and ‘cut offs’ were introduced. Cut offs were derived from the normal distribution of AG and IgM titres which were observed in a test population. From this distribution, the upper and lower cut off limits could be determined. The reading for a specific test had to fall between these two values to be considered positive. These values were determined by one of the institutions on the diagnostics grant. Before the cut offs were introduced positives and negatives were decided by looking at the difference between the

control sample and the test sample. The cut offs gave the test readings a meaning derived from a control population.

Yet with each new improvement, the extent of what is not yet known becomes clearer. The issues of interpretation run deeper than which test, graph or cut off is used. In the words of a senior clinician at Tulane, a concept which is hard to grasp but immensely important is that “just because something isn’t negative it doesn’t mean it is positive”.<sup>120</sup> The laboratory produces results of ‘positive’ ‘negative’ or ‘indeterminate’ which are based on numerical values produced by the ELISA. Working out the significance of those numerical values, and how they should be applied, is an extensive task. Quite aside from the issues of cross-reactivity which I discussed earlier, infected individuals will naturally be found to have different levels of virus (or IgM) in their blood.<sup>121</sup> Dose of infection can also make a difference. Plus these levels also change over the course of the illness as the virus and antibodies develop or reduce. To arrive at meaningful cut offs the distribution of AG or IgM titres can be plotted (as a bell-curves) for positive and negative samples within populations. For a well-researched and common disease this is relatively easy to do. But collecting adequate samples to comprehensively plot the bell-curves for Lassa fever can take years and was still on-going. Moreover, characterising positive samples is more difficult as there are fewer of them. Thus positive results come with more ambiguity hence the phrase, “just because it isn’t negative, it doesn’t mean it is positive”. At present, the cuts off should also be couched in considerable caution; in some ways, for the time being, the positive sample is unknowable.

There are also concerns about finding and characterising an appropriate negative population to be used as the control. Whose blood is used is important because blood is not the same. The recombinant assays have been tested on samples coming through KGH but also on blood bought from a US blood bank and from Senegal. ‘African’ blood is talked of as being ‘sticky’. It is said to cross-react more and produce more background, though this was a matter for debate. Comparisons are of course relative, but the differences can be striking. The US blood bank controls had optical density readings so low that they made all Sierra Leonean samples which were tested against them look positive. At one stage the researchers had to take

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<sup>120</sup> Tulane medical clinician, telephone interview, 27/07/2012

<sup>121</sup> Fascinatingly it has been observed with other viruses that people can seroconvert, meaning there is evidence of the virus in their blood, after having been around the virus or around people with the virus without having been infected themselves. I was told that sometimes laboratory workers test positive for viruses they work with without having contracted the disease.

samples from the Sierra Leonean Lassa team to act as the negative controls: “when using the American controls you will take everybody to be positive” laughed one Sierra Leonean laboratory technician. Trying to achieve stability across the board is difficult. When working on an Sierra Leonean sample the advice was to use a Sierra Leonean sample, and when working on a US sample, a US sample should be found. A negative is not the same everywhere.

A story recounted to me by one of Tulane’s clinicians, who support the doctors at KGH, highlights the importance of understanding these issues when interpreting laboratory results. For the purposes of this example we shall say the ‘cut off’ for a negative antigen sample is 0.025.<sup>122</sup> Anything below that figure is considered negative. A sample was received from a patient who felt generally well but their AG ELISA result, at 0.027, was just over the cut off. They were recorded as positive, put on the Lassa ward and commenced with Ribavirin. The doctor taking care of the patient at KGH became concerned when the antigen levels did not change significantly with treatment. He contacted the clinician at Tulane to discuss the case. The Tulane clinician suspected that the case was not really a positive: the titre levels were borderline and the patient’s symptoms were mild. Not knowing ‘the value of the test’ is a problem the world over he told me. In this instance the doctor at Kenema had made the common mistake of being “too heavily reliant on the test result in decision making”.<sup>123</sup> The value of the test, he told me, is that it should assist in making treatment and diagnostic decisions but should not determine them. He and a second clinician emphasised that results should always be contextualised with clinical signs and with the time the test was taken. A laboratory test result represents only one aspect of disease however its partial nature is easily forgotten.

There are times however, when those other aspects do find their way into the laboratory and in turn they can influence interpretation. The laboratory is not routinely informed of the clinical condition of the patients whose samples they are testing. However KGH is small and bits of information were passed between the laboratory and clinical teams, for instance if the patient had serious symptoms or where they were from. Even these small details can affect interpretation and given diagnosis. This was noticeable when test results are borderline. In such cases, standard procedure is to repeat the test but if this is not possible then the technicians are more willing to bend the rules. Laboratory staff spoke about how if a test was

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<sup>122</sup> These figures are illustrative

<sup>123</sup> Tulane medical clinician, telephone interview, 27/07/2012

indeterminate or borderline and the sample was from somewhere further afield, then they would say the result was positive. This was a precaution because they know that a second sample would take longer to get. This can work the other way too. In another case the result of the statistical test indicated that a sample was negative. However the graph, which was still printed, showed the test sample to be a similar level to the positive control. The technician decided to say it was indeterminate because he knew the patient was in KGH and that a second sample could be taken easily.

## 6.5 The value of a test: limits to laboritization?

Great efforts were made in the laboratory to establish control and stability in Lassa diagnostics. There was a move from use of the live virus to the recombinant proteins. The cold chain was also tightened up as was the interpretation of the results. However, in all of this tuning and disciplined human action (Pickering, 1995) there are always limits to what can be controlled. I have highlighted some of these: people, temperature, techniques, knowledge about the distribution of the virus in a population. There are always ways for nature to get around the imposed order. One researcher exclaimed to her colleagues that the old samples they were working on had mould on them: she joked that they looked like beer and were making her thirsty. Even with solar powered freezers and a vastly improved cold chain, care still has to be taken with reagents and controls in storage as they begin to decay with daily usage. I was told how even the samples which had not been colonised by mould could not be entirely trusted. Changes in temperature as a result of breaks in cold chain can damage the proteins: “They go away, they fall apart, and you start to lose the ability to take any given sample, do an assay and then give the results any relevance”.<sup>124</sup> Workaround strategies, such as dividing the samples into smaller vials (a process called aliquoting) so they did not have to be removed from the freezer repeatedly, are employed to reduce this occurring. But it is a continual battle against material and non-human agency.

There are some fundamental limits to the laboritization. Most dramatically there are limits to the value of a test. If there were reservations about the ‘dogma’ of Lassa, there is little visible reservation about the emerging view of Lassa, or at least not amongst the laboratory’s dominant voices. Though the more senior members of the Tulane team were brimming with confidence in the new diagnostics there were more cautious voices among the Sierra Leonean

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<sup>124</sup> Tulane laboratory scientist, Kenema, 02/03/2010

staff and some of the doctoral students which suggested that the confidence was not shared by all.

The reduced time and (reportedly) improved sensitivity was positively received but trust in the new tests was not instant. There were doubts about the sensitivity of the IgM test which seemed to be picking up more cases than usual. Before the 'cut offs' were introduced one technician confided in me that he thought it was picking up too many positives, or as he put it, it was "too sharp". The dynamics in the laboratory mean that often these concerns were not fully expressed while Tulane researchers were there. After their departure I found one of the Sierra Leonean technicians performing his own validations. He was testing the new assay against the old assay on a panel of old samples from the freezer. There was clearly a desire to see for himself that the new assays were as good or better than what he was used to. He explained to me: "with these new tests we want to be sure there is no doubt, so when we say someone is negative then they really are negative". A number of times the Sierra Leonean technicians emphasised that they were performing a different role to the researchers. Their job was to provide real-time diagnosis of patients they said, and so lives depended on the assays they ran. Understandably this carried an immediate sense of responsibility and I think it goes some way to explaining their caution in working with the new diagnostics. One of the technicians emphasised the obligation he felt to make sure that the new assays were reliable with the phrase, in Krio, "*let we no lie*". Similarly, when the practice of keeping IgM patients on the general wards first started there was some unease about whether it was the right thing to be doing as it went against years of experience. A few staff members felt strongly that it was risky and the tests were not fully developed or validated.

The unacknowledged uncertainties are encapsulated by the regulation vacuum. There is no FDA or WHO approved diagnostic test for Lassa fever. This means there is no clear benchmark which has to be obtained before the new diagnostics can be introduced. Although validation tests are being done back in the US, the recombinants were introduced into routine practice before they had been fully developed. The positive and negative samples had not been comprehensively characterised and sensitivity and specificity figures had not been settled. A revealing example of this tension could be found in the protocols for the new recombinant assays: they read "For research only, not for use as diagnostics" though in practice they were being used as diagnostics.

This is not to say that there is a better alternative. Neither the traditional nor the recombinant assay had been validated and it is more than likely the recombinant assay is better. It is also a positive development that there are routine diagnostics at KGH at all. However, the likelihood is that these vacuums of certainty will continue with regard to diagnostics. One Tulane clinician admitted that “FDA approval is the holy grail of medical research” and the rigour required simply may not be possible for a remote West African disease.<sup>125</sup> This is not unusual and others have indicated that it may well be representative of diagnostics in both developing and developed countries (Mabey et al., 2004). Still these uncertainties are little acknowledged. In practice much of the on-going uncertainty and ambiguity is ‘black-boxed’. The business of the clinical laboratory is to make a binary pronouncement on the presence of a pathogen. It is not usually in the business of admitting these lingering doubts. Yet, ‘positive’, ‘negative’, or at a push, ‘indeterminate’ does not reveal the full extent of uncertainty.

There is a paradox. The position and utility of the laboratory depends on the assurance it provides: “the laboratory makes the tests, but equally the tests make the laboratory” (Cunningham, p218). A laboratory technician described their role as producing a diagnosis which is “really reliable”. This was as opposed to the doctors “who can try”, he said, to diagnose but who cannot accurately determine a Lassa diagnosis on clinical signs alone. Improvements in laboratory diagnostics have meant that the diagnosis of Lassa fever is done on increasingly narrow terms, on specific proteins within the Lassa virus. This narrowness is the source of the laboratory’s strength; it has improved sensitivity and specificity I was told. But there are further implications. As a classification tool changes, different elements of the classification system come more or less sharply into focus (Bowker and Star, 2000). With this in mind, it is striking how the laboratory offers very specific and in some sense restricted information, yet it does so with great authority. Only the identification of active virus (AG) or an immune response (IgM) counts and increasingly the immune response does not always count. The restricted nature of the information is also the source of its authority. Ian Hacking has written “The assay that is chosen, settled on, creates the criteria of identity for the substance of interest. It creates its own truth. It is self authenticating, for there is nothing else to authenticate it” (Hacking, 1988, p284). This does not mean that the disease is being invented. But it does mean that the terms under which it is investigated are critical and the

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<sup>125</sup> Tulane medical clinician, telephone interview, 27/07/2012

picture that is presented is limited. Even the ‘gold standard’ which new diagnostics are measured against only becomes the ‘gold standard’ through the same processes of authentication. The process of ‘laboritization’ narrows a diagnosis of Lassa fever down to a blood sample which is further manipulated into specific proteins. A question that needs to be asked is while the viremia of Lassa fever is promoted into sharp focus what others aspects of the disease are obscured?

As the diagnostics improve, confidence in them grows. But the story I recounted before of the very low-titre ‘positive’ case is a warning that this needs to proceed with care. Similar cases are described in the following chapter. In practice however, many of these uncertainties get forgotten as the laboratory churns out results; they are hard to process and they are often hard to do anything about. This is especially true when the pressure and risks involved in knowing that someone’s life may depend on the assay’s result are considered. But there has been some disagreement about the way they have been dealt with, or ignored, as in the case of the new interpretation of IgM. For example a recent publication asserted:

*“Recent studies in which IgM antibody responses are reported to not be consistent or helpful in the diagnosis of acute Lassa fever are based on a recombinant assay whose specificity has not been validated and contradict published data and years of field experience to the contrary”* (Bausch et al., forthcoming, 2014).

The issue of how to interpret IgM is clearly problematic and in the above quote it appears that what some have referred to as dogma is also being used to challenge the ‘emerging paradigm’. This is a far cry from the confident dismissal ‘they are sick with something else’. The implications of these debates will be continued in the next chapter.

## 6.6 Conclusion

This chapter traced how the narratives which present Lassa fever as a global threat and a worthy target for enhanced technology directly influence practice in the laboratory. Most notably the biodefense angle has provided funding for research. These narratives are modified in the laboratory setting: the biodefense global threat is not necessarily seen as being realistic but it represents a research and commercial opportunity for scientists. Indeed, in this Sierra Leonean setting the BSL norms are also not strictly adhered to. I borrowed Knorr Cetina’s term ‘laboritization’ to describe the transformation and manipulation of people and objects as they are processed by a laboratory. It is on the basis of these manipulations



that the enhanced authority of the laboratory and its diagnostics is claimed. But, I also suggested that laboritization has limits and that it represented a particular, narrowly defined, form of diagnosis. By concentrating on one aspect of Lassa disease, which increasingly is the presence of Lassa antigen, other aspects are lost: the roles of IgM and clinical symptoms have been downplayed and are the source of disagreements. The variability of ELISAs, the difficulty in characterising positive samples and the problems of applying a test result in clinical practice are all areas where laboritization is shown to be incomplete and where uncertainty and ambiguity are pervasive.

Processes in the laboratory can be considered under the framework of the mangle of practice. Practice is based on goals such as improving sensitivity and specificity, producing a commercial product or circumventing BSL restrictions. Achieving these goals is done by building on existing technology such as recombinant proteins and ELISA assays. This repertoire of technology is part of the technological regime which encompasses BSL regulations, funding landscapes, international university and private research collaborations. Pickering highlighted the importance of tuning and stabilization in the mangle of practice and it is these processes which occupy the laboratory. The tests are being tuned to achieve a stabilization between material and human agency: through assay protocols the agency of the environment and technologies are brought under control. Human agency is simultaneously curtailed as the technicians are called upon to be increasingly disciplined. Material and human agency can threaten this stability. The blocked up plate washer which caused 'high background' colour in the ELISA's results is a good example. This is what is sometimes called 'human error': a failure to be disciplined enough and it allows the resistance of non-human agency to break through. Interestingly this was initially interpreted as the uncontrollability of the local conditions: Sierra Leone's hot and humid environment which made the reactions faster. Another area of tuning was in the increasing use of statistical tests and cut offs to interpret the ELISA results which can be viewed as a human attempt to exert some order over the variability of the test and the populations it sampled. The next chapter will pick up on the challenges posed by limits to laboritization and it illustrates how the workings of the mangle of practice continue in the clinical setting.

## 7 ‘Classic Lassa’: diagnosis in a clinical setting

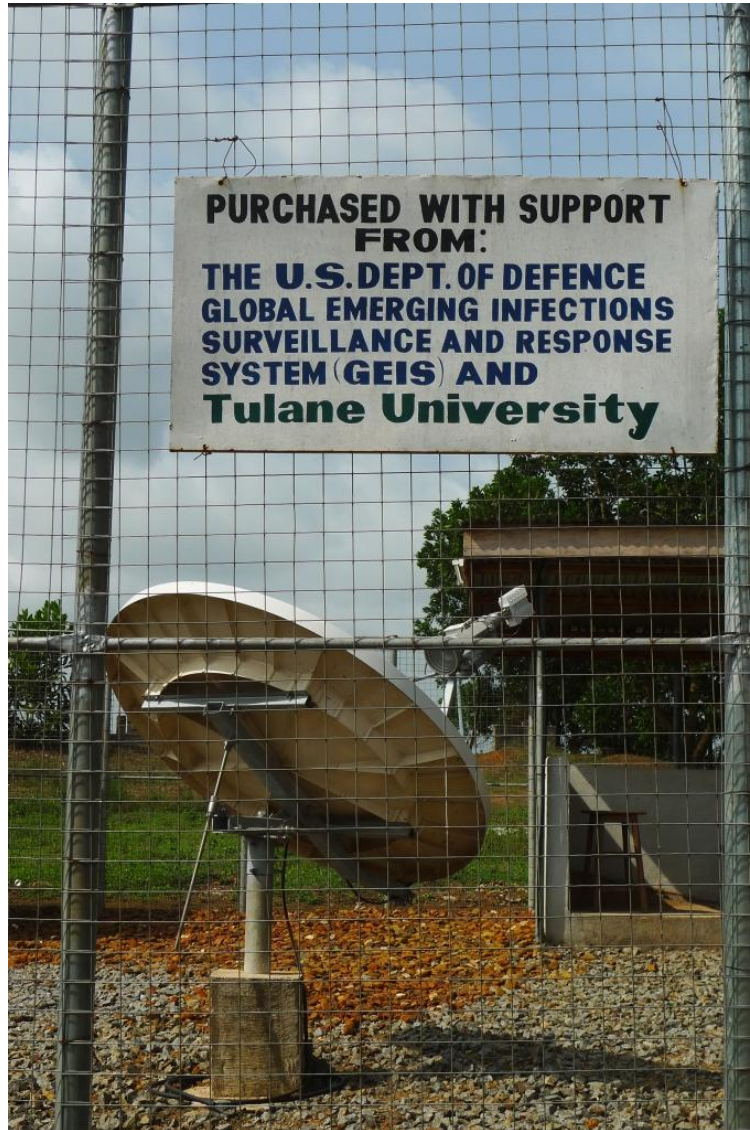
In this chapter the practice of diagnosis in clinical settings takes centre stage. The chapter starts by examining case definitions for Lassa fever as an example of how the disease is framed in formal documents. The rest of the chapter is taken up with contextualising the way diagnosis actually happens in clinical settings. With back up from the laboratory, the case definitions are supposed to funnel people in or out of Lassa treatment. However, as I show processes around the hospital do not follow the neat pathways envisaged in the case definition forms or by the Integrated Disease Surveillance and Response (IDSR) guidelines. I describe the messier processes which come into play and I find that diagnostic, and treatment decisions are negotiated between a much wider set of concerns and voices. The data presented here is based primarily on events at Kenema Government Hospital (KGH) and so is rooted in the official diagnostic system. Observations made at KGH are complemented by those from peripheral health units (PHUs) and hospitals in the ‘Lassa Belt’.

One day, during my walk to KGH, a man stopped me to ask where I was going. He said he wanted to come with me. Intrigued as to his response, I told him I was going to the ‘Lassa ward’ and asked if he still wanted to come. He pulled a shocked face and exclaimed: “No, I will not go to that place!”. The ward’s fame is far reaching but the place itself is full of contradictions. For all the alarm, including rumours of lethal injections in chapter five, the atmosphere around the Lassa ward is mostly calm, slow even. When ‘town power’ is on, nurses from the general wards may slip onto the isolation ward to charge their phones if they can avoid being told off for going behind the faded ‘do not cross’ line on the floor. The calm is pierced however when crowds gather after a death, or when the Lassa ambulance drives through the hospital gates and the people inside can be seen wearing face masks and other personal protective equipment (PPE). Seeing the ambulance drive along the main road in Kenema, masked faces inside, can be especially eerie. One nurse, working in the North of Sierra Leone told me that she had avoided working in East Sierra Leone because of Lassa fever. Nurses working at KGH were well aware of the risks they faced; they remembered colleagues who contracted Lassa at work and died, including Dr Conteh whose story is internationally known.

The framings and narratives which were described in chapter four cross-sect the clinical setting in various and conflicting ways. Clearly, Lassa fever stands out around KGH. An additional distinguishing feature is that treatment for Lassa fever is free. Lassa fever was grouped with a small minority of ‘exceptional’ diseases, such as HIV and TB, which also receive free treatment (at least until the Free Health Care Initiative (FHCI) was introduced in 2010). It is not simply the vertical style programming (which is not so unique) and isolation that differentiates Lassa. So far these features are simply suggestive of the endemic local disease narrative where Lassa is marked out as serious but localised. The ‘exceptionalism’ of free treatment actually contradicts the neglected disease narrative, until one looks closer and finds that the Lassa ward had to use expired drugs for a substantial period until a second donation from the Chinese Government was forthcoming. For the even keener eye there are intriguing symbols of external interest which reflect the global threat narrative. There are signs around the hospital that report the US Department of Defense (DOD) as funding various Lassa projects: the satellite for internet signal is shown in figure 23 and the DOD is also funding a new ward. The dilapidation of the ward matches the dilapidation found throughout the hospital but in that respect this once neglected disease is emerging on both a local and global stage with investments in diagnostics, treatment and research.

In the clinical setting Lassa has many unusual textures: high fatality, isolation, lethal injection mythology, free treatment, conspicuous outside interest and investment to name a few. The bureaucracy and infrastructure of Lassa fever, including the ward buildings and the case definition and surveillance forms, suggest that Lassa fever can be dealt with separately. However as the following pages show, in practice, Lassa is not as separate from its typical clinical surroundings as is imagined.

**Figure 23 A satellite listing financial supporters**



## **7.1 Formal clinical diagnosis of Lassa fever**

It is well documented in the scientific literature that Lassa fever is hard to diagnose clinically due to the non-specific nature of its symptoms (Bausch et al., 2000, McCormick et al., 1987a, Monath and Casals, 1975). Thus, case definition forms are used to provide guidance for healthcare professionals in the region. Pinned to the walls of PHU's, the official first tier of government health care who refer on to hospitals, are the simplified case definitions I introduced in chapter four (see Table 2):

*“Any person in or travelling from an endemic area for Lassa fever (eastern Sierra Leone, Liberia, or southern Guinea) with fever  $>38^{\circ}\text{C}$  less than 3 weeks duration not responding to at least 48 hours of appropriate anti-malarial and anti-biotic treatment, typically with chest pain, vomiting, sore throat, and muscle aches”.*

Figure 24 shows a case definition form developed for the surveillance of Lassa fever, Yellow fever and Dengue fever in Mano River Union countries. This is more detailed than the simplified case definitions. The expanded case definitions are used in hospitals or some PHUs in places with high Lassa incidence. An older Lassa-specific case definition which had been developed by Merlin, the aid organisation who had run the ward previously, is pinned to the wall in the Lassa ward. It is similar to the one shown here. Both forms work on the same principles of differential diagnosis reached from patient history and clinical presentation. Symptoms are grouped into major and minor signs. A fever (measured as over  $38^{\circ}\text{C}$ ) is the first thing to be established in both forms. A differential diagnosis is built up *including* any patient with fever for under three weeks, and then *excluding* other fever-producing illnesses by non-response to treatment (i.e. malaria or typhoid). A final test of inclusion is done by checking that the patient has either two major, or one major and two minor signs of Lassa from the list.

According to instructions on these case definition forms, once a suspect Lassa fever case is encountered by a healthcare worker the treatment pathway is clear. In Merlin’s older form, which predates the routine availability of laboratory diagnostics, the reader is advised to isolate the patient and commence full-barrier nursing while the Lassa ward is notified. At the time my fieldwork began the procedure was similar but with the additional step of collecting a blood sample for confirmation by the laboratory. Chapter five described some of the pathways a patient may take from home to a clinic or hospital. Sometimes the outreach team will also identify suspect cases in the community on their contact tracing trips. For suspect Lassa cases identified outside of KGH there is a dedicated ambulance to pick patients up and take them to the ward. Once diagnosed with Lassa (one assumes) there would be little room for manoeuvre: the protocol is isolation and treatment with Ribavirin for 14 days on the Lassa fever ward.

There are signs in the ward to remind caregivers of isolation procedures (see figure 25). Isolation procedures were described in chapter four and include: washing hands, wearing protective clothing, disposing of needles, syringes and other waste appropriately, and lastly,

safe burial practices. Bowls of bleach diluted in water are placed behind the 'do not cross' line so that medical staff coming off the ward can disinfect themselves (see figure 26). A fence has been built to separate the ward entrance from the main part of the hospital and a small visitor's reception area was built within the fence, with separate areas for visitors and patients.

**Figure 24 Lassa fever case definition form**

<p style="text-align: center;"><b><u>Surveillance for Viral Hemorrhagic Fevers in the Mano River Union Countries</u></b></p> <p style="text-align: center;"><b><u>Definition for a Suspected Case of Lassa, Yellow Fever, or Dengue Hemorrhagic Fever</u></b></p> <p>✓ Fever &gt; 38°C for LESS than 3 weeks AND</p> <p>✓ ABSENCE of signs of LOCAL inflammation (i.e. the illness is systemic) AND</p> <p>✓ ABSENCE of a clinical response after 72 hours of anti-malarial treatment and/or a broad-spectrum antibiotic AND</p> <p>✓ 2 major signs OR 1 major sign AND 2 minor signs</p> <p><b>Major Signs</b></p> <ul style="list-style-type: none"> <li>• Abnormal bleeding (from the mouth, nose, rectum, and/or vagina)</li> <li>• Edema of the neck and/or face</li> <li>• Conjunctival or sub-conjunctival haemorrhage</li> <li>• Jaundice</li> <li>• Spontaneous abortion</li> <li>• Buzzing in the ears or acute deafness</li> <li>• Persistent hypotension</li> <li>• Confirmed contact with a patient suffering from Lassa fever</li> <li>• Elevated liver transaminases (SGOT/AST)</li> </ul> <p><b>Minor Signs</b></p> <ul style="list-style-type: none"> <li>• General malaise</li> <li>• Headache</li> <li>• Retrosternal pain</li> <li>• Muscle or joint pain</li> <li>• Vomiting</li> <li>• Cough</li> <li>• Sore throat</li> <li>• Abdominal pain</li> <li>• Diarrhoea</li> <li>• Proteinuria</li> <li>• Leucopenia &lt; 4000/<math>\mu</math>L</li> </ul> <p>MRU LFN Workshop, Kenema, July 13, 2006</p>
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Figure 25 Sign at the Lassa ward's entrance



Figure 26 Lassa ward entrance, with faded red 'Do not Cross' line on the floor





The form's approach to diagnosis is linear: from patient history and clinical presentation it progressively builds a case for suspecting Lassa fever through stages of 'counting in'. The 'rational' provision of appropriate healthcare is built on that. The case definition sets out a number of requirements a patient's illness must meet: time (length of fever), non-response to treatment and evidence of key Lassa symptoms. There are two assumptions here: first that the diagnostic and treatment process will progress in a linear fashion similar to that described; and second, that the disease will make itself known (albeit after an initial period of non-specificity) by manifesting itself into a collection of defining characteristics which can be ranked as major and minor symptoms. This version of Lassa fever and of treatment processes is based on an 'ideal type' disease-specific model of disease, as described by Rosenberg (2002).

The patient's trajectory is depicted as simple while the doctor's decision making is rational, it implies an account similar to what Berg has described: "the healthcare worker being confronted with a patient's problem, and deciding upon a specific intervention by means of a step by step, cognitive process" (Berg, 1997, p1082). In reality, when facing multiple uncertainties and ambiguity, decision making is not so simple. There are other concerns which the doctors and nursing staff face which affect their diagnostic and treatment decisions. With a disease like Lassa there are also important considerations to be made around risk: risk to the patient, risk to other patients and risk to themselves. The trajectory described by the form also takes it for granted that all the necessary information is available. In the form, the treatment process, the disease, and even the patient are purified versions of real life; it is the 'principles of medicine' which Mol and Berg (1994) distinguished from the 'practice of medicine'. The diagnostic process is more nuanced than categorising patients by ticking symptoms off a list.

## **7.2 Diagnosing Lassa fever in practice**

Above I have outlined the case definition and protocol for diagnosing Lassa fever which can be described as the formal clinical framing of the disease and its diagnosis. I have suggested that it is a linear model of diagnosis, based on idealised notions of disease presentation, both in terms of a patients' treatment seeking and care trajectory, and of the disease's symptoms. The practice tells a different, more complex, story. A doctor working at a major hospital in the



Lassa belt, his hospital a major source of referrals to Kenema, summarises some of the difficulty in diagnosing Lassa:

*“we usually do our diagnostics on physical examination and history taking which is quite restricted...we probably miss quite a few cases.....we have this case now coming in with high fever, for about 2 days, and it could be anything, varying from malaria, up to typhoid, up to Lassa. You just have to wait till certain signs and symptoms evolve...but you know it's not always a case of classic symptoms of red eyes and vomiting and so on”.<sup>126</sup>*

Things are rarely as simple as they first seem.

### **7.2.1 Diagnostic pathways**

A patient's journey, or diagnostic pathway, is mediated by many things: people, framings of disease, availability of treatment, money, local contexts and use of laboratory results. Diagnosis in the clinical setting emerges through interactions between these elements. The following sections detail the factors which were influential in this process. Clinical diagnostic pathways are extremely variable. Arriving at an official health post is neither the start nor the end of the story. People enter the hospital from the kind of settings outlined in chapter five for different reasons, and in different states: some are mildly sick visitors to the outpatient ward; others are comatose when admitted; they may have come straight from a village or have been transferred from another health provider. The more fortunate will have resources for treatment and be accompanied by friends and family who can provide health workers with a full overview of the patient's symptoms and treatment history. Other arrive alone or semi-unconscious on the back of a motorbike with a driver or companion who cannot supply the full illness history. Many never come to the hospital. Once at a health post a test for Lassa fever is just one of many treatment options. At KGH people are tested for Lassa fever for a range of reasons: some fit the case definition, others have a blood sample taken as part of contact tracing from known cases (and may not visit the hospital themselves initially); some people are referred from other health posts specifically for Lassa tests and treatment; a patient may ask to be tested specifically; increasingly, doctors order tests to 'rule it out' as a precaution without really suspecting Lassa.

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<sup>126</sup> Clinician, Panguma, 22/02/2010

### **7.2.1.1 Getting a referral: querying Lassa**

Much depends on the manner in which a patient arrives at the hospital. There is often talk amongst the healthcare workers that patients are to blame for late referrals with severe disease as they stay in their villages too long, ‘taking herbs’ and ‘running from’ the hospital. Although delays certainly occur at this point, for reasons explored in chapter five interviews with ex-Lassa patients made it clear that it is also true that many patients do go to PHU’s or hospitals in good time, but can be held up there for days before Lassa is queried. For both patients and health workers spotting Lassa is difficult, even for those with a great deal of experience. Doctors, patients and ward records all offer examples of times when patients were treated for other sicknesses and Lassa is only picked up at the last minute. In chapter five I recounted a widowed husband’s story of being with his late wife at the hospital for 14 days before Lassa was finally queried. Ward records show patients who are discharged having been treated for something else, supposedly on the mend, only to return when symptoms persist. Unfortunately many admissions to the Lassa ward, from both hospitals and communities, are recorded when late and severe symptoms have already started: coma, convulsions, bleeding.

What are the complications which cause these delays? Why, with a case definition which clearly sets out the important signals and chronology, does Lassa get missed? One basic point to make is that for all the PHU and hospital staff who know the case definition and are familiar with Lassa there are many who are not so well acquainted with it. In areas where Lassa is common, where nurses may have come face to face with the disease or with the outreach team, nursing staff may be comfortable with the key signs. However, Lassa fever is not a standard part of national training for nurses in Sierra Leone and many are not familiar with the case definition. The Lassa fever outreach team have conducted training sessions in the past and they do ad hoc additional ones where possible, either on visits to villages or hospitals. Complete coverage is not possible and would likely be complicated by turnover and the numbers of healthcare workers at government posts who are not officially on payroll but who provide services to the community. One nurse, working in a Northern district, told me she had some lessons on Lassa fever years before but that she did not know it “deeply”. This situation is echoed across the regions of Sierra Leone where healthcare workers have heard of the disease but know little of its detail.

Even for well-trained experienced healthcare workers, who know the case definition, there can still be a delay: in regards to the non-specific symptoms, the doctor in Panguma noted that the case definition has a delay built in to it by advising clinicians to treat and observe non-response. Although there is a rationale for this in terms of differential diagnosis, he felt there was a trade-off and in some cases waiting was inappropriate. At his hospital, based a good few hours from KGH over bad dirt roads, time was limited. In response to those conditions, he and his nurses told me that when they recognised patients with 'classic signs' they often decide not to wait but to send the patient straight away. Waiting to send a sample on the back of a motorbike and then waiting for the results, and only then calling the ambulance from Kenema to come and collect the patient risked too much of a delay.

In terms of logistics and links between health care providers much depends on the outreach team who do far more than just contact tracing, sample collection and sensitization. The backbone of the outreach team is two Mende men, from Eastern Sierra Leone, who know the villages and healthcare workers in the region very well. One is married to the head nurse of Lassa ward and all of them have worked there for well over a decade. They are an essential link in the diagnostic system's chain and often nurses ring their mobile numbers when they have suspect cases. Another surveillance and outreach officer who was officially senior to them, but who had come from Freetown, had noticeably less affinity with these rural areas and inhabitants. The outreach team would, in addition to their official duties, get involved with village health affairs. In Tokenga the outreach team advised the villagers in their campaign for a clinic and in at least two other villages they assisted in mediating in conflicts between nurses and the community. There is a dedicated ambulance for Lassa patients, provided for free, and many of its journeys are arranged by the outreach team. On occasion the outreach vehicle will be converted into an ambulance when urgent cases are found out in the field. The outreach team do their best to forge links between peripheral health posts and KGH, within a plural and at times fractured health system. And as chapter five demonstrated there are a number of other providers of therapeutic care who the sick can consult.

What kind of healthcare provider a patient goes to see when they are ill depends on a number of factors. In chapter five I showed how people say they prefer Western medicine but they disapprove of, and dislike depending on, the drug peddlers who they are aware sell counterfeit or expired drugs. In rural villages people emphasised that they would like official

healthcare to be made more easily available to them. Yet, even in that favourable context the authority of staff sent to communities to run Government health clinics is not a given and must be earned. Nurses in government health posts need to work hard to establish relationships with the communities they serve which match the ties already established by existing embedded providers. A nurse in a well-established (and Lassa heavy) mining town told me that when she first arrived her clinic was empty as patients preferred to go to these existing providers. The quality of these other providers is varied, as is knowledge of Lassa. Nurses told me that they did receive referrals from informal providers, such as pharmacists, at times. However, nurses were also of the opinion that some informal providers kept treating patients as long as they could so that they would receive payment. In chapter five, Tokenga's community members repeated the Lassa fever health promotion message to me and said that a Lassa victim should go straight to hospital, but they also reported instances where Lassa fever was treated independently of KGH. Chapter five showed that not only are these informal and village based providers diverse but so are people's reasons for choosing them over a government hospital. Instead of being based on misunderstandings or ignorance of biomedicine, such choices are dependent on assessments of the social relations within health systems.

#### **7.2.1.2 Dysfunction in the system?**

The politics of village healthcare can affect diagnostic pathways. Conflict between nurses, who are often 'strangers', and village communities are not uncommon. Sometime these relationships can become dysfunctional; the headquarter village in Dodo chiefdom (Tokenga's chiefdom) had a history of rejecting the community health officers, there were often disputes with the nurse who was well established there and at times she would refuse to work. The outreach team would sometimes be called to mediate on these occasions. I witnessed how Lassa fever care and prevention could become strategically enrolled in local politics: in one town which had a history of Lassa, the new Community Health Officer (CHO) made an attempt to gain some popularity by promising to supply a cat for every house in the town to improve rodent control if he was still there in six months (he was not). In another town the health prevention message of rubbish attracting rodents fed into complaints by some residents about other residents leaving their environments dirty and about the ineffective community sanitation officers. At one town meeting it was claimed that the sanitation officers only looked after the wealthy. Passing laws and imposing fines (for not cleaning, for eating rats or eating

cats) was a popular solution “whether he is the chief’s son or not!” shouted the man at that meeting.

Disputes can disrupt the provision of care and with acute diseases like Lassa fever the costs of these can be high. One of the especially tragic stories I told in chapter five demonstrates this: recall the family who lost three children to Lassa fever and where the mother, who survived, was left with hearing problems. They lived in a mining village which had its own PHU with two registered nurses. One of these nurses had even had training on Lassa fever. But when the father had taken his son, who was sick with fever, to the clinic neither nurse had suggested anything other than malaria was wrong. The boy grew more seriously ill and died. When another of the man’s sons fell sick a few days later he returned to the clinic but again they noted nothing particularly suspicious. He described how the nurse used a ‘*prova*’<sup>127</sup> to diagnose the boy with malaria and then prescribed anti-malarial drugs, which they did not have in stock. The man took his son to another clinic in a neighbouring village but the second boy died on the trip. When he returned he found that the children’s mother and another sibling had fallen sick. Finally, the nurses contacted the hospital in Kenema. The father explained that there was long-standing friction between the two nurses. He said the nurses were more involved in their own conflict than in taking action to care for patients or equip their clinic properly. It may be relevant that this was a mining village with a transient population where arguably community solidarity may have been more limited and less able to tackle on-going failures in basic healthcare provision. These events seemed to galvanise villagers to take action, backed up by the outreach team, they demanded that the two nurses be removed and replaced.

Once at the hospital the uncertainty and diversity of pathways does not end. Extracting the full and necessary information to apply a case definition from patients is difficult, whether they are admitted straight to the isolation ward or to a general ward. When deliberating over whether to admit a new patient or clerking a new admission the nurses have to use whatever information they can. Scrutinizing the forms that are sent with patient, there are often gaps or inaccuracies. Illness and exposure histories are often not extensive, the case notification form may not be fully filled out, personal details of the patient are missing or conflicting in different forms. Patients turn up with referrals and no full treatment history, and they or their family

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<sup>127</sup> A rapid diagnostic test

are often unable to give it. The outreach team also try to fit parts of the jigsaw together, visiting case contacts. Sometimes in these contexts the histories that are reported are suspected of not being accurate. Nurses can be very sceptical about the information given to them by patients:

*“they keep these patients until their condition is going bad....that is the general habit of our native people. They don’t seek the hospital advice as early as possible, they keep their children for a day, 2, 3, or 4 but when they come they never give the correct history. When we ask them how long has this child been sick they say just for 2 days, but if we go and ask another relative, or a neighbour, he or she will say that he has been sick for a week or two.....it is difficult to get the histories, they don’t give the actual history”.*<sup>128</sup>

Miss-communication or the total failure of information flow becomes lethal in the case of Lassa fever, and as one clinician commented to me, is almost made worse by one of the basic principles of the case definitions: clinically someone is to be suspected of Lassa once they have been treated, and found to be non-responsive, for anti-malarial and antibiotic drugs for a period of 72 hours. He told me that what can happen is that the 72 hour period will be observed after which the patient is referred to the next tier in the health service but although the patient may arrive there still in one piece unfortunately their treatment history may not. Thus, health workers at the next level start the process again, causing further delay.

Many factors can get in the way of comprehensive treatment histories. As well as the problems with record keeping, patients may not have been told or remember what they have taken and nurses often distrust what is reported to them. In particular they assume that people do not report time and use of any alternative therapies accurately. I also observed what appeared to be an attempt to conceal a patient’s exposure history; it was actually a doctor who was disputing the dates a young girl had stayed in his household (in a Lassa endemic area). His account differed from what the outreach had been told by others and they guessed that he was trying to avoid the stigma of a Lassa infection being contracted under his roof. In general, it is hard to tell what information is true and whether the nurses should be so dismissive of patient’s accounts, but what is clear is that doctors and nurses make decisions under considerable uncertainty.

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<sup>128</sup> Paediatric nurse, Panguma, 22/02/2010

### 7.2.1.3 Building a solid case

Returning to the case definition, the exclusion of the differential diseases is particularly troublesome, in part because ‘non-response’ is hard to judge when the quality of the treatment given is unclear and because many patients are co-infected making exclusion tricky. The intractable messiness of health and treatment is particularly apparent here. Despite the case definition requiring that patients have been treated with, and found not responsive to, antibiotics and anti-malarials there is a working assumption that this won’t have happened. At the Lassa ward they still treat most people for malaria on arrival (if drugs are available or purchased by the family), even when their records report that they have been treated for it – and as is required by the case definition. The assumption that malaria hasn’t been excluded is rooted in a number of factors: non-adherence to treatment, the possibility that drugs were counterfeit or expired, or miss-reporting and miss-management of cases. The Lassa nurses do not even trust the treatment history of cases referred from within KGH; only patients coming from the nearby MSF hospital were expected to have been treated appropriately for malaria. These factors seriously undermine the possibility of applying the case definition with any validity and in practice it means diagnosis takes a very different shape making it distinctly unpredictable and non-linear. When it was still routine practice to admit non-laboratory confirmed cases to the Lassa ward the steady stream of admissions who soon began to recover once they are commenced on anti-malarials is a reminder that that scepticism is justified.

Another element affecting the capacity to establish a reliable diagnosis of Lassa and to exclude differential diseases is the financing of healthcare. The national (and international) funding of healthcare influences treatment seeking pathways because it determines the choices available to patients and clinicians. The assortment of payment policies and vertical programmes have a bearing on medical practice in a very real sense. Some diseases have free tests and treatment, most do not; and if a donor is not paying then it is left for the staff to do what they can with both the hospital and the patient’s scarce resources.

These negotiations not only account for particular decisions, they are also part of the knowledge base used to make decisions. Shadowing ward rounds with the doctor invariably meant trying to piece together what bits of treatment or tests a patient had had. ‘What about the labs?’ ‘What about the treatment?’ Time and time again when the doctors asked these

questions the nurses reported that they had not been done, usually on account of the patient's inability to pay for them: '*moni no dae*' (the money is not there).<sup>129</sup> While the primary burden falls on the patient here, the doctor and supporting health staff are left with little to go on, investigations are confined to physical examination, diagnosis is symptomatic, prognosis involves waiting to see what happens and clinical decisions are made under considerable uncertainty. What was poignant was that often patients had made considerable efforts to get to a hospital, paying for transport and for hospital admission, but were left with no money for treatment. Getting to hospital entails significant cost alone; finding out what is making a person sick once they arrived there involves further financial strain which many patients (not covered by FHCI) cannot afford. Investigating a case, even to the minimal extent that the case definition requires, is often not possible. Fever, one of the most fundamental symptoms in the case definition is not always possible to measure in the manner that is called for: the Lassa ward, for example, did not have a thermometer<sup>130</sup>, and it is unlikely that many PHUs would have had one.

In the place of so many unknowns other strategies for deciding how cases should be treated arise. For malaria, there is a strong tradition of presumptive diagnosis which was also recommended by the WHO for a long time (D'Acremont et al., 2009). I overheard the doctor telling his students to "assume, don't even ask" about malaria. When I first sat in on outpatient consultations with a different doctor he asked me to write prescriptions for him as he dictated. I was having trouble keeping up at first with the lists of drugs for each patient. Here treatment was certainly the diagnosis, and when I asked him to slow down or repeat things he laughed and told me "you'll get used to it". Very quickly I did.

In this section we have seen that clinical diagnosis in practice is much messier than the path set out in the case definition. Not only is it not linear, it can be chaotic and there is usually significant uncertainty. Furthermore we do not see the 'hanging together' that has been implicit in descriptions of diagnosis in higher income settings, supporting Street's scepticism about its universality. In the Papua New Guinean clinical context Street describes a value being placed on uncertainty and sees nurses 'working against' those who try to seek closures.

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<sup>129</sup> Laboratory tests for Lassa fever are free. Laboratory tests for other conditions are done by the general laboratory which charges on average between 3,000-50,000 Leones (£00.54p to £9.00) for analysis. Though some tests are as much as 150,000 Leones (£27.00).

<sup>130</sup> Tulane medical clinician, telephone interview, 27/07/2012



In KGH I did not see resistance to diagnostic closure, but there were some issues with the flow of information which at times meant things didn't 'hang'; in a healthcare context with multiple providers and only paper records, both forms and patients can get lost. Tracking a patient down within the hospital grounds can be difficult but outside, without full or permanent addresses, patients disappear. Efforts are made to keep any serious or probable looking cases in or near the hospital while test are being run, but some get away: there was a suspect case from the outpatients who was supposed to come back for monitoring, on hearing about them an experienced nurse laughed "you won't see him now", and they didn't. Patients would sometimes resist to be admitted, or plead to be discharged. I never saw a patient refuse absolutely but I did hear of occasions; while I was there, there was a cluster of cases from the same household in Tongo (a mining area). There had already been three cases of Lassa linked to the house including one death. A fourth man fell ill after staying there, but despite vomiting blood he chose to return to his village instead of going to the Lassa ward, and his village is where he was reported to have died.<sup>131</sup>

### 7.2.2 Classic Lassa?

In addition to the variability of diagnostic pathways there is a fundamental problem of recognising Lassa fever. In terms of referral and treatment decisions, there are some symptoms on the case definition's list which appear to have more currency than others in health workers decision making. 'Classic symptoms' or 'classic signs' as they are known by healthcare workers are: bleeding, red eyes, high fever, sore throat and a swollen face most typically, to that more mundane symptoms such as diarrhoea, side pain and vomiting are added. There is no comprehensive or definitive list, but the same symptoms are mentioned when nurses are guessing the status of someone awaiting a test, or deciding whether to refer, admit, or treat.

As I have outlined fulfilling the requirements of the case identification form is not always possible and patients are often referred to the ward on symptoms alone – apparently often primarily on the basis of the 'classic signs'. One nurse told me, "sore throat, fever and red eyes, we don't waste time"<sup>132</sup>. Another classic sign is bleeding, which is associated with the later stages of the disease. The same nurse explained of bleeding, "we don't waste time with it at all....that is the final stage, whether we order the tests or not we just have to conclude that this

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<sup>131</sup> Lassa history 12, Tongo, 26/04/2010

<sup>132</sup> Paediatric nurse, Panguma, 22/02/2010

is Lassa, we don't even take the sample we just call for ambulance to take the patients".<sup>133</sup> Here the health workers decisions are based on weighing up risks to themselves and to patients and classic signs are taken as a strong indication of risk.

Symptoms like red eyes and bleeding in particular are reminders of Lassa's alarming reputation and of the risks facing healthcare workers: "we are at a very great risk. Because when these people come with one or two signs of Lassa fever, we don't know whether it is actual Lassa or not, so we just have to play with this patient".<sup>134</sup> Querying Lassa, starting isolation and referring that patient is a safer option for healthcare workers. Indeed such is the power of these signs that there are cases who are referred to the Lassa ward inappropriately, for instance at separate times: a man who was vomiting blood but had no other clinical signs; a girl with a bleeding nose; or another who had been referred by KGH to Freetown for an operation but was sent back when he was found to have some bleeding in his mouth. Such panic and risk aversion makes sense, when the classic signs reveal themselves the nurses have to protect themselves. This was brought home to me after a case was contracted on the grounds of a hospital in the Lassa belt. The outreach team conducted a training session with the student nurses there in which they advised them to use gloves and not to 'play' with suspect patients. However, in a shocking admission of the situation they faced, the matron stood up straight after and told them not to even ask for gloves because there weren't any and that "only god can save you". A final, equally unhelpful, piece of advice was simply that they should not let a patient be sick on them.

Once at the ward there are similar judgments to be made about the numerous risks Lassa poses to patients and staff. As I touched upon in the preceding section, some patients are referred to the Lassa ward before their samples have been tested; some are referred on the back on a positive test result. Staff on the Lassa ward then need to decide whether to admit, treat or observe. Evidence of classic signs and severity of symptoms figure strongly in these decisions. At the start of my fieldwork it was common for suspect cases to be transferred to the isolation ward before the results were back; as the tests took longer there was a lengthier window of uncertainty during which the reasoning was that it was better not to delay or 'play' with Lassa. There was also the real possibility of traumatising a patient or doing them harm by starting treatment mistakenly, as one researcher put it, "you could argue if Lassa doesn't

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<sup>133</sup> Paediatric nurse, Panguma, 22/02/2010

<sup>134</sup> Paediatric nurse, Panguma, 22/02/2010

kill you then the treatment will". While that may be over-stating the case, a course of Ribavirin is certainly not a treatment to be taken lightly and there were cases, which I will come to, which were treated erroneously causing serious side effects. Later on, as tests got quicker, admitting patients to the ward without test results became less frequent.

On the admission forms there are two options to choose from if a patient's sample has not yet been sent for testing: 'suspect Lassa' or 'probable Lassa'. An old treatment algorithm of Merlin's which was stuck to the wall defined 'probable' as cases which fulfilled all the case definition criteria (pre-laboratory tests) and hence should be treated, and patients not meeting all the case definition's requirements were to be treated as suspect and monitored but not receive treatment initially. However, when I asked nurses how they defined the categories of 'probable' and 'suspect', specifically on what basis they allocated patients to each category, there was no clear consensus or unanimous method. One defined 'probable' as patients who were contacts of known cases. 'Probable' was widely used to mean that the patient was considered to have a higher probability of being sick with Lassa than a patient classed as 'suspect'. But in general the terms which nurses used to divide patients up seemed flexible. The most important outcome of this classification was the decision about whether to treat with Ribavirin or not. Thus, in practice the classification of patients as 'probable' and 'suspect' was largely the result of the nurses' or doctor's decision about whether a patient needed to be commenced on treatment.

Rather than following a protocol or classification to the letter, the nurses appeared to make the decision based on their assessments of classic signs and the severity of symptoms. One brief exchange went:

Nurse 1: "*e don do de test?*" (has he been tested?)

Nurse 2: "*No, but e get classic signs, we de commence Ribavirin*" (no, but he has classic signs, we are starting Ribavirin)

Severe symptoms (such as convulsions, coma) and classic signs were a strong incentive to start patients on treatment as early as possible. Nurses could make this decision without the doctor and frequently did. As soon as such cases arrived at the ward the nurses would start preparing the vials of Ribavirin for an initial dose. These practices incorporated an intimate knowledge of Lassa, an appreciation of a patient's condition, likely stage of disease, a weighing up of the risks of waiting or starting treatment to a patient's health and chances of survival. In

such instances these concerns override the formula set out by clinical protocols or case definitions. I once asked the doctor in charge about treatment protocols (other than the Merlin one from the wall), to which he replied there weren't any "just what is in our heads". Though this is not quite true (as there were treatment protocols for instance the dosage and length of treatment with Ribavirin, burial procedures, or discharge protocols), many of the clinical decisions were left up to individual's judgements to which there could be considerable flexibility.

Another area of clinical decision making concerns nurses practices of personal protection and risk aversion. The safety concerns of the protocol are tangential to the practicalities of carrying out duties on the ward. If the ward is full and there are multiple patients requiring intravenous Ribavirin each at separate times the nurses would, by protocol, have to be in full PPE almost constantly. The inconvenience and discomfort of this was enormous in the humid heat and on a hot, badly ventilated ward. Nurses would sometimes emerge from patient's rooms soaked with sweat. Relaxation of the safety rules are tolerated because they are a practically burdensome, a fact which is recognised by senior staff. There are resource limitations too, for instance the 'appropriate disposal of needles' requires 'sharp boxes' and an adequate supply of needles to ensure that nurses do not need to 're-cap' them. Such resources are not always available, and given the heavy treatment schedule for Lassa patients, the nurses are required to re-cap and re-use needles (across one patient's treatment period, not across patients) thus breaking a golden rule of hospital hygiene and safety. Alternative rules of thumb were explained to me. In practice some nurses would make assessments of the level of risk a patient presented and adjust their level of PPE according to that. One nurse told me that if a patient was bleeding, perhaps a miscarriage, or vomiting substantially he would dress in full protective gear but would not always 'gown up' if he considered a patient to be 'stable'. For him, this level of risk was one he felt comfortable with and it was also something which he argued he should be able to have some degree of control over instead of simply following a protocol. It was for his own protection he reasoned.

'Classic Lassa' is a framing of Lassa that comes out of the health care workers own experiences with Lassa, and of their knowledge of what Lassa looks and feels like in a patient. In contrast other nurses, who do not have experience with Lassa, can name a few symptoms but say they do not 'really know' Lassa. When confronted with a suspect case nurses' knowledge is

combined with an appreciation of the treatment options and the risks that come with them, for instance; scaring the patient by admitting them to isolation, getting treatment started as early as possible to give the patient the best chance of survival, risking their own or other patients lives by not isolating or referring to Kenema. A lot rides on the 'classic signs', yet the quote I started with hinted at a problem: "it's not always a case of classic symptoms". There is a deeper ambiguity; these classic signs and lists of major and minor signs are based on data collected about the symptoms observed in the clinic over a number of years. However those were also collected at a time when laboratory diagnostics were not reliable or routine, so what then, are the underlying clinical definitions of Lassa based on? A disjuncture is opening up between classificatory practices and the tacit and practical knowledge used in clinical decision making is caught somewhere in between. If it was ever certain, it seems more uncertain in some respects now. Here I will give some examples of the ways the classic signs may not be so clear-cut or reliable.

To begin with although the 'classic signs' have a core group of symptoms some healthcare workers add their own. In Panguma, both of the Sierra Leonean nurses who I interviewed spoke of 'black vomit'<sup>135</sup> as a 'symptom' or warning sign of Lassa:

*"he (the previous doctor) chose this black fluid to be one of the symptoms of Lassa fever..... when the patient comes to hospital and we suspect them of having black fluid and at the same time running temperature, we just have to attribute it to be Lassa. ....the community people delay this patient in sending him to hospital".<sup>136</sup>*

The nurses were unsure if it was from internal bleeding or use of herbal medicine, but when black vomit was observed it was a cue to suspect Lassa and was interpreted as a sign of delay.<sup>137</sup> Black vomit is mentioned in some of the literature on Lassa fever (Ogbu et al., 2007) although not frequently. In Panguma however, it appears to be a 'classic sign'. Interestingly the senior doctor at this hospital, a European man, was confused as to the significance of 'black vomit':

*"There is another thing which sometimes confuses me, and I have not really found out, what they mean with black vomit disease. If that is actually a thing which comes from the community which could fit in with either Lassa, but could also fit in with use of local drugs.....if I read my annual reports from the past there are people diagnosed with black vomit disease, which is not a clinical term. If you look into a clinical tropical book you would not find black vomit*

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<sup>135</sup> I have heard black vomit mentioned in regard to Yellow fever too.

<sup>136</sup> Paediatric nurse, Panguma, 22/02/2010

<sup>137</sup> Outpatient nurse, Panguma, 22/02/2010

*disease....they use it and they are brought in that way, like a child is brought in with black vomit disease. It is not officially diagnosed on our clinical charts but they use that term, black vomit disease. That sometimes confuses me to what say what does it actually mean. Is it a community thing, or is it really something which is embedded in the clinical situation in Sierra Leone?”<sup>138</sup>*

What ‘classic signs’ and ‘black vomit’ show is that even when formal case definitions exist, there will be alternative local working definitions, and local additions to the disease profile. These classification systems are part of the regime that laboratory diagnostics, old and new, are used within.

For all the talk of classic signs, and dependence on them to make assessments, Lassa frequently proves itself to be unpredictable or at the least the laboratory results do not always concur. That Lassa fever’s clinical presentation is non-specific is well known. But the reliance on the classic signs and the notion that Lassa will emerge in this typical form is often undermined. Either the classic signs never appear or they are clearly evident but when the blood sample comes back it is negative for Lassa. As one doctor told me, there are always cases which take you by surprise. Most recently for him was the case of a pregnant woman who had given birth to a baby at five months who did not survive. The woman was despondent, unresponsive and he suspected stress from the trauma. She also had problems with a swollen abdomen. He and another doctor were treating her for days but had no real leads until she started bleeding from her IV site. They tested her for Lassa and it came back positive. He was still extremely surprised by this result, particularly due to the absence of fever. He asked me: “can you imagine? She was not hot at all”. In hindsight he felt he should have recognised her malaise as a symptom of Lassa yet there was very little else to go on until it was too late. Even without the ‘classic signs’ the case proved to be a fatal. Other times there are cases which have all the classic signs but which tests later show are not Lassa. Their symptoms may have looked so typical that they had already been admitted to the ward and commenced treatment. Mostly the patients are discharged from the ward but in some cases where the patient is clearly very sick, nurses confided that they have, on occasion, continued treatment, reasoning that it could be another VHF for which Ribavirin may be effective.

One ‘sign’ which I haven’t mentioned but which is a cornerstone of Lassa’s framing in Sierra Leone, and could be said to be tacitly included the ‘classic signs’, is geography and exposure history determined by time spent in a Lassa endemic area. This has long been understood as

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<sup>138</sup> Clinician, Panguma, 22/02/2010

the Eastern and Southern provinces of Sierra Leone. The Western area towards Freetown and the North of Sierra Leone have traditionally not been associated with Lassa fever. This was ingrained in popular culture as well as clinical practice. A few Freetown residents even told me they disliked, or even avoided, travel to the East. One man told me he always brought his own food with him. A nurse explained that although she trained in the East, the reason she had looked for work in Northern provinces was to avoid Lassa: “we thought it had a special area” she told me. Such ideas made their way into clinical practice; for instance the man I mentioned previously who was turned away from Freetown as he had been in Kenema and had some bleeding in his mouth.

However, the strong association with Lassa and the Eastern Sierra Leone is beginning to unravel. In 2011 an outbreak in the Northern Province of Makeni was recorded. This caused a sensation as a South African national died and there were (inaccurate) reports in the press that a woman running a ‘rat meat restaurant’ had been the source. In an interview with a doctor who was involved in treating some of those affected in this outbreak, she acknowledged how she and her colleagues were slow to recognise Lassa as they associated it so strongly with the East of Sierra Leone. She added that when they began to send samples to Kenema they were not really suspecting to find Lassa, as well as the geographical issues the cases did not look classic “he was not bleeding...we didn’t recognise it as Lassa, he didn’t have the typical Lassa symptoms, but we checked it because we wanted to check it for the other things”<sup>139</sup> (other viruses which they could test for at Kenema and which seemed more likely).

Indeed, the supposed certainty with which diagnostic inferences have been made from a patient’s travel history (as having been in or not been in a Lassa endemic area) is based on severely limited knowledge about the spread of Lassa. As discussed in chapter 4 there are serious underlying doubts about the distribution and prevalence rates of Lassa fever in Sierra Leone and West Africa. These cases from the north seem to confirm that the association between place and diagnosis is unravelling or changing. The uncertainties about ecology, climate and prevalence which surround Lassa fever are, in this view, central to diagnostic practice. The questions over whether it is a forest zone disease or whether it is linked to rainfall and other climatological factors (see Fichet-Calvet and Rogers, 2009) map on to local understandings of prevalence, and thus regionally textured framings of Lassa, which challenge

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<sup>139</sup> Lassa history 13, Makeni, 29/04/2011 (this interview was with a doctor who had been treating a Lassa patient and subsequently became infected)

the long-standing diagnostic inferences based on them. New research into these issues (See Gire et al., 2012, Moses et al., 2012) will undoubtedly bring further implications for diagnosis across the region. In the meantime in-country WHO officials discussed the need for broadening out surveillance in all of Sierra Leone's regions, to "raise the suspicion index for Lassa" as one put it.<sup>140</sup> However Ministry of Health and Sanitation officials admit that in a context of scarce resources, Lassa fever is not yet a national priority; though that may change if too many health workers, also considered as scarce resources, are lost.<sup>141</sup>

### **7.2.3 Laboratory results in clinical practice**

Into this mix are thrown the laboratory tests, the subject of the previous chapter which I have alluded to at various points in this one so far. In general there is a synergy between the tests and the clinical signs. But as we have seen key treatment decisions are not always based on a test result, they are often made before and very occasionally in spite of one (i.e. the Lassa negative patients who are kept on Ribavirin or kept on the ward for observation). The KGH doctors have a healthy scepticism of laboratory results. One doctor took care to remind me that they "weren't gospel". Yet some were deemed more reliable than others. Lassa fever tests were respected on the whole, whereas tests for malaria and typhoid were not well trusted. The doctor emphasised that latter point to his students by waving a negative malaria result from in front of them while ordering a course of anti-malaria drugs for the patient: "are we to trust a mere bit of paper?" he said. The Lassa ELISA is not dismissed in this way and patients were admitted or discharged as a result. Much of the variation in diagnostics pathways I have described so far concerns what happens before a test. Now I want to turn to what happens after the result is received and what has changed with the new diagnostics. Although the result is trusted (though some doubts remain) it is not the definitive factor in treatment decisions. That, in principle, should come as no surprise to anyone who has had some involvement in diagnostics or medicine. Both Tulane clinicians emphasised that a test should not be used alone but rather in conjunction with other tools of investigation or methods of appraising symptoms. In practice, the way in which the meaning of a test result is negotiated for clinical decision making can be surprising; in the previous chapter I noted there had been some disagreement over the 'new paradigm' for interpreting IgM, here we see the clinical implications of those disagreements.

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<sup>140</sup> WHO representative, Freetown, 29/04/2011

<sup>141</sup> Senior MOHS official, Disease Prevention and Control Directorate, Freetown, 28/04/2011



One change with major clinical implications is the reduction in the time it takes for a test result to come back. The result is that unless a suspect case looks particularly severe the decision to treat, and admit, is made after and on the basis of the test result. There are far fewer people who start treatment and are admitted mistakenly. There is another more complicated change in practice concerning the way IgM positive results are interpreted and dealt with. When I started fieldwork a positive result on the IgM or AG ELISA was considered a positive Lassa diagnosis. Such cases were admitted to the ward and the decision to start treatment was based on symptoms and clinical condition (as described above). Now IgM positives are frequently not considered a clinical diagnosis of Lassa fever. Many such patients are not admitted to the ward and, as a Tulane researcher explained to me, they now think they are “sick with something else”. As the last chapter demonstrated, if once the laboratory researchers complained that “doctors speak for what we know” about Lassa fever, the reverse now looks to be coming true. IgM patients were often kept on the general wards after their results came back. There appeared to be a growing sense that the IgM patients did not need any special attention and were considered stable. An IgM positive result was being described by more senior healthcare workers to the patients and nursing staff on these wards as meaning the patient had “conquered the Lassa”. In effect the developments in the laboratory, and the ‘emerging view’ that IgM stayed in a patient’s body for much longer than previously thought, was overturning the established diagnostic interpretation and the clinical routines which had been built on them. But as I noted in the previous chapter this is not without some contestation.

More recently a clinician from Tulane explained how things were evolving with regards to IgM interpretation: the IgM could still have some diagnostic purpose in that it was “suggestive but doesn’t confirm” a recent Lassa infection, but for treatment decisions an IgM test “really isn’t clinically relevant” because an “IgM positive doesn’t mean a patient should be treated”.<sup>142</sup> What is important here is that there begins to be a separation between the purposes of diagnosis, say for research or surveillance, and clinical decision making. This is the same clinician who earlier emphasised the value of a test; that a test should assist, not determine, clinical judgement and decision making. Here, the interpretation of the test depends on its relevance and ability to inform the practical decision being made. IgM loses its clinical relevance, and diagnostic authority, because it cannot assist in making treatment decisions.

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<sup>142</sup> Tulane medical clinician, telephone interview, 27/07/2012

The meaning and power of the test comes from what it can set into motion as a result. A positive IgM case is made in practice through treatment decisions not simply by the identification of IgM in the sample.

Initially these deliberations and routines concerning IgM seemed in a state of flux; when I left Sierra Leone the fact that IgM patients were being kept on general wards was not widely shared, even amongst the team. As it became more commonplace (and public) there was some unease amongst a few staff members who were cautious about modifications to the established protocol which were understood as essential for minimising further infections. There was a feeling that the new criteria for diagnosis was not tried and tested.

Earlier I mentioned bottlenecks in the flow of information and it was particularly apparent in these cases. The Lassa ELISA results are given to the doctor in charge of the Lassa ward and are not kept with the patient's notes on the ward. In many cases the nursing staff were uninformed of the test results, including whether the patient being kept on their ward and cared for by them was an IgM positive. Even the other doctors were not always kept up to date with results, even from tests they had ordered; the doctor in charge of the maternity ward seemed to routinely have to chase up the results. Initially for these IgM cases he would push for positive patients to be transferred to the Lassa ward, arguing they were 'Lassa patients'. However, when I returned in 2011 just under a year after my main fieldwork period, IgM patients were routinely kept on the wards: the doctor in charge of the Lassa ward and the maternity ward doctor now had a running joke about their struggles over transferring patients but in reality the practice that IgM patients often stayed on the general wards was well established. There was still some mystification about the results, with one nurse on the male ward telling me that "they do not tell us directly that this is a Lassa patient, they say he has the immune response". She was unsure as to what exactly the results meant and asked me, "that IgM, what is it?"

Another aspect of this is that patients are often not told of their Lassa results. There has always been a culture of shielding patients from Lassa fever before it was confirmed; it might be referred to as 'Lassa fever' or 'the bleeding disease'. Not telling the patients was probably not such a departure from routine clinical practice as patients are not told a lot on the whole. Guided by an assumption that patients will panic or won't understand, IgM cases are

sometimes only told indirectly or not at all: “they told me I have been exposed” was what one patient reported to me. I interviewed a woman who had tested positive for IgM and had been kept on the general ward. It became clear in the interview that she had never been told what sickness had made her ill and she asked me to come to the hospital with her to find out from her records. In light of the claims that improved diagnostic technologies will reduce uncertainty, examples such as this ask whose uncertainty is being reduced. She described never having been so sick before. I had seen her when she was on the general ward and she certainly seemed very ill. This raises some doubts about the assumption “that they are sick with something else”. Although the ‘emerging view’ from the laboratory was that these cases were not necessarily acute Lassa cases this had to be confirmed, because although it *may not* be Lassa, it was also possible that it *was* Lassa.

It is also a reminder that laboratory diagnostics cannot hold all the information necessarily for patient care. Therefore, in addition to the re-interpretation of IgM there was a new emphasis on how ‘stable’ the patient was; this was a determining factor in whether a patient should be moved. Though in this assessment Lassa, as ever, proves itself to be unpredictable. The doctor in charge of the Lassa ward told me after his first six months in the job “if there is one thing I have learnt in these months it is that Lassa patients are unreliable! They can come in one day and be stable and the next day they are bleeding...they can explode!” He explained AG patients get put on Ribavirin even if they look stable or well, whereas they observe IgM positives, watching how the condition changes, adding that “sometimes they are worse than the antigen patients.” This means the new practice of keeping them on wards required considerable care and attention from all those looking after them. The head nurse on the Lassa ward actually seemed quite keen to admit IgM patients who looked sick: when an IgM case who she had pushed for the doctor to transfer took a turn for the worse she shot me a knowing look and said “see, she is being sick now”.

This brings me back to the point made above about the bearing the test has on the practical decisions at hand. Here we see that many decisions made in clinical settings are based on fairly ambiguous assessments of condition, but also on much more social considerations of how nurses or patients may react and how important it is for them to know. In this ambiguous middle ground of classification, are the patients and their contacts for whom the consequences are very real. These new un-admitted IgM patients avoid the experiences that

come with being Lassa positive: they avoid the trauma or stigma of being on the isolation ward; alternatively, if they did have an acute case of Lassa, they could miss out on the experienced (and free) care which they would get if they had been admitted to the ward. When patients leave the Lassa ward they are given a list of rules, or as one ex-patient described them “laws”, to follow: precautions to take when eating, going to the toilet or having sex, which are aimed at reducing further infections as the virus has been isolated from urine, saliva and semen when it is no longer detected in blood. Given that such efforts are made to trace contacts of cases on the ward, in this grey area of acute or past infection, it is striking that some cases which could be acute do not have their contacts traced and are not told of the risks, including informing the people caring for them who could be at risk of nosocomial infection. The mangle of practice processes people with very different effects.

Despite the case for the continued importance of clinical judgement and knowing the ‘value of a test’ there were other signs that laboratory results were perhaps overshadowing clinical observations. Thus to some extent clinical diagnostic procedure has become laboritized but the incomplete nature of laboritization is not always acknowledged. The interpretation of AG test results offers some examples. Antigen positive cases had always been taken seriously and it was one area where the ward’s nurses and established protocol reached consensus. There was certainly no covering up of AG positive cases. Clinical staff told me that AG cases were always treated, without fail. Such a statement should be considered in relation to the following: as is protocol, after a confirmed positive case which has been treated and admitted to the ward, anyone who may have been in contact with the patient is advised to look out for any Lassa like symptoms during the incubation period. On one such occasion, a health worker in a hospital which had recently dealt with a Lassa case had a mild fever. In an effort to be responsible, but not thinking it was really Lassa, the health worker reported their symptoms to KGH. By the time it had been arranged to take a blood sample the symptoms were nearly all cleared up and the staff taking the blood commented that ‘this couldn’t be a Lassa case’. However, the result came back Antigen positive. The health worker described their surprise and the following interaction occurred after a second test also proved positive:

*“They run my test back and they said you are Lassa positive still, you need to be admitted. Sure? I don’t want to be, I am feeling fine, no problem! No, you need to be admitted (they said), and you need to start treatment.....I didn’t want that but they convinced me anyway<sup>143</sup>”.*

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<sup>143</sup> Lassa history 13, Makeni, 29/04/2011

As the result has been Antigen positive the decision was made to admit the patient to the ward and commence on Ribavirin; the patient had been resistant but submitted in the end. After a few days on treatment the patient was experiencing numbness and seizures as a result of an adverse reaction to the treatment. The side effects were far worse than the symptoms which had prompted the test and which had cleared up, she reported, five days before ever starting the treatment. In this instance the treatment decision was very much based on the laboratory results. They could also have been acting out of precaution due to a possible exposure to another case but this was done in the face of extremely mild, and increasingly absent, clinical symptoms. The patient later told me: “the protocol says, antigen positive, start treatment. And I want to tell you have a question mark about that”. Her case was unusual, but it revealed the inflexibility of the existing treatment protocol and the significance and alarm surrounding AG positive results.

There is a mantra that AG positive cases do not survive and that they are worthy of alarm. It may be true as a general rule but it is not a failsafe one, and it is one which may need to be revised; particularly relevant is the possibility that as surveillance improves and laboratory testing becomes more routine it may be the case that more mild AG (and IgM) cases are detected. If that does happen then the clinical pathways and implications of an AG positive result need to be more diverse than simply treatment according to a protocol.

#### **7.2.4 Diagnostic interactions and decision making in clinical settings**

As I outlined in chapter two, diagnosis is much more than a moment or a test result. It is collaborative effort, where people’s focus is often on holding multiple care processes and concerns simultaneously, and not just identifying an underlying cause (Goodwin, 2010, Mesman, 2010). The preceding discussion has built on this view and portrayed Lassa diagnosis as better understood as an accumulation of moments along variable pathways. The diagnostic process encompasses a range of conditions, constraints and opportunities, throughout which a number of people play a part in decision making. In this section I focus on the discussions which healthcare workers have over particular cases in order to show how contingent a diagnosis can be. For outsiders it can seem shocking that a disease like Lassa fever, a biosafety level 4 (BSL-4) pathogen where isolation is advised, has any elasticity in diagnosis and treatment. Visitors to KGH were often surprised by the apparent flexibility. I have already touched on some of the dimensions which make a difference: the classic signs,

the uncertainty facing clinicians, a plural and at times fractured health care system as well as the variable presentation in patients. Here I give some examples of how these factors feed into particular treatment and diagnostic decisions.

Dwelling on this issue of decision making and patient pathways it should be appreciated how many people are involved; there are many competing voices taking part in diagnostic and treatment decisions for Lassa fever at KGH. One case in point is this: a technician from the laboratory had come looking for the doctor to deliver some results. He stopped by the Lassa ward where some nursing staff are gathered talking with two members of the outreach team. One result was inconclusive on the IgM and he asked the others: “who is this Mohammed, where is he?” A couple of the outreach team recall the patient from the day before, “yes, he was sick”, but they do not know where he is now. Apparently he had been a contact of a recent case. They discuss the length of time since the onset of Mohammed’s symptoms and the technician suggests that the result could be indeterminate because the IgM was only just beginning to appear in the blood. He thinks that a second sample needs to be taken but first they have to locate the patient. One of them has a mobile number for him; they call him, and find that he was admitted to the general ward where he is receiving a blood transfusion. It is agreed with the laboratory technician that a nurse should go and assess him once the transfusion is complete. An hour or so later, the nurse, two members of the outreach team and I go to find him on the ward. The patient’s face is puffy but otherwise he does not have strong clinical signs. The nurse comments that he looks strong and that he does not really have the illness history, even though was a contact of a recent case. One of the outreach team protests “he was sick yesterday, bring him (to the ward), he is from the Lassa belt!” The nurse hesitates and says it is the doctor’s decision. We all go to the doctor who is seeing patients in the outpatient consultation area. The details of the case are reported to the doctor. They all agree a second sample is necessary but views differ on whether to move the patient to the ward in the meantime; the two outreach team members are pushing for that option, arguing he was a contact of a known case. The doctor asks about the tests and the patient’s condition. He checks the test was the ELISA and not the prototype rapid test which is being used alongside the ELISA in some cases. The nurse reports that he considers the patient to be stable and so for now the doctor decides the patient should remain where he is. This consultation with the doctor takes place in under three minutes and the doctor never actually examines the patients.

Another illustrative example also took place on the outpatient ward after the sister of a nurse at the hospital was found to be positive for IgM. The laboratory results are delivered to the Lassa ward while I am there and so I go with one of the nurses on shift to discuss the case with the doctor. The doctor queries TB because, he says, the patient has night sweats. He says that telling her she has Lassa may panic her and it could be that the fever is caused by TB; he reasons that starting treatment for Lassa could confuse matters, and make the TB harder to diagnose, if that were the case. The doctor calls the head nurse on the Lassa ward, who has seen the patient and talked with her sister, to ask her opinion. She is keen to admit but the doctor feels that the fever is not high enough, a guess in the absence of a thermometer. If it were Lassa making the patient sick, he says, then the symptoms would be more extreme; the signs are 'not classical'. The nurse counters this and says the patient is sick, but she is just trying to be strong. She is persuasive and at first the doctor seems swayed towards a decision in the nurse's direction. The doctor indicates they should start Ribavirin and see if there is a response, meanwhile they should take sputum to test for TB. He repeats that his main concern is working out what is causing the fever. However there is then a U-turn when the doctor looks again at the test results. The evidence of IgM he re-interprets as meaning the patient is on the mend, returning again to the uncertainty about what is causing the fever. In Krio, their interaction is as follows:

Doctor: "*e bin well by inself*" (she has got/is getting better of her own accord)

Nurse: "*e bin strong for fight am*" (she has been/is being strong to fight it (the Lassa))

Doctor: "*let we give tests the benefit of the doubt*"

The doctor then asks the nurse again what she wants to do. She replies admit and start Lassa treatment, while they wait for a sputum result on the TB. However, the doctor disagrees and evoking the new interpretation of IgM results he says "let's do it scientifically": the patient should be admitted, temperature monitored but no Ribavirin for now. But he does want to order a sputum test and even to start TB treatment today to see if it reduces the fever. The head nurse says the patient may as well go home then, but the doctor and the other nurse say it is better to admit them to the ward so they can be monitored properly. Back on the ward the head nurse is explaining to me that IgM's can still have problems when she gets a phone call from the doctor saying they should start the Ribavirin after all and hold back on the TB medicine. The reason he gives her is that Lassa fever can kill quickly whereas with TB they have more time.

As well as showing that decisions are made collectively, these examples provide an illustration of how a range of concerns cross-section in clinical practice and diagnostic decisions: the problem of co-infections (in this case TB); the importance weigh up different evidence, how reliable is the history, what other signs are there, the 'science' of the test result; of great importance are basic clinical signs, if a patient's 'looks ill', 'stable' or 'strong'. In this the clinical priority is shown to be the basic status of a patients' health, and how that intersects with ideas about other diseases, the expected presentation of Lassa, and the risks that are involved. In the Lassa fever ward records there are frequent annotations for 'the doctor to please review' which gives the impression that the doctor is making the decisions. It is true that the doctor has authority but nurses, and others, on the Lassa ward and team have great experience and work with considerable independence – they also fight as the above example shows, to put their view across. In essence, the diagnostic pathways and treatment decisions are established by a number of different voices, who have had different levels of contact with the patient. It can be done over the phone, with physical examinations, by looking at test results; what matters is the way all these aspects combine to make a credible case for Lassa fever in a patient.

### **7.3 Conclusion**

Clinical settings are particularly interesting as they are the sites where multiple streams of people, knowledge and evidence intersect. Such convergences are central in the mangle of diagnostic practice. There is a tug-of-war in this setting between resistance and accommodation, ideals and messy realities. This is combined with a struggle for balance between the use of tools designed to be the mainstay of the official diagnostic system, such as the case definitions, referral procedures and laboratory results, and the unpredictable appearance of both patients and the virus in Sierra Leone's clinical settings. When applying these tools health workers frequently find they do not fit. Either the virus or the patient does not present as they should: major symptoms are not detectable or the referral forms do not contain full treatment histories. In response to these uncertainties there are some practice-based framings, rules of thumb, which health workers apply to deal with risks both to patients and themselves: 'classic signs' provide some tangible evidence to proceed on, though they may be unreliable. It is also a time of change in the clinic, some of the most well established framings including classic signs and the presence of IgM antibodies are becoming less



definitive, even misleading, as laboratory diagnostics are developed: the laboratory can now provide results faster and, on one level, test results are increasingly influential in treatment decisions. But although treatment decisions are often deferred until the laboratory results arrive, there are other ways in which those results are less decisive than they used to be. The contention around the significance of an IgM positive result has meant that treatment options are variable, perhaps more than before. Meanwhile Antigen positive laboratory results have had its significance affirmed. This affirmation has been in the face of cases (admittedly only a few) where antigen was found but the patient themselves was not visibly 'ill'. Overall there is increasing diversity in the diagnostic pathways and the laboratory tests have not entirely conquered the clinical domain. The process of laboritization which was shown in the previous chapter to be incomplete even in laboratory settings is found to be even more limited in the clinical context.

## 8 Conclusion

By now the idea of diagnosis as a singular or straightforward process should have been dispelled. Intuitively this may seem obvious; diagnosis can be tricky and it may take several attempts to get right. But when the 'correct' label is applied by the 'correct' technology there is an implicit assumption that the case is closed. So it is surprising that even for Lassa virus, a pathogen considered so dangerous that extraordinary biosafety and isolation procedures have been applied for its identification and management, neither diagnostic or treatment pathways are set in stone. What is more, 'new and improved' diagnostics do not appear to have curtailed this variability. Indeed, across village, laboratory and clinical settings, we have now seen that Lassa fever diagnosis is by no means the linear pathway undergoing 'laboritization' that optimistic narratives of technological revolution presume. Instead, a different picture has emerged which portrays diagnosis as a series of negotiations between people, pathogens, instruments and contexts. What can now be said about diagnosis and new diagnostic technology and how has the conceptual framework introduced in chapter two helped to explain the dynamics of diagnosis?

Chapter two argued that the emerging 'sociology of diagnosis' literature had not addressed key issues concerning innovations and expectations about diagnostics. I used science and technology studies to illuminate dimensions of technology, knowledge and practice which I highlighted as important but overlooked aspects of diagnosis. I proposed that diagnosis should be understood as a system which, on account of plural health systems, I defined broadly as including village healers as well as government and biomedical providers. This broad perspective on diagnosis called into question some of the literature which had been developed about diagnostic practice in European and American settings and which emphasised the 'hanging together' of assorted socio-technical assemblages in medicine (for example Mol, 2002). Therefore, Pickering's notion of a 'mangle of practice' was employed as a means of characterising the patterns and processes of practice within the diagnostic system. The 'mangle of practice' concept was chosen because it is not overly prescriptive and so allowed for an examination of the diversity and unpredictability of diagnosis. I also explored framings and narratives of disease and diagnosis and, in doing so, a dominant narrative was identified which promotes the idea that new diagnostics are making diagnosis increasingly scientific. This narrative is based on a specific and mechanistic framing of disease, as

identified by Rosenberg (2002). It was suggested that framings and narratives of Lassa fever itself would be varied, and would thus influence approaches to diagnosis. Equipped with a framework which focused on framings, narratives and practice, this thesis addressed the following questions:

How are developments in laboratory-based diagnostic technologies incorporated into the process and practice of Lassa fever diagnosis in Sierra Leone?

- How is the diagnosis of Lassa fever framed and how do these framings relate to diverse narratives about the disease's significance and control?
- How is Lassa fever diagnosed in practice and how do different framings and practices intersect with each other?
- How do new diagnostics influence the uncertainty surrounding diagnosis?

In chapter three I set out the methodological underpinnings of this work. A multi-sited ethnography was chosen for exploring framings and practices within the diagnostic system because it combined a focus on context specific processes with an appreciation of the linkages between them. Inquiry into the diagnostic system was achieved with ethnographies in three sites: the village of Tokenga, the 'Lassa lab' and the wards of Kenema Government Hospital (KGH). Chapter four provided some context about Lassa fever and Sierra Leone's healthcare context, and it outlined a version of the diagnostic system articulated by the WHO, Sierra Leone's Ministry of Health and Sanitation (MOHS) and scientists. Their framing of the system prioritises laboratory and biomedical knowledge, which is reflected in its formal boundaries and centralisation around KGH. This conceptualisation of the system relates to a convergence between three overarching narratives about Lassa fever: Lassa as a global threat, Lassa as an endemic West African disease caused by problematic local practices, and Lassa as a neglected zoonotic disease in need of a scientific solution. All three arrive at similar solutions: more basic science and applied biotechnology is needed to control Lassa fever; establishing fast, scientific and accurate diagnostics is essential to surveillance as well as to effective disease control. Diagnostics are portrayed as the 'building blocks' of health system strengthening and wider capacity development. I concluded the chapter by introducing two underexplored areas of research which deserve attention: the longer term dynamics of Lassa fever; and Lassa fever as part of everyday life and practice. In chapters five, six and seven I focused on exploring the latter in the three sites mentioned above. Each site represents different settings in the

diagnostic system where aspects of the system interact. In each setting, relationships between framings, narratives and practices were examined, paying attention to the use of technology and the implications for uncertainty. Finally, at the end of each chapter, principles from the mangle of practice were used to draw out features of practice in each setting. In this conclusion I revisit and synthesise these.

## **8.1 A mangle of practice: the diagnostic system**

The negotiated processes of diagnosis can be usefully characterised as a ‘mangle of practice’ which Pickering (1995) describes as an interlocking pattern of resistance and accommodation between human and non-human agency. For Pickering scientific knowledge, which must be understood as inseparable from the practice of science, emerges in this mangled way. By using the mangle of practice to describe diagnosis I am asserting that an individual diagnosis emerges in a similar fashion. Diagnostic pathways depend on the application of heterogeneous tools, routines and conceptualisations of disease; their application is structured by the interplay between the resistance and accommodation of diverse forms of agency which are encountered along the way, including that arising from negotiations between them. The emergence of a diagnosis is contingent on these interdependent, but variable, relationships, which means it is unpredictable.

The attraction of Pickering’s mangle of practice is that it deals with the complexity of knowledge, practice and agency. Yet, apart from the pattern of resistance and accommodation, which Pickering insists repeats itself endlessly, the mangle of practice does this without imposing limits on what may or may not emerge. This is appropriate for a study exploring diagnosis in a context where its processes and practices were little studied. Significantly, it did not presume linearity or ‘hanging together’ which has characterised literature on diagnosis in high income settings. The mangle of practice does not, however, deal with the problem of subjectivity in relation to knowledge and practice in any extensive way. Pickering says human action is orientated by goals, and that models and theories based on previous experience are used to interpret resistance and to reach stabilisation, all of which implies a certain bounded subjectivity. But what about clashes between these goals or theories when many people are involved in reaching a diagnosis? I have modified the mangle of practice to account for the impact which such differences have on diagnostic interactions. By conceptualising the diagnostics system as a mangle of practice, but simultaneously dividing it into sites, I have

explored how *different contexts, different framings and different practices* intersect within the mangle.

The modified version of the mangle of practice presented here means that there are some site specific aspects of the mangle of practice, and there are others which relate to interactions between them. I review these in turn now, beginning with those which are site specific.

In Tokenga, diagnostic practices are based on categorisations of fever and on the social, political and financial relationships through which healing must be negotiated through. In Pickering's terms, there is a stabilization between 'ordinary sick' (including 'small fevers') and ordinary treatments. 'Tablets' and 'herbs' can be obtained easily within the village and are the first line of treatment. The persistence of symptoms presents the first sign of resistance which must be accommodated. When familiar treatments do not work there could be a number of reasons: poor quality drugs sold in the heat on petty trade stalls could be the explanation, but equally it may be that the complaint is not an 'ordinary sick'. Already there are a number of possible strategies to deal with the apparent resistance: another tablet, some 'bitter barks', or perhaps a visit to one of the local providers of **hale** (medicine). With persistence and increasing severity a fever can become a 'big fever' and an 'ordinary sick' can become a 'hospital sick'. Resistance causes explanatory classifications to be modified which opens up new pathways for treatment. Although in some villages Lassa fever and 'big fevers' may increasingly be talked about as the same thing, the 'big fever' category is not disease specific. It is a practical classification, based on symptoms, which suggests a move to the next level of health care. But with that accommodation, other resistances emerge. The classification of a sickness as a 'hospital sick' does not necessarily result in a trip to a hospital. 'Hospital sick' carry high risks and their realisation is beset with barriers. In order for a disease to become a 'hospital sick' both money and the assistance of kin is required to make the physical transition to a hospital. Furthermore, the implications of such a move are framed differently. Perceptions about the cost and quality of official healthcare are often negative which can be the reason alternative informal providers are sought. More dramatically, the rumours of fatal injections can be a motivation for people with suspected Lassa fever to go *anywhere but* KGH. In the response to the ultimate resistance, the failure of treatment and death, a final accommodation is sometimes applied in order to make sense of the events. The version of the truth offered by the laboratory diagnostic, known in Krio as the '*prova*', is questioned: if

witchcraft is 'behind' a sickness then it can cause a laboratory test to show up positive to mislead doctors, in such cases the doctor's medicines will do no good. Significantly, the application of witchcraft explanations to Lassa fever in Tokenga tended to occur after death and hospital treatment. Though the aetiology of a 'hospital sick' can include sorcery, this co-exists with an understanding that symptoms need to be treated with biomedicine.

In the laboratory the mangle of practice rests on achieving a stable relationship between the ingredients, technique and interpretation of the assay. In order for results to be considered reliable and valid there needs to be consistency in all three of these areas. This is done by building on and 'tuning' existing ELISA technology: recombinant proteins, improved sample storage and cold chain, revised protocols and standardised methods to interpret results. As part of this, great effort is made to 'discipline' human action so that it is able to overcome material agency. However both human and material agency can refuse to conform. Heat and humidity, blocked plate washers and forgotten timers can all contribute to the inherent variability of an ELISA. Other circumstantial considerations can also creep in and influence interpretation of results. For instance a technician's interpretation of borderline results can be influenced by hearing about a particular patient's symptoms, or of how far away the sample they are working on comes from. I used Knorr Cetina's notion of 'laboritization' (1999) to characterise the manipulation of social and natural orders of objects in the laboratory. These manipulations are supposed to exclude the world outside of the laboratory to stop it interfering with the validity of its results. I suggested that laboritization had some limitations. The laboratory makes a diagnosis based on a narrowly defined, and self-authenticated (Hacking, 1988), assay target. Indeed, increasing stabilisation in the laboratory was achieved by a narrowing down of the diagnostic criteria to certain aspects of Lassa fever: the detection of antigen proteins emerged as the key diagnostic indicator and the presence of immunoglobulin M (IgM) was afforded less significance. Yet the laboratory's claims to diagnostic authority were shown to be limited by examples where a patient's clinical symptoms contradicted test results. More intrinsic limitations were that the stabilisation of practice that enabled the laboratory to 'produce' good samples (and good results) concealed some areas of uncertainty. Notable examples are the 'inherent variability' of ELISAs and the problems of characterising the positive samples which give the test results relevance to the population it is being tested in. In these ways, the laboritization processes can be viewed as incomplete. The tick next to 'positive' or 'negative' serves to 'black box' some of these

uncertainties but it cannot eliminate them. In the clinical setting the narrowness of the laboratories diagnosis becomes a problem and, as I shall now review, the results must be re-interpreted in conjunction with other signs and symptoms.

In the clinical setting the patterns of resistance and accommodation are largely shaped by actors having to negotiate between the messy realities of Lassa fever and healthcare in Sierra Leone on the one hand, and the standardised tools used to diagnose the disease on the other. In contrast to the case definition forms which presume a linear approach to treatment and an 'ideal-typical' (Rosenberg, 2002) presentation of Lassa fever, patient's actual symptoms and referral pathways are consistently variable. To accommodate the misfit other principles are applied. Rules of thumb (Bowker and Star, 2000) about 'classic signs', and the risks which they pose, guide healthcare worker's actions and decisions. Laboratory tests, which were not available when many of these practices developed, are now available in a matter of hours. To some extent, the new laboratory tests have reduced the importance of some of these informal practices: diagnostic and treatment decisions are usually deferred until 'the labs' have been completed. Yet, though the results are quicker and deemed to be more reliable there is a paradox in that they do not always convey clear treatment pathways. The interpretation of the IgM ELISA in particular is a matter for debate. Some members of the Tulane team have insisted that an IgM positive status is clinically irrelevant but for healthcare workers at KGH the IgM positive patients have become a tricky group to deal with.<sup>144</sup> They present a number of questions: is Lassa fever making the patient sick or something else? Is the patient stable or should they go on to the Lassa ward? There is actually an expanded array of treatment options for these patients. There are also times when Antigen results do not fall in line with observed clinical symptoms triggering a similar set of questions. Such cases highlight the multi-dimensional nature of disease presentation which improved laboratory tests cannot bypass and of which they only grasp one aspect. The interactions between the resistance presented by complex diseases, and the tools and treatments used to define and accommodate them, continue even after a laboratory result is received.

The interactions between aspects of the mangle across these sites can now be considered. The emergence of a diagnosis involves the circulation of objects and concepts. By concepts I mean

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<sup>144</sup> Personal communication with people working at the Lassa ward has confirmed that healthcare workers there still treat IgM results to be significant. Some IgM positive patients may be kept on general wards but others are admitted to the ward and treated with Ribavirin.

framings of Lassa fever, such as ‘big fever’ or ‘classic Lassa’ which are translated across sites. This is in addition to the more concrete passage of blood samples, pharmaceuticals, herbs, and ELISA reagents. The interfaces through which these things pass, be they artefacts, concepts or people, have multiple sides and meeting points. A doctor may encounter a patient when symptoms are just beginning or when the patient is already unconscious. The patient may provide a full treatment history or a patchy one. The laboratory may receive a sample straight from the KGH ward or one from near the Liberian border which has not been refrigerated. The information which accompanies some of these objects influences the way they are dealt with as they travel between settings. Consider the ‘hot’ sample in chapter six which caused the laboratory technicians to ‘double glove’. There are moments in these interactions where alternative pathways open up. Patient histories often reveal that they were tested, ‘diagnosed’ and treated for something else prior to Lassa fever. In a world of co-morbid infections it is easy to find evidence which supports alternative diagnostic pathways.

Two points run through all of this. First, the practical circumstances as to how a patient or sample enters the diagnostic system are incredibly important. Quicker diagnostics can influence this but they cannot control it. Second, there are considerable differences in the way disease is defined and enacted at various stages in a diagnostic pathway. Again, a new diagnostic can provide an additional enactment of disease but it does not exclude the existence of others in the process. The process of diagnosis in the official system involves the transformation of ‘fever’ into ‘Lassa fever’ and then into ‘Lassa virus’. This transformation is ‘confirmed’ by the laboratory which is unique in its ability to identify the “causative micro-organism” (Cunningham, 1992 p224). But this transformation does not happen seamlessly.

### **8.1.1 Framings within the mangle of practice**

Before sore throats, fevers and red eyes can become Lassa fever or Lassa virus they must go through a number of different guises. A feature of framings is that they are partial and contain fundamentally different perceptions of the risks and outcomes involved. Understanding how these relate to diagnostic practice and pathways is critical. By considering the role of framings in the mangle of practice the possibility that framings could be sources of resistance was raised. This possibility stems from their imposition of particular ways of seeing the case at hand which could obscure other aspects of the disease or pathways for dealing with it. As such, framings would then account for significant variation in diagnostic pathways.



Taking the interactions between parts of the mangle together, some patterns emerge about the way Lassa is framed: classifications used in surveillance and written protocols frame Lassa as one continuous entity. Although defined in different ways by the case definitions and the laboratory tests, the implicit expectation is that the disease can be standardised and transferred between them. Coherence is assumed: the symptoms come first and are 'confirmed' by the laboratory test. Just as Mol (2002) challenged this in regards to diagnosing atherosclerosis, here I have tried to emphasise that there is discontinuity between framings and enactments of Lassa even within the formal aspects of the system. The transition from fever to virus does not happen smoothly, the various enactments do not always 'hang together'. In the process of diagnosis, diagnostic tools can contradict each other. Even in patients considered to have 'classic signs', the symptoms and test results do not agree surprisingly often. For a moment there are two pathways, two (or more) diagnostic possibilities, as two distinct realities are enacted. Occasions such as these serve to underscore the non-uniform, non-linear nature of diagnosis. This becomes more apparent outside of the clinical setting, when the name 'Lassa' can imply the archetypal 'hospital sick' which no-one but the doctor at KGH should attempt to treat, or it can mean that the doctors at KGH will give patients a lethal injection.

One of Pickering's aims with the mangle is to link the micro and macro of scientific practice. The interplay between these scales is clearly visible in the unfolding debate about how to characterise Lassa fever in West Africa and within Sierra Leone. The recent paper by Gire et al. (2012) on whether the expanding endemic areas of emerging infectious diseases, Lassa fever included, are the result of a real spread or simply better detection is an example. In this thesis I have highlighted some of the practical implications of such debates. Framings of Lassa fever's regional prevalence influence diagnostic practices. The significance afforded to a history of travel within the 'Lassa belt' in forming a diagnostic profile is evidence of the importance of regional framings of prevalence within Sierra Leone. The distinction which is drawn between West Africans and non-West Africans when interpreting IgM results in the 'new diagnostic paradigm' (Branco et al., 2011b) is evidence of these dynamics at an international level. This last example also reflects a shift in the rationale behind a diagnosis. It was claimed that IgM was no longer diagnostically relevant in West Africans because it could not be considered a marker of recent infection and so was not helpful in treatment decisions.

There the diagnostic classification was being made on the basis of its utility in assisting treatment decisions. For a while IgM patients were described as not having Lassa fever. But while IgM status may not prove an infection is recent it also does not prove that it is not. Thus, again, the new paradigm is only partial, and perhaps also somewhat rash.

As noted by Bowker and Star (2000), there are both flexible and rigid classifications of Lassa fever in the diagnostic system. One of the more ridged framings of Lassa fever is that around Antigen positive cases. Historically, these have been considered as non-debatable. The stakes were too high, “antigen patients do not survive” said the nurse, they must be admitted and treated. Such eagerness to treat antigen cases is, of course, due in part to the severity of symptoms which ward staff have seen kill too many people ‘too quickly’ already. But, I suspect, it is also based on a long-established tacit separation between ‘hospital cases’ and the mild ‘in the community’ cases which go uncounted. With this in mind, cases at hospital and with positive results are assumed to be serious. Rightly so, no one would want to be accused of complacency. However, if surveillance expands and doctors continue to order tests as routine, there needs to be sufficient flexibility in both the Antigen and IgM treatment protocols to deal with atypical or mild cases. Once rapid diagnostic tests (RDTs) are in use this would become even more important. Protocols are needed to deal with mild and asymptomatic cases so that patients are not subjected to unpleasant, possibly harmful and traumatic treatments. As the patient who received treatment for mild symptoms after an antigen positive result put it, “have a question mark about that”<sup>145</sup>. The interpretation of laboratory results has gone through many stages to minimise error, that effort should be mirrored in the clinical setting to ensure that laboratory results are appropriately re-contextualised with the patient’s condition.

In contrast to the laboratory’s narrowly defined concepts of Lassa fever, other parts of the system depend on fluidity and breadth. In the village the effectiveness of disease categorisations such as big fever and small fever, and to an extent the classic signs in the clinical setting, depend on being somewhat vague. They allow for other considerations to be taken into account and respond to the ambiguous circumstances in many settings. The framings and enactments of disease as ‘small’, ‘ordinary’, ‘big’ or ‘hospital’ fit in with the narratives and categories which people use to negotiate the health landscape around them. As

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<sup>145</sup> Lassa history 13, Makeni, 29/04/2011

has been shown elsewhere artificial distinctions between formal and informal, legitimate and illegitimate, or traditional versus biomedical (Cross and MacGregor, 2009, Leach et al., 2008) are not driving motivations. Rather, the therapeutic landscape is cross-cut with various forms of disease, medicine, and expert knowledge in which social relationships are pivotal to patterns of access. The reality is that the therapeutic landscape as experienced by people in the East of Sierra Leone is at odds with the official infrastructure for diagnosing and treating Lassa fever which is restricted to KGH. It is not surprising that patients with 'big fevers' can end up elsewhere.

In a context where the superiority of formal or government health services is not always evidenced, it is not clear that a trip to the hospital will result in positive outcomes. For Kema's husband every step towards the hospital was a step into terrain he could not afford; he returned to his village twice in an effort to 'find' money to pay for the escalating treatments she needed, but which in the end, did not save her. In contrast, the father who decided against taking his dying son to the hospital exercised the only control he had over the situation. His justification was that his son "has died already"<sup>146</sup>. From the perspective of doctors or surveillance officers this may seem like irresponsible, ignorant or non-compliant behaviour. An accusation is often that villagers 'do not understand'. This thesis shows that they understand very well but that with understanding come implications which they assess with criteria which are relevant to their lives.

### **8.1.2 Implications of the mangle**

Taking a 'mangled perspective' on diagnosis challenges the 'underlying cause' view of diagnosis. It does this without resorting to an argument which says that disease is entirely socially constructed, or by otherwise avoiding the study of diseases with identifiable pathologies. It shows that a number of underlying causes can emerge, their meanings and their identification the result of negotiations which makes versions of an underlying cause visible. The mangle of practice presents a view of diagnosis which is 'de-centred' and 'emergent' (Pickering, 1995, 2008) which means that no one technique, place or person defines it, yet they all shape it; rather than being pre-determined a diagnosis unfolds across and through these different parts. This contributes two things: first, an understanding of diagnosis which takes practice and technology seriously and second, an understanding of

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<sup>146</sup> Lassa history 8, Foindu, 12/05/2010

diagnosis which appreciates the uncertainty involved. On the former, some studies of diagnosis which have tried to account for the role of technology have been overly deterministic. For instance, grand claims are made about the power of technology: the introduction of novel tools has enabled the creation of new diagnostic classes (Jutel, 2006); or technological developments in diagnostics have meant that diagnosis replaced prognosis in medical importance (Christakis, 1997). The mangle resists the draw of technological determinism and instead shows how these technologies are integrated 'into the thick of' agency (Pickering, 1995). On the latter, by combining the mangle of practice with framing, this thesis has been able to explain the tensions and differences in the process and practice of diagnosis in a way which does not assume these diverse parts 'hang together' as has been implicit elsewhere (see Mesman, 2010, Mol, 2002). The mangle of practice characterises the diagnostic system without implying coherence because it also emphasises the unpredictability and resistance of diagnosis. By introducing the notion of framing into the mangle of practice, it has been possible to see the extent to which a disease entity goes through many different forms as it is manipulated, judged, isolated, re-contextualised, guessed at, argued for, and standardised within the diagnostic system. This has also highlighted that stability in one setting does not equal stability in another. As such diverse framings and contexts are a source of unpredictability in the mangle of practice.

## 8.2 Challenging narratives

With the characteristics and implications of the mangle of diagnosis now outlined, in this section I will discuss how they relate to some of the policy narratives which commonly surround diagnosis and diagnostics. To do this, I have drawn out some of the assumptions which are implicit in those narratives of technological optimism and will discuss the key findings of this thesis in relation to each in turn.

### **Diagnosis is a linear process**

The steps outlined in the Integrated Disease Surveillance and Response (IDSR) and case definitions for Lassa fever assume a number of sequential steps in one direction. They are based on the principle of a standardised disease entity which can be transferred along a linear pathway through the system. What this does not appreciate are the complex arrangements of social and technical dimensions which make up the process of diagnosis: social relations of sickness; the pervasive normality of fever in such contexts; the wide availability of **pu hale**

(white people's or Western medicine) from different sources; the trial and 'non-response' of other medicines; conflicting evidence from co-morbid infections and other diagnostic tests; and haphazard referral patterns. More fundamentally there are differences in the way Lassa fever is framed and enacted which can signal alternative diagnostic pathways.

### **The main diagnostic challenges facing resource poor settings relate to limited infrastructure and access**

In scientific and policy discourses the inadequacies of diagnosis in low resource settings are portrayed primarily in technical terms and relate to limitations in capacity and infrastructure. This is then paired with limitations in access, where barriers are understood as financial and geographical (see Burgess et al., 2006, Girosi et al., 2006, Pang and Peeling, 2007, Urdea et al., 2006). Some authors have gone further and indicated that 'context' matters and that 'one size fits' all models may not be appropriate (Pang and Peeling, 2007). The contextual issues which have been briefly mentioned include decentralised and complex healthcare contexts, and multiple vertical and un-integrated programmes and providers (Bates and Maitland, 2006, Petti et al., 2006). Until now, these issues have not been explored empirically as new diagnostics have been introduced.

This thesis has shown that the above considerations do not begin to explore the complexity of low resource health systems and the implications of new diagnostics within them. First, there appears to be a very narrow definition of access. People in Sierra Leone have access to a number of healthcare providers, what matters, is the way they choose between them. Strengthening laboratory and diagnostic systems means addressing why people choose not to use government services. Cost is important<sup>147</sup> but opinions about the quality of care received in hospitals are relevant too. A stated preference for **pu hale** in hospitals is tempered by a dismissal of the way it is provided, demonstrated in the frequently repeated Krio phrase '*pass you pull moni*' (not unless you pay). Fears about the risks that going to a hospital can bring, whether it is lethal injections, high prices, maltreatment, or time away from farms should be considered seriously in efforts to improve diagnostic systems. Second, laboratory knowledge is not valued equally by all. Elsewhere, distrust in laboratory quality has resulted in underuse (Polage et al., 2006). With Lassa fever, the laboratory is generally considered to be high

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<sup>147</sup> It is telling that after the introduction of the FHCI ward records showed a rise in the number of patients from the target groups covered by the FHCI being tested and diagnosed with Lassa fever after the policy was introduced (Moses et al., 2012).

quality but even so there are competing sources of knowledge and claims to diagnostic authority in the diagnostic system. This includes secret societies, traditional healers, informal and formal providers of Western medicine. Informal sources of care, both traditional and biomedical will likely remain important parts of the diagnostic system. Since my fieldwork, it has been reported that traditional birth attendants (TBAs) have been banned in Sierra Leone (Whitaker, 2012). Even though pregnant women are now covered by the Free Health Care Initiative (FHCI), a policy which bans TBAs may be ineffective (or counterproductive) in settings where women are still hours from official healthcare. The fact that the TBAs authority is rooted in the Sande society is also likely to mean that any ban does not play out easily. In relation to other informal biomedical providers, such as pharmacists and 'village doctors', it has been suggested elsewhere that stretched governments need to find ways of using and regulating them more effectively (Peters and Bloom, 2012). Such providers are indeed part of the diagnostic system and their role within it must be considered.

There is a need for better health education throughout the diagnostic system, including for healthcare workers and communities. Poorly designed health information has been shown to be a problem elsewhere (Allen and Parker, 2011, Parker et al., 2008) and potentially Lassa fever is no different. While the outreach team have impressive dedication, they use a sensitisation video which was made decades ago and is in English, a language most people in Sierra Leone cannot speak fluently. The message is simply 'do not eat rats' and 'take fever cases to the hospital'. This information is simplistic and of little use to rural communities. In these communities there is a widespread misunderstanding about which *arata* (rat) carries Lassa fever and questions are raised about the role of eating *arata* in causing infection: people point to times when they or others have eaten rodents and not fallen ill, and also to times when somebody fell sick who had not eaten rodents.

Finally, the developments which hold such promise also have problems of their own: experts have highlighted how the reality of many of these innovations in diagnostics, RDTs and laboratory based, is that they are often small scale, not properly validated, poorly regulated and lack quality control (Mabey et al., 2004, MacArthur, 2009, Peeling and Mabey, 2010). Again, with Lassa fever, similar patterns are evident. At various stages doubts have been cast about their validation from both within the Tulane team, the Sierra Leonean technicians, and the WHO. And, as I will describe in the following sections, the new diagnostics present new

complexities and uncertainties which require overlooked capabilities to deal with. In that sense, the 'technical' difficulties are more complicated than they first appear and, more significantly, new innovations bring new challenges.

**Diagnostics are the 'building blocks' on which healthcare system strengthening and broader capacity development can be built**

In chapter four I described how establishing diagnostics in the laboratory at KGH has been presented as a first step which will pave the way for further research and capacity development (Khan et al., 2008). This is also underlying the WHO's suggestion to make the 'Lassa lab' a 'centre of excellence' for the region to improve surveillance. The practicalities of realising these promises have been, and will probably continue to be, complicated. Differences in opinion about who and what the capacity development is for has caused tensions between Tulane, the WHO and the Sierra Leonean government. Arguably a large part of this has been due to the 'securitization' (Elbe, 2010) of Lassa fever, which is related to the narrative, identified in chapter four, which paints Lassa fever as a 'global threat'. In chapter one I asked to what extent biodefense and infectious disease control agendas converge, as had been tentatively suggested elsewhere (Mabey et al., 2004, Peeling and Mabey, 2010). The case of Lassa fever shows that the framing of diseases as security threats as opposed to public health problems has restricted the kind of activities which get funded. For Lassa fever, activities have been focused on basic research and technological 'fixes' which will be sold to the US military. The focus on basic research and medical interventions represents trends in health innovations more generally (Bloom, 2009). This, in turn, relates to an underlying problem with approaches to innovation. Innovation is often conceived in the narrowest terms to mean the invention of novel technologies. This is accompanied by the idea that these inventions can then be transferred to new settings where they diffuse (Bell, 2009). This overlooks the broad and heterogeneous innovation processes which occur as technologies (including organisational innovations) are adapted in different contexts. The result, Martin Bell argues, is that the narrow capabilities involved in production receive more attention than the wider 'complimentary capabilities' (Bell, 2009, p47) such as those involved in the localised adaptations of technology. Elements of these dynamics can be observed in approaches to health system strengthening and can be found in the case of diagnostics for Lassa fever. Health system strengthening is a 'catch all' phrase which conceals the fact that in reality approaches are often disease specific (Marchal et al., 2009) and as such it also relates to the

debates about vertical and horizontal programming. The investment and treatment arrangements for Lassa fever are disease specific, vertically planned, highly centralised and highly technologically focused. Some of this is due to the need for isolation, but it also relates to the narratives of global threat explored above. As an example it serves to show the limitations of these approaches: the practice of Lassa fever diagnosis cannot be separated from other aspects of the healthcare system. The empirical chapters in this thesis have emphasised aspects of the therapeutic landscape which are pertinent to Lassa fever diagnosis, including: unorganised and informal healthcare, alternative forms of knowledge and authority, various framings of disease, limited training for nurses, poor health information about Lassa fever and issues of healthcare financing. Improving diagnosis means addressing the dynamics in these broader parts of the diagnostic system. As such this thesis repeats the need for broader approaches to health system strengthening (Travis et al., 2004) and to innovation (Bell, 2009).

Finally, in chapter two I drew attention to the assumptions behind the ‘specific disease model’ (Rosenberg, 2002) of healthcare systems and questioned whether they would follow the same trajectories as they had in Europe and America. In light of the above discussion about context specific innovation processes, it is worth noting that diagnostics, like pharmaceuticals before them (Bledsoe and Goubaud, 1985), are adapted into Sierra Leone’s open plural medical systems. This follows patterns elsewhere in African settings (Reynolds Whyte, 1982, 1992). The co-existence of biomedical and ‘other’ disease causation beliefs is evidence that the co-production of ‘specific diseases’ and healthcare systems do not follow the same lines.

### **Improved diagnostics will reduce uncertainty**

In the laboratory much of the activity around improving the diagnostics is driven by a distrust of the Lassa fever ‘dogma’ and a prevailing sense of uncertainty about existing research on the disease. The new diagnostics are argued to be more specific and to have therefore reduced uncertainty. This represents a common theme in diagnostics. The uncertainties problematised and targeted in the laboratory relate primarily to sensitivity and specificity and to time. Results can now be received faster and the likelihood of false negatives or positives is reduced. Thus, in these two areas there have been real reductions in uncertainty. However, incomplete knowledge pervades many more aspects of diagnosis, and in some respects new diagnostics have increased uncertainty.



New ambiguities and uncertainties have opened up as new 'diagnostic paradigms' are integrated into existing practices. The debate about the interpretation of the IgM is one new area of doubt. What this reveals is a deeper ambiguity about disease classification. Commenting on new diagnostic tools for sleeping sickness (African trypanosomiasis), Deborggraeve and Büscher (2010, p437) ask "Does a positive molecular test result indicate a current infection in all cases and does every infection lead to disease? We do not yet have clear answers to these questions, and thus cannot consider molecular diagnostics as the golden bullet, as is often done". There are similar questions concerning the significance of Lassa fever test results and their relationship to observed symptoms, for which there are no clear answers.

There is also considerable intrinsic uncertainty which is not easily eliminated and is not always acknowledged. The process of laboritization is incomplete and the ELISA is 'inherently variable'. This point is accentuated by the lack of conclusive validation and regulation for the new diagnostics and vocal disagreement about how to interpret some aspects of them. It may be that some of this uncertainty will be reduced over time, if full validation is achieved. However, doubts similar to these have been reported elsewhere and so may be typical of diagnostics in low resource settings (Mabey et al., 2004, MacArthur, 2009, Peeling and Mabey, 2010). Furthermore, there is a more fundamental problem about the validity of using a test in a population where disease prevalence is unknown as discussed in chapter two. This thesis has demonstrated that knowledge about the prevalence of Lassa fever is severely limited. In addition, the incomplete characterisation of the distribution of positive samples in West African populations also calls into question the reliability of a positive result. In this sense the practice involved in developing (and using) the test is a kind of circular fumbling in the dark: validity of tests are confirmed against a gold standard but little is known about what the disease looks like in a given population.

Finally, there is an issue about whose uncertainty is being reduced. At KGH and in follow up exercises in villages, both patients and communities were not told their results reliably. At times this was a deliberate strategy based on an assumption that the patients would panic and not understand. Although rumours about medical research are rooted in deeper asymmetrical relationships (Geissler and Pool, 2006) withholding information can only serve to create

space for suspicion by denying people full participation. Questions I was asked by patients and community members spoke to these concerns. Some were practical, such as is Lassa in our village? Whereas others hinted at deeper concerns, such as why did they ‘pull’ my blood and what are they doing with it? In addition, there are the people who test negative for Lassa fever whose uncertainty is not especially reduced. As Lassa fever diagnostics improve it serves to highlight that there are plenty more diseases out there which are equally unknown.

As attention is focused on narrow conceptualisations of uncertainty and risk, such as sensitivity and specificity, the broader ambiguities and inherent uncertainty in diagnosis can be overlooked. Taking these into account, the claim that uncertainty has been reduced looks problematic. There is a further point about the importance of the social context in which claims about uncertainty can be made. In the Sierra Leonean context uncertainty is cultivated and is an important strategy for maintaining traditional forms of power and authority (Ferme, 2001). Diagnostics do not reduce the ambiguity which pervades most aspects of Sierra Leonean life. In fact, in some ways, diagnostics simply fit into the established patterns of hierarchy and secret knowledge. Biomedicine, with or without enhanced diagnostics, is another area of knowledge which rural Sierra Leoneans are excluded from and subjugated to. The concealment of results mentioned above is a perpetuation of this. Similar to what has been reported by Last (1981) in Nigeria, responses tend to vary from an apparent unquestioning acceptance to suspicion; yet, underpinning these reactions is the pervasive idea that meaning is not stable and things are often not what they seem.

### **Diagnosis introduces order (out of messy symptoms)**

With the new uncertainties discussed above there is an argument that actually, rather than heralding order, there is increasing complexity and disorder. New diagnostics are not introduced on to a blank slate; rather they are introduced into a system brimming with distinct approaches to classifying Lassa. They cannot, therefore, be said to introduce order or knowledge where there was none. Instead, they should be seen as adding to, or modifying, some of the existing classification practices. Perhaps there has been a move to a more theoretically biomedical form of classification by which I mean that treatment decisions are usually deferred until the assays have looked for evidence of an immune response. However, across the board, the availability of faster and more sensitive ELISA tests has resulted not in more assured practices but rather in more debate and ambiguity over what to do and how to

interpret their results. The result has been that diagnostic pathways have become increasingly diverse. For example IgM positives can now be left on general wards or taken into isolation. An interesting way of thinking about the way laboratory diagnostics fit into the established diagnostic process is to consider their capacity to rule cases in or out. In the case of IgM it is no longer clear if a patient should be 'ruled in' or 'ruled out'. And there have been a few cases where antigen positive results 'ruled in' patients who perhaps should not have been. As Tulane's clinicians emphasises, laboratory diagnostics have to be used in conjunction with other signs and symptoms. In this light laboratory results begin to look more like a 'discursive resource' (Willig, 2011) than a definitive diagnostic statement

### **Laboratory diagnostics introduce reliable scientific knowledge where before there was ignorance or guesswork**

The 'technological fix' narrative, identified in chapter four, asserts the authority and 'science' of the new diagnostics. I have already discussed the implications of new diagnostics on uncertainty and order; here I make two further points about the notion of scientific diagnosis. First, claiming to be able to achieve a scientific diagnosis, as some have done (Miettinen, 2001), is misleading. In the interpretation of test results, both inside and outside of the laboratory, a number of what might be called 'social factors' have been shown to be important. I have also shown that within the 'reliable' scientific approach to diagnostics in the laboratory there are a number of concealed ambiguities which arguably make the results less reliable than they first appear. The issue is not that science cannot be considered social in any way, or that if it is, it is somehow less valid. Indeed this thesis has shown that the assessment of wider signs and symptoms are needed to make the laboratory results more valid. However, expectations about new diagnostics and assessments of the current limitations in low resource settings appear to be based on knowledge deficit models: that without laboratory diagnostics there is only ignorance or unreliable guesswork. This thesis has shown that many different types of knowledge can be considered relevant and valid in the process of diagnosis. Furthermore, it does not always follow that increasing 'scientific' knowledge about a particular subject will reduce ignorance: as Einstein is reported to have said, "as our circle of knowledge expands, so does the circumference of darkness surrounding it".<sup>148</sup> With Lassa fever it is certainly the case that as diagnostics are developed, and more research is carried out, more questions arise.

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<sup>148</sup> I am grateful to Andy Stirling for making me aware of this quote and its relevance here. I have not been able to find the original source.

### **A revolution?**

The preceding pages have highlighted the importance of being measured about technological progress. Predications of a revolution in the biotechnology industry have already been challenged (Hopkins et al., 2007, Nightingale and Martin, 2004). This thesis, and the discussion of innovation processes in the preceding pages, supports their arguments that innovation can lead to increased complexity which in turn needs new capabilities to deal with. As such innovations in diagnostics will not be a 'silver bullet' and technical and health system change will likely be more incremental than revolutionary. To deal with these new complexities the investment which is being put into diagnostics for Lassa fever in the laboratory would ideally be matched elsewhere. It should be directed not only into other laboratories in Sierra Leone and West Africa, but also at peripheral health settings and public health activities in local communities. It should include consideration of the social, political and economic dynamics of therapeutic practice which this thesis has highlighted. However, while funding is attached to articulations of Lassa fever which emphasise 'global threat' narratives the scope for these broader activities may continue to be limited. It is possible that the Sierra Leonean Government, the WHO or other actors may find alternative pathways for action but, until they do so, the diagnostic revolution predicted by some may not happen as quickly or as full scale as might be hoped.

### **8.3 Conclusions and future research**

Diagnostic technology is an area of health innovation which is increasingly attracting attention. So far, limited attention has been directed at these developments in critical anthropology or policy analysis, with the exception of some work on malaria rapid diagnostic tests (Chandler et al., 2008a, 2008b, 2012). The growing field of global health anthropology does not seem to have engaged with the subject yet (see Lock and Nguyen, 2010, Nichter, 2008). And the implications for another growing, but vague, field of health systems strengthening (Marchal et al., 2009) needs also to be considered. Established debates about vertical and horizontal planning are also relevant. For its own part, this thesis has demonstrated that a combination of science and technology studies and medical anthropology can be usefully applied to highlight issues in this emerging field. This thesis has been able to show that, even at this early stage, some problematic narratives about diagnostic technology and its influence on low resource settings can be identified. Taking a practice-based

perspective has highlighted the complexity of 'doing' diagnosis in a range of contexts where multiple framings of disease are involved. Specifically, the 'mangle of practice' approach has highlighted the unpredictability and uncertainty of diagnostic processes.

The limited previous attention to the perspectives of people living and working in endemic Lassa fever regions provides the basis for the empirical contribution made by this thesis. So too does the wide-ranging approach to diagnosis which has been taken here. Exploring framings and the practice of diagnosis in three different sites, a village, a laboratory and a hospital, has been an important initial step in highlighting the hidden perspectives of those who are most at risk from Lassa. While I did not find a culture of Lassa-specific community based diagnosis and healing, I was able to show how approaches to Lassa fever are embedded in local categories of disease and healing. More research on the local dynamics influencing health seeking is still needed. This is all the more urgent as Lassa fever is increasingly detected in areas previously considered as non-endemic. Across laboratory, clinical and community settings, contrasting and incomplete ways of knowing Lassa fever intersect with each other. A closer look at practice highlights that people have a complex, conflicted and contingent approaches to negotiating Lassa fever and therapeutic landscapes. Such nuances are lost in the more well-known framings and narratives about emerging or exploding epidemics, or unhygienic and uneducated communities.

In relation to the overarching narratives of technological optimism and revolution a number of points can now be made. First, the challenges related to diagnosis in low resource healthcare settings are not simply a lack of knowledge or technology.

They are systemic, broad and context-dependent. Second, approaches to innovation and health system development which assume universal 'upward flows' of information, and 'outward flows' of capacity development from central and vertical programmes, do not capture the reality of innovation and healthcare. The diversity of people, tools and practices involved in diagnosis suggests that broader approaches to innovation and technical change are needed. A narrow focus on 'hardware' and infrastructure such as cold chains overlooks the importance of complementary innovation capabilities and complimentary approaches to disease control. As well as 'centres of excellence' what is needed are approaches which recognise the importance of appropriate health promotion in communities and training for healthcare workers. More than that, diagnostic processes must be seen as embedded in the

institutional delivery of healthcare. This means, for instance, that improving diagnosis involves getting to grips with unregulated and informal forms of healthcare which thrive. Lastly, no innovations in medical technologies can overcome the social and economic reasons behind particular communities' vulnerabilities to Lassa fever and therefore these factors need equal attention.

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## Appendix 1: Interview details

Interview Category	Total <sup>149</sup>	Date	Location	Description	Name Pseudonym <sup>150</sup>	Interview reference (for in-text citation)
Tokenga's <sup>151</sup> health and healing practitioners	6	17/03/2010	Tokenga	'Witchdoctor', Male	N/A	N/A
		16/03/2010	Tokenga	Imam, Male	N/A	Imam, Tokenga, 17/03/2010
		09/03/2010	Tokenga	Informal nurse, Male	Mohammed	Informal nurse, Tokenga, 09/03/2010
		16/03/2010	Tokenga	Visiting drug peddler, Male	N/A	Drug peddler, Tokenga, 16/03/2010
		<i>20/02/2010</i>	<i>Tokenga</i>	Resident herbalist, female	N/A	Herbalist 1, Tokenga, 20/02/2010
		<i>20/02/2010</i>	<i>Tokenga</i>	Resident herbalist, female	N/A	Herbalist 2, Tokenga, 20/02/2010
Tokenga household interviews	5	13/03/2010	Tokenga	Senior male and female members of household	Musa family	Musa family, Tokenga, 13/03/2010
		12/03/2010	Tokenga	Senior male and female members of household	Sannoh family	Sannoh family, Tokenga, 12/03/2010
		13/03/2010	Tokenga	Senior male and female members of household	Samai family	Samai family, Tokenga, 13/03/2010
		13/03/2010	Tokenga	Senior male and female members of household	Amara family	Amara family, Tokenga, 13/03/2012
		13/03/2010	Tokenga	Senior male and female members of household	Turay family	Turay family, Tokenga, 13/03/2010
Lassa histories Tokenga	6	18/02/2010	Tokenga	Interview with Lassa survivor, teacher, male	Sheku	Lassa history 1, Tokenga, 18/02/2010

<sup>149</sup> Interviews not recorded are in italics

<sup>150</sup> Names of interviewees and any patients they refer have been changed in the text

<sup>151</sup> The name of the research village has been changed

		19/02/2010	Tokenga	Interview with mother and brother of deceased Lassa case, dead man was a Kamajo	Deceased name was Mambu	Lassa history 2, Tokenga, 19/02/2010
		19/02/2010	Tokenga	Interview with husband of deceased Lassa case	Deceased name was Mariama	Lassa history 3, Tokenga, 19/02/2010
		09/03/2010	Tokenga	Interview with husband and mother in law of deceased Lassa case	Deceased name was Kema	Lassa history 4, Tokenga, 09/03/2010
		11/03/2010	Tokenga	Interview with husband and brother of deceased Lassa case	Deceased name was Jina	Lassa history 5, Tokenga, 11/03/2010
		11/03/2010	Tokenga	Interview with Lassa survivor, farmer, male (and brother)	Bockari	Lassa history 6, Tokenga, 11/03/2010
Lassa histories other (positive)	21	10/04/2010	Kenema	Interview with Lassa survivor, trader, female	Adama	Lassa history 7, Kenema, 10/04/2010
		13/05/2010	Foindu	Interview with husband and wife, lost 3 children, wife survived	N/A	Lassa history 8, Foindu, 12/05/2010
		24/04/2010	Tongo	Interview with Lassa survivor, student, male	N/A	Lassa history 9, Tongo, 24/04/2010
		27/04/2010	Tongo	Interview with Lassa survivor, famer, male	N/A	Lassa history 10, Tongo, 27/04/2010
		14/04/2010	Kenema	Interview with Lassa survivor, nurse, female	N/A	Lassa history 11, Kenema, 14/04/2012
		26/04/2010	Tongo	Interview with Lassa survivor, diamond miner, male	N/A	Lassa history 12, Tongo, 26/04/2010
		29/04/2011	Makeni	Interview with Lassa survivor, European clinician, female	N/A	Lassa history 13, Makeni, 29/04/2011
		13/04/2010	Foindu	Interview with Lassa survivor, female	N/A	N/A

		13/04/2010	Foindu	Interview with Lassa survivor (female) and her father, farmers	N/A	N/A
		07/05/2010	Kenema	Interview with Lassa survivor, student, female	N/A	N/A
		08/07/2010	Kenema	Interview with Lassa survivor, housewife	N/A	N/A
		12/04/2010	Kenema	Interview with Lassa survivor, student, female	N/A	N/A
		09/05/2010	Kenema	Interview with Lassa survivor, trader, female	N/A	N/A
		13/04/2010	Kenema	Interview with Lassa survivor, farmer, male	N/A	N/A
		20/04/2010	Kenema	Interview with Lassa survivor, business man, male	N/A	N/A
		19/04/2010	Kenema	Interview with Lassa survivor, no work, male	N/A	N/A
		17/04/2010	Kenema	Interview with Lassa survivor, student, male	N/A	N/A
		11/05/2010	Largo	Interview with Lassa survivor, farmer, female	N/A	N/A
		28/04/2010	Tongo	Interview with Lassa survivor, housewife, female	N/A	N/A
		29/04/2010	Tongo	Interview with Lassa survivor, mining business, male	N/A	N/A
		27/04/2010	Tongo	Interview with Lassa survivor, housewife, female	N/A	N/A
Lassa histories (negative)	2	22/04/2010	Kenema	Interview with Lassa negative patient from Lassa ward, Canadian business man	N/A	N/A

		13/05/2010	Kenema	Interview with Lassa negative patient from Lassa ward, housewife, female	N/A	N/A
Tulane	4	02/03/2010	Kenema	Doctoral student – laboratory specialist, male	N/A	Tulane laboratory scientist, Kenema, 02/03/2010
		11/04/2010	Kenema	Doctoral student – rodent ecology specialist, female	N/A	Tulane rodent ecologist, Kenema
		27/07/2012	Skype	<i>Tulane researcher, medical clinician, male</i>	N/A	<i>Tulane medical clinician, telephone interview, 27/07/2012</i>
		27/03/2010	Kenema	Tulane Clinician, male	N/A	Tulane medical clinician, Kenema, 27/03/2010
Clinical (Panguma)	3	22/02/2010	Panguma	Interview with clinician at Panguma, male	N/A	Clinician, Panguma, 22/02/2010
		22/02/2010	Panguma	Interview with paediatric nurse at Panguma, male	N/A	Paediatric nurse, Panguma, 22/02/2010
		22/02/2010	Panguma	Interview with outpatient nurse at Panguma, male	N/A	Outpatient nurse, Panguma, 22/02/2010
WHO/MOHS	3	14/12/2012	Geneva	WHO, Lassa fever coordinator, Global Alert and Response, female	N/A	WHO representative, Geneva, 14/12/2012
		29/04/2011	Freetown	<i>WHO, Freetown, male</i>	N/A	<i>WHO representative, Freetown, 29/04/2011</i>
		28/04/2011	Freetown	Director of disease prevention and control, male	N/A	Senior MOHS official, Disease Prevention and Control Directorate, Freetown, 28/04/2011
Total	50					