Appendix I: Ethics Approval ScHARR

The University Of Sheffield.

Cheryl Oliver
Ethics Committee Administrator

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Our ref: 0562/CAO

23 May 2011

Muhammad Saddiq
ScHARR

Dear Muhammad

Reconceptualising health systems: A case study of Rigasa, an Urban unplanned settlement in Northern Nigeria

Thank you for submitting the above research project for approval by the ScHARR Research Ethics Committee. On behalf of the University Chair of Ethics who reviewed your project, I am pleased to inform you that on 23 May 2012 the project was approved on ethics grounds, on the basis that you will adhere to the documents that you submitted for ethics review.

The research must be conducted within the requirements of the hosting/employing organisation or the organisation where the research is being undertaken.

If during the course of the project you need to deviate significantly from the documents you submitted for review, please inform me since written approval will be required. Please also inform me should you decide to terminate the project prematurely.

Yours sincerely

[redacted]

Cheryl Oliver
Ethics Committee Administrator

Appendix II: Security Assessment

Security risk assessment and mitigation plan

As with many countries Nigeria has unsafe regions. Recently there had been an escalation of violence in Kaduna and Yobe states. I was in Zaria (in Kaduna state) for my fieldwork when the recent deterioration of security that occurred as a result of explosions on the 17th June 2012 in 3 churches - 2 in Zaria and 1 in Kaduna town - followed by some youths blocking the highway linking Kaduna and Abuja injuring and killing motorist in a reprisal attack. There is still no clear information about total casualties but colleagues at ABU Teaching Hospital in Zaria have confirmed to me that they have received some corpses and managed scores of injured victims from the explosion in Zaria.

Following the violence that erupted the state government have imposed a total restriction of movement across the state to prevent further violence. I was due to be in Rigasa on 18th June 2012 but had to call off. There have been minor incidents of violence since the curfew was announced but calm is gradually returning so we are hoping that the restriction of movement will ease soon.

However, judging from recent developments Rigasa is turning out to be the epicentre of the violence in Kaduna state and I have been advised by staff at Kaduna State ministry of health and contacts living in Kaduna against conducting the research in the area because of the high security risk involved. I am therefore proposing to shift the location of the study to a relatively safer environment Tudun Jukun in Zaria which provides the kind of environment for exploring my research question as Rigasa, though on a much smaller scale.

The new location

Tudun Jukun lies outside and to the north of the old walled Zaria city. Both Zaria city and Tudun Jukun had expanded linked with other settlements to form the greater Zaria conurbation. Tudun Jukun t has an estimated population of about 200,000. Its population is predominantly Hausa with few Yoruba and other ethnicity that have integrated with the indigenous community. The original residents of the area are farmers. Other settlers are mainly small scale traders and in the better off areas there are few civil servants. Tudun Jukun shares a lot of similarities with Rigasa that makes it a suitable alternative to address the research question proposed for this study. It is an unplanned, informal settlement. It also has other features that have been identified when selecting Rigasa for the case study including overcrowded housing, poor environmental features such as open sewage, poor disposal of refuse and human waste that spill on to streets, almost total absence of public public services such as water supply, schools and health care facilities.

Basis for assessment

The following assessment and mitigation plan rely on three main sources. First, advice made available by relevant security agencies and local officials in Nigeria including those related to restriction of movement in specific areas. The government where necessary restricts movement in some area or entire States when there is concern about escalation of violence.

Second, my assessment of the situation based on my local knowledge of Nigeria. I was born, grew up and lived almost my entire life in Nigeria. I have travelled and worked in different parts and I am presently in Nigeria and therefore able to give a first-hand assessment of the security and safety concerns relating to the current violent insurgency happening where I live in the country. Finally, I am in regular contact with my supervisor who provide further support and advice in managing security and safety concerns related to the research based on guidance by the University of Sheffield.

Assessment

Regarding security, based on recent trends there are 3 potential sources of violence under the current situation in Northern Nigeria:

First, presence of a structure or institution that is a potential target for the insurgent group *jama'atu ahlis suns liddawati wal jihad popularly known as* Boko Haram (BH) in an area. Such targets are police stations, military barracks, churches and major educational institution. Apart from one church on the outskirt of the settlement there is none of those targets listed here in Tudun Jukun.

Second, presence or suspected presence of BH members in an area will make such place a target of attack by security agencies that have been indiscrete and equally brutal in the way the carry out their operations often leading to injuring or killing of civilians. Tudun Jukun is a relatively highly integrated community and an outsider can easily stand out therefore it is going to be very difficult for BH to hide in the area. Although the population is predominantly Muslim it is populated by sect that has no sympathy for BH. I was informed that the late leader of BH has made attempt to recruit from the area in 2007 but was chased out. So, it is unlikely to have locally produced BH as well.

The third risk for violence is an area being in transition zone between Muslim and Christian neighbourhoods where there could be risk of reprisal attacks. Tudun Jukun is surrounded by neighbourhoods that are predominantly settled by Muslims and generally Zaria population is not as segregated as Kaduna. That's the most likely reason explaining why there were no reprisal attacks in Zaria last Sunday even though 2 churches were attacked in the town while in more segregated communities in Kaduna reprisal attacks have occurred.

Generally, there are also concerns about deterioration of ethnic relations in the country. There are many groups and individuals that are working very hard to avoid this.

Risk management plan

Risk	Likelihood (specific to new selected site)	Impact	Management
Road traffic accident	Low	Variable	Minimise amount of travel Tukun Jukun is selected to be accessible on foot from current residence. Travel on foot

Direct victim of terrorist attack	Very low	High	Avoid churches, military barracks, and education centres
Police & military reprisal	Very low	High	Suspend work in aftermath of incidents until calm returns and all restrictions of movement lifted In addition, only restart work after consultation with supervisors, Carry University of Sheffield documentation at all times, Dress inconspicuously
Communal violence	Very Low	Medium/ high	Suspend work in aftermath of incidents resume only when calm returns and all restrictions of movements lifted by local authorities, Dress inconspicuously, Always make telephone contact with community informants before any travel
Curfew by authorities	Medium	High	Respect all curfews
People suspicious and unwilling to co-operate with research	Very low	Medium	Change recruitment strategy, change research location
General deterioration of ethnic relations in the country	Low	Medium/ High	Pull out of the country and consider other alternatives for the research

General rules

1. Observe all normal health precautions (local drinking water, bednets)
2. Maintain at least weekly contact with supervisors
3. Always share travel plans in advance, and advise of any unscheduled events
4. Suspend all travel/physical contacts when incidents occur. Only restart after consultation with supervisors
5. Use telephone interviews where possible
6. Pull out when security situation deteriorate

In summary, Tudun Jukun present safer and suitable alternative to Rigasa under the current circumstance, and me and my supervisors are actively identifying, managing and mitigating what risks there are. Should the situation reach a point where it is no longer safe to carry out the study based on my assessment of events on ground, advice from security agencies or from the University of Sheffield I will pull-out and consider other alternatives for my research.

Appendix III: Weighting of relevant ethics committees in Nigeria

Criteria and their weighting for selecting where to apply for local ethical review in Nigeria

CRITERIA		NHREC	KMoH-REC	ABUTH-REC
Existence of a well-articulated guideline		+ The National Code of Health Research Ethics (NCHRE) but generic.	-	-
Jurisdiction over research site		+ The whole country	+ The whole of Kaduna State.	+ Zaria and environs.
Robustness of processes and procedures	a. composition	+ Members identified on website.	- Information about membership not available.	- Information about membership not available.
	b. oversight	- The focus is mainly on regulation of other HRECs and even that is not done effectively. List of accredited HRECs on website is out of date	- no oversight system in place	- no oversight system in place
	c. efficiency	- No clear timeline when approval can be secured.	+ Approval can be secured quite rapidly is followed up by personal communication.	- Very in efficient, the earliest an approval can be secured is 6 months and there are cases that lasted well over 3 years.
	d. understanding of research context	- Deals with generic ethical issues and not peculiar ethical issues that apply in different parts of the country.	+ More likely to be familiar with contextual issues because of operational relationship with communities.	+ More likely to be composed of individuals with firsthand experience of research in the area.
Cost		± unclear	+ no fees	+ no fees
Clear signposted process to follow		none	none	none
Pluses		3.5	4	3

Appendix IV: Ethics Approval (KMoH)

MINISTRY OF HEALTH, KADUNA STATE

All Communications to be Addressed to:
THE HON. COMMISSIONER
Quoting Reference and Date
Tel: (062) 248084
(062) 248252

Independence Way,
P.M.B. 2014,
Kaduna.
Kaduna State, Nigeria

MOH ADM/VOL.I./744/98

28th June,2012

School of Health and Related Research (SCHARR)
University of Sheffield
Regent Court, 30 Regent Street
Sheffield S 1 4DA
Tel: (+44) (0) 1142220771

RE:- RESEARCH ETHICS APPLICATION

With reference to your letter above dated 8th June 2012.

I am directed to inform you that, having gone through your research proposal titled Reconceptualising Health Systems. A case study of Rigasa an Urban Unplanned settlement of Northern Nigeria.

The Medical research and ethics Committed have granted you permission to carry out your research.

Accept our best wishes.

[redacted]

DR BUTAWA NUHU
Deputy Director Primary Health (DC)
For: Hon. Commissioner.

Appendix V: Information Sheet

Participant information sheet (individual Interview)

School of Health and Related Research
University of Sheffield
Regents Court
30 Regent St
S1 4AD

Muhammad Saddiq
PhD Student
Tel: 08054043450
muhammad.saddiq@sheffield.ac.uk

4th June 2012

Research Project Title: Reconceptualising Health Systems: A Case Study of Tudun Jukun, an Urban Unplanned Settlement in Northern Nigeria

Introduction

I am a PhD student at the University of Sheffield studying ways that people organise and solve health problems in their community and I have selected Tudun Jukun for my research. I would like to invite you to take part in the study which is supervised by Graham Jones, a Lecturer in Social Science and Health at School of Health and Related Research of the University of Sheffield. Before you decide if you would like to take part, I would like to explain why the research is being carried out and what it would involve. I would be grateful if you could read the following information and discuss it with others in your neighbourhood before you decide if you wish to be involved in the research. You have at least 2 days to think about if you want to take part in this study. If you would like more information, please feel free to ask me (Muhammad Saddiq contact details above). Please take as much time as you need to decide whether or not you wish to participate.

What is the project's purpose?

This research is a study of how people interact and work together to solve health problems in Tudun Jukun. This include understanding their experience of the health problems; what they do to solve them; things that enable or prevent them from solving the problem and if the approaches they use are working for them. Findings from this study could be valuable for policy makers and practitioners because the understanding of how people work in their settings to address health problems will enable development of better programmes that could improve the health system. The University of Sheffield is partly funding the PhD under which this research in organised

Why have I been chosen?

You were chosen because you have been resident in Tudun Jukun for at least 6 months, have experienced or is experiencing health problem, and I believe you can speak clearly about your experience and know a lot about Tudun Jukun.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep (and be asked to sign a consent form) and you can still

withdraw at any time without it affecting any benefits that you are entitled to in any way. You do not have to give a reason.

What will happen to me if I take part?
If you are willing to take part, please return the attached consent form with your contact details (address and telephone number) on the attached return slip so that I can contact you to make an appointment. Part of the research would involve talking to you about the details of your feelings and experience regarding health problems in Tudun Jukun. The interview would be recorded, but only with your permission. This is to prevent me from missing important details from the interview. The interviews would follow the interview topic guide (attached). During the interview, you do not have to answer any questions that you do not wish to. These interviews will be carried at place of your choice and at a time convenient for you and will last approximately 45-60 minutes. You may be asked to consider taking part in a follow up interview to provide further examples that may help improve understanding of some ideas.

There is no any financial payment for participating in this research, however if you prefer an interview location outside your area arrangements would be made to transport you to the preferred place or to cover any reasonable travel costs that you may incur in attending the interview.

Everything that you say will be treated in the strictest confidence and your name and details will not appear in the research report without your expressed approval. The audio recordings of what you said during this research will be used only for analysis and for illustration in conference presentations and lectures. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

What are the possible benefits of taking part?
Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will better our understanding of how the health system works and the findings may be used to develop better programmes to improve health system in this and similar places.

Who has ethically reviewed the project?
This project has been ethically approved via The National Health Research Ethics Committee (NHREC), Nigeria and the University of Sheffield School of Health and Related Research (ScHARR) Research Ethics Committee review procedure.

Thank you for reading this information sheet. I look forward to meeting you in due course, should you decide to participate in this research.

Muhammad Saddiq
PhD Student

Graham Jones
Supervisor
Tel: (+44) (0)114 222 0771
Email: Graham.Jones@sheffield.ac.uk

Return Slip

If you are willing to take part, please fill in contact details below and return it to the District Head so that I can contact you to make an appointment.

Name:

Phone Number:

Address:

Appendix VI: Consent Form

Participant Consent Form (individual interview)

Title of Research Project: Reconceptualising Health Systems: A Case Study of Tudun Jukun, an Urban Unplanned Settlement in Northern Nigeria

Name of Researcher: Muhammad Saddiq

Participant Identification Number for this project: **Please initial box**

1. I confirm that I have read and understand the information sheet dated 4th June 2012 explaining the above research project and I have had the opportunity to ask questions about the project. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐
3. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. ☐
4. I agree for the data collected from me to be used in future research ☐
5. I agree to take part in the above research project. ☐

_____	_____	_____
Name of Participant (*or legal representative*)	Date	Signature
_____	_____	_____
Name of person taking consent (*if different from lead researcher*)	Date	Signature
To be signed and dated in presence of the participant		
_____	_____	_____
Lead Researcher	Date	Signature
To be signed and dated in presence of the participant		

Copies:

When completed: 1 copy for participant; 1 copy for researcher (Muhammad Saddiq)

Appendix VII: List of Interviewees

Code	Sex	Age	Synopsis
IP001	Female	90+	Hypertensive, ?epileptic
IP002	Female	60+	16 births
IP003	Male	80+	looked comatose first time but had a lengthy interview the following day
IP004	Male	60+	Victim of wall collapse
IP005 – PP001	Female	47	Lost a child after having had medicines bottle broken over the weekend not knowing where to refill
IP006	Male	40	Woke up paralysed and lay in a room on his own for 3 days until was found by business associates
IP007	Female	40	Mother of a 3-year old child that is failing to thrive
IP008	Male	90+	Diabetic/hypertensive relative
IP009	Male	60+	Happy with treatment of “salt” illness at Shika
IP011	Male	50+	House next to a gully
IP012	Male	55	House next to refuse dump
IP013	Female	23	Young housewife
IP014	Male	80+	Retired First Bank Employee - Hemiparetic
IP015	Female	60+	Bled and lost baby
PP002	Female	60+	Traditional healer
PP003/IP010	Male	60	Ada Makaho – religious healer
PP004	Male	52	Member PHC management committee
PP006	Male	60+	Herbalist
PP007	Male	70+	Traditional barber-surgeon
PP008	Female	50+	Traditional healer
PP009	Male	48	Magajin Gari
PP010	Male	50	Consultant physician and corp.
PP011	Female	50	In-charge PHC T/Jukun Nurse, Midwife, CHO, Paediatric Nurse
PP012	Male	60	MD Muslim specialist hospital
PP013 (1)	Female	50	Nurse at Maternity Wusasa missionary hospital
PP013 (2)	Female	50	Nurse at delivery suite Wusasa missionary hospital
PP014	Male	29	Chemist/medicine shop owner
PP015	Female	50	Haematologist
PP016	Male	30+	Medical Officer/volunteer
PP017	Male	30+	Health office Zaria LGA
PP018	Female	40	Nurse/Gambo Sawaba Hospital
PP019	Female	30+	Doctor/ Gambo Sawaba
PP020	Female	47	Nurse, Midwife, Public Health, RH, CHO – Deputy Director Maternal and Child health Zaria LGA
PP021	Male	30+	Paediatrician
PPFGD001	Males		
PPFGD002	Males		
PPFGD003	Males		

Appendix VIII: Interview Guide

This served only as a guide to the researcher and therefore amenable to change as the research unfolds. It was only be used to keep the discussion from deviating too far from the substantive research area and to ensure that key areas of the research question are covered. Otherwise the individual was allowed to talk uninterrupted about their experiences.

Introduction:	
I am interested to find out about you and how you are. Could you please tell me about yourself, where you spent your childhood, and how you come to live here, and how long you have been living here?	
Understanding ideas, beliefs, assumptions about the experience of health problems in Tudun Jukun:	
When I contacted you, you were trying to address [*the health problem*], so what happened since then?	**Prompts:** • How would you describe [*the health problem*]? • What other similar problems would you like to talk about?
Understanding processing involved in solving health problems and decision about alternatives in Tudun Jukun:	
Can you describe your experience dealing with [*the health problem*]?	**Prompts:** • How did it start? • What was the first thing you did? • What have you done since it started? • How did it affect your normal life? • Did you seek help? Where? Why?
Understanding how outcomes are evaluated:	
Participants reflections on outcomes	**Prompts:** • Do you think your action was useful? • In what ways were they useful? • Is there anything that you would like to have been different where you seek help? • How do you think the help you received could be improved? • What sorts of things do you think would most improve the lives of people living in this locality? • Is there anything else that you would like to add?
Invitation for further explanation:	
Would you like to be invited for further discussion on this issue?	

Appendix IX: Snapshot of database of problems encountered

ID	Description of the nature of the problem	Context	Measures implemented	Expectations and meanings
IP002	I slept 7 nights draining water (liquor/birth fluid) without telling them. […] I told her, this pain, except if I am dying, I have never experienced any pain like this in my life except if it is for childbirth. So, if this pain is not for childbirth then I think I am dying.	It is awo but not really awo. She wasn't that competent. Honestly, they are not up to it. Up to the time I delivered my last daughter, Maman Rabi (the health worker at the PHC) was thinking my pregnancy was just 7 months.	It was on the 8th [night] I went to this [female] doctor and told her all that has been happening but now it has stopped. […] All the same I tried and tried and tried and went all the way to here, that's where I did my awo (prenatal care), here at Dandali and told the doctor, Maman Rabi (mother of Rabi), I am going to give birth. She said haba (= I don't think so), you wouldn't have been able to come this far to this place on your own. [...] She said okay let me write some medicine so you can give [your] children to go and buy it for you? She wrote some medicines for me.	I came and give [my] children to go and buy them for me. But, the pain kept on increasing. […] But by Allah, as he was returning, I entered room and yarinya (= baby girl in this context) dropped, I delivered. […] He was saying all this and that but as soon as I enter room the girl dropped. Usually if you feel that way it means you are progressing. You should know how [a] child turns.

IP012	I woke up and I felt my stomach was aching and the children took me to hospital. […] I woke up and I felt that. I was vomiting and my stomach was tightening. and I was not thinking that [pause] because I am not the type that like eating anyhow. because if I knew that I had eaten badly, mixing this and that , then I would have thought which among them was responsible for upsetting my stomach. no, but it wasn't like that. I was told that it the sides of my kidneys that were affected. and they tried and got me the medicine. but not that I ate some food, no it was not like that.	and you see when we went there, and when we went there they accepted us, they did not talk about anything, they were just focusing on the treatment that they were supposed to do. […] excellent. when we went, my kidney was disturbed, but when we went they tried and do the proper treatment. they did some imaging and admitted me to the ward and continue to give me medicine. it was later when I was better than they gave me the bill and I paid. [...] I spent 5 days there. alhamdulliahi yawwa and I enjoyed how they did their work. and I see that even these young [trainees] come there because it is a new place in the morning. and because they come there and they teach them and sometimes they will come with the doctor about ten of them sometimes or even more. they will be going round and they will be instructed and thought the work. you see in this case they will understand more. for me I can see that there is a progress here since if you know and you are teaching someone then progress will come into a situation. but not that you know and refuse to show others.	I woke up and I felt my stomach was aching and the children took me to hospital. […] yes for profit. yes. that was where we went. we explained it to them. I they did everything that they were going to do there and alhamdulillahi we got relief.	yes for profit. yes. that was where we went. we explained it to them. I they did everything that they were going to do there and alhamdulillahi we got relief. […] it was because I heard about this one that I decided that that was the proper place to go. and that was it so we went there. and Alhamdulillah we too got the result that we sort.

IP013	yes, the truth is I was afraid. because right from the beginning I was afraid for the child. I born him premature at 7 months pregnancy. […] ones you look at the nature of the child you'll know that he is not that healthy even now.	if someone is ill or a difficult labour before he could get a doctor he had to go to Tudun Wada. Here at Tudun Jukun we don't have any. Here at Tudun Jukun we don't have any clinic except the small clinic there and they do not take deliveries. That is the biggest problem that we get as a woman. That is our biggest problem for us as women. We had to go to Tudun Wada or go to Sabon Gari. That means we don't have any hospital and you see we have big men in the neighbourhood. [...] when you go and you are going to give birth the usually send you to Tudun Wada. so, you see they were supposed to send me to Tudun Wada. but they told me that it was not labour. [...] I tried and struggled and came back home. [...] I didn't know because that was my first ever [labour]. so I tried with great effort and returned home. and the following morning the birth came to me with ease. I was alone at home except for one nurse that they called she came and took the delivery. [...] yes. the truth is people are different. for me, I was married into this house. and my culture and their culture is not the same. they are Hausa and we are not Hausa. even my parents had fought with them so that we can go to hospital so that they can put the child in the incubator that he will grow up healthier. […] yes, but the opinion of his father is even if I say it I know I will not get what I want so that is why I just kept quiet.	I gave birth to him at home. […] they told me that my pregnancy was 7 months and 6 days so it is not labour. […] I was alone at home except for one nurse that they called she came and took the delivery. she lives in this neighbourhood. she came and took the delivery of the boy. ones you look at the nature of the child you'll know that he is not that healthy even now. that was why his illness scared me. but now here he is Alhamdulillah. [...] I took him for the assessment that they do when a child is 9 months old and then after that one months apart. you know there is a nurse that comes here to check her at home. [...] yes, they express it and pour into a cup. [...] the truth is since he was … since he was eight months old when I took him to that clinic that was the very first immunisation he had	once you look at the nature of the child you'll know that he is not that healthy even now. that was why his illness scared me. but now here he is Alhamdulillah. […] the small one is healthier and stronger and better in all aspects. […] okay, now about the child, he is a child that all his younger siblings are bigger than him, all of them, but I can say this is Allah's creation but if there is any advice that you can give me about what I can do for the child. you know every illness Allah has sent down its treatment first before he sent the illness, so regarding the child what can I do for him? because the child's body is not strong.

IP015	Yaryaya developed tear during the delivery	and Fatima suggested that she will repair the tear by stitching it but they refused	and opted for home treatment which involve seat-bath with solution of detol and a local herb (Bagaruwa). IP015 said she got healed within 7 days and is presently six months preganant.	and opted for home treatment which involve seat-bath with solution of detol and a local herb (Bagaruwa). [...] she got healed within 7 days and is presently six months preganant.
IP015	I am waiting until the month has started. that is the 8th month as they said. so, when the month starts then I will tell her. maybe on the 1st day of the month or the 2nd day of the month. I say to her, Hajiya Ladidi, since this is her first birth and you are the type that worries about childbirth. she doesn't have the heart to stand labour. I will tell her if Yaryaya showed you a sign that this is her condition you should talk to them to take her to hospital. you should say that they should take her to hospital.	now it is the children that are giving birth. now the wife of my last son, the one that I said they have all died except him, he is here, his wife is pregnant. and there at the hospital, she goes to hospital, they told her, they did [ultrasound] scan for her and told her that everything is fine, she is fine and the child inside her is fine too. we do not know the unseen but they told her that she is going to give birth to a boy in the 8th Month (August). [...] Fatima conducted the delivery at home and administered all the necessary immediate postpartum care. Fatima was paid about N2000 (<£10) for this sort of service and she does it to other families in the neighbourhood.	yes, the coming month. so that is what we are waiting for. but for me, now if she comes to give birth, once she shows the sign of labour, they will take her to hospital. […] I was told she (Yaryaya) gave birth at home assisted by the same nurse (Fatima from Dr. Bello) who assisted the daughter inlaw of her co-wife.	yes, I moved there. the boy is now running all over the place. […] wallahi before he reaches 6 months, wallahi he had become really strong and was trying to lift himself up. he is strong. laughs

Appendix X: Vignettes 1, 2, 3 and 4

Vignette 1: Child born at seven months of pregnancy (IP013)

Naja is a 23-year-old housewife. She is married into an extended family household setting where she lives with her husband, his uncles, brothers and their wives. She was quick to point out during the interview, unlike majority of residents of Tudun Jukun including her husband's extended family she is not of the Hausa ethnicity as she explained: "for me, I was married into this house. And my culture and their culture is not the same. They are Hausa, and we are not Hausa. [...] My father is Yoruba [the dominant ethnic group in south-western Nigeria] and my mother is from Kagoma there at Kafanchan [from Southern Kaduna]."

Naja has serious worries as she puts it: "Here at Tudun Jukun we don't have any clinic except the small clinic (PHC Tudun Jukun) there, and they do not take deliveries. That is our biggest problem for us as women. We have to go to Tudun Wada or go to Sabon Gari." She added that "If someone is ill or is in a difficult labour before he could get a doctor he had to go to Tudun Wada." The inability of the PHC at Tudun Jukun to offer comprehensive services for women that need it in the neighbourhood in addition to the inadequate training and lack of experience of the staff were to have a significant impact on Naja when she started having pains in her belly seven months into her first pregnancy. When the excruciating pain started, she did not know what was happening, as she puts it: "I didn't know because that was my first ever [labour]." She then went to the PHC at Tudun Jukun and complained to them but "they told me that my pregnancy was seven months and six days so it is not labour. So I tried with great effort and returned home."

Reflecting on that experience now, she said: "When you go, and you are going to give birth, they usually send you to Tudun Wada. So, you see they were supposed to send me to Tudun Wada. But they told me that it was not labour. [...] I tried and struggled and came back home." Fortunately for Naja at that time as she puts it herself: "the following morning the birth came to me with ease. I was alone at home except for one nurse that they [her mother in-laws] called. She came and took the delivery."

Naja's fear, however, did not end with the "easy" birth, as she said: "because right from the beginning I was afraid for the child. I had born him premature at seven months of his pregnancy." This fear was further compounded by her awareness of the attitude of her husband's family about hospital care. As she explained: "People are different. For me, I was married into this house. And my culture and their culture is not the same. They are Hausa, and we are not Hausa. Even my parents had fought with them so that we can go to the hospital so that they can put the child in the incubator so that he will grow up healthier." The situation became even worse because the child got ill and even now at the age of "2 years and four months" he had continued to be unwell. She explained that "once you look at the nature of the child you'll know that he is not that healthy, even now." Despite the boy's evident illness, Naja was not allowed to take the child to the hospital as she explained: "but the opinion of his father is even if I say it (I want to take him to the hospital), I know I will not get what I want so that is why I just kept quiet". She added that, "since he was born, it was only when he was eight months old when I took him to that clinic. That was the very first immunisation he had."

She said afterwards "I took him for the assessment that they do when a child is nine months old and then after that one months apart."

Naja is still hopeful and still looking for ways to help her child so that one day he will improve. As she said: "he is a child that all his younger siblings are bigger than him, all of them, but I can say this is Allah's creation but if there is any advice that you can give me about what I can do for the child. You know every illness Allah had sent down its treatment first before he sent the illness, so regarding the child what can I do for him? Because the child's body is not strong [...] But now here he is Alhamdulillah (we praise Allah)." But even "the small one is healthier and stronger and better in all aspects."

Vignette 2: 80-year-old man with progressive loss of function of legs and hands (IP014)

Eighty-year-old Malam Mudi is a retired Bank officer. He was among the first set of people that settled in Tudun Jukun, then a small farm settlement on the outskirts of Zaria. Malam Mudi is a friend of the late district head of Tudun Jukun (the father of the current district head). He values his outstanding service record at the Bank, which earned him a special recommendation from the then European owners. The trust and friendship he enjoyed from the late district head was also very important to him. Even though he always gets invited, Malam Mudi regrets that now he is not able to attend important events that are happening in the neighbourhood such as marriage and naming ceremonies. During the interview, I sat on the mat next to where he laid on a raised concrete platform in front of his house. Malam Mudi could not stop bringing up what he thought are the most important problems affecting Tudun Jukun, which are the increasing levels of poverty, bad governance and the violence that is happening in the area and around the country. He believed that only a just and fair leadership can change the situation.

For the past one year, Malam Mudi developed an illness that remains a mystery to him. It started suddenly, initially with some struggle he can rise on his own but could not stand up on his feet but with great effort he could get up and go everywhere. Then it worsened, and he had to drag himself on his buttocks. His condition further deteriorated when his hands became affected, and he could no longer support himself to get up again. He is now unable to rise from sitting or lying positions and therefore had to be lifted up by his children to wherever he had to go. This mobility problem resulted in a significant change in his routine. Around 11 o'clock every morning his children will carry him outside and place him on the mat in front of his house and then they will lift him back into the house again at 8 o'clock in the evening. So, he spends his entire day lying down, during the day on the veranda in front of his house and at night in his room. Malam Mudi is particularly upset that he can no longer attend important community events and perform simple tasks like ablution, and his routine Muslim prayers (salat) have become stressful. He is apprehensive about the uncertainties he faced while at the same time he does not want to give up hope or stop trying. He said: "whether we are going to die this way or there is a fortune of getting up again I don't know."

Malam Mudi did everything he can to improve his health. For example, one of Malam Mudi's neighbours brought a doctor, who works in the university teaching hospital in Zaria, to see him at home. The doctor "will prescribe medication, and they will go and buy and when that is

finished he will come and check again and prescribe another one again, and they will buy it. That's how we have been doing." Malam Mudi was also taken to the famous traditional healer located in one of the villages near Zaria called Salenke. He asked: “have you heard about Salenke? [...] I have been there, and I got tired of going there." There is also another private hospital owned by a doctor called Dr Lirwanu where he was taken. Regarding the private hospital, Malam Mudi said: "I tried him too as much as I can and I gave up." He left the private hospital and resorted to home remedies that consisted of herbs that he applies locally on the legs, and some that he drank. "We packed and came and are trying home remedies that I apply [on the legs] some I drink." He had always continued using the home remedies since then even though there was no improvement in his condition. Malam Mudi had also been to a ‘hospital' located in Kaduna city the capital of Kaduna state about 60 miles from Zaria. The health centre is owned by someone with some formal community health training but has become very popular with people in the state and beyond. The owner of the health centre was said to have a machine that can tell all the problems that a person has when placed inside it. Afterwards, the ‘doctor' will dispense standard combination of pharmaceuticals that is believed to be capable of treating all diseases. As Malam Mudi explained: “when he gives you medicine, if that medicine were to be missing [you can go] round all the chemists shops in Kaduna and [will not] find it, those medicines." Once you lose the medicines, you have to go back to the ‘hospital’ for replacement. However, Malam Mudi have tried the medicine to no avail, as he explained: "I went to the place and went back again and again the last one that I collected was supposed to last for two weeks, but I couldn't get up so I never went back again."

There is one place though that Malam Mudi is reluctant to try, the university teaching hospital, for a number of reasons as he explained: "I didn't go. The reason is the problem of Shika [itself], and that's what stopped me from going, they have so many problems. There is someone that works there, and he said we should go together, and he is going to sponsor everything. But I said no. I said no because I know what it entails going there. [...] if you don't have any strong person that will be on your case that will insist that they address your problem it is just futile going there." He added that, "even this one [the doctor that comes is from there] but since he is not insisting that we should go there, and he has been brought here, I think he must have understood something." Therefore, the doctor's silence despite being one of the doctors there at the teaching hospital was interpreted as a suggestion that there was really nothing better that can be done even if he were to go there.

Despite all Malam Mudi’s efforts, his condition remained poor and deteriorating. He recognised that all the efforts he is making to get improvement have so far failed. He summed up his thoughts in this explanation: "what I will say is that, may Allah bring relief. Because when you are trying a medicine you would like to observe some improvement in your condition, for example, for me to be able to get up from where I am sitting and use my legs to go here or there. Right? That will be an improvement. But we are trying them and seeking [relief] from Allah but there is no any change." He described his situation as "wandering in the dark." He appears to be learning to accept his predicament and believed that relief will only come when Allah wills. So he wouldn't say whether all his efforts have been successful or not. In his words: "whatever we do, if Allah did not agree, then you will continue suffering. So, we have to leave things to Allah." He was grateful that he lived all his days healthy and that this

was the only time he remembered being this ill. He considered it a test from Allah, and it is not right to "rush Allah." He is balancing between accepting his current situation as a matter of destiny, " test from Allah," while remaining hopeful and waiting!

Vignette 3: Home Birth (IP015)

'Halima' is a middle aged divorcee who bore a total of fourteen children, out of which only six are alive now. Two of her children died during childbirth while six died in early life. Halima got married early and was the second of two wives. It is a thing of pride to Halima that she had all her births at home and none in a hospital, except her last. She believes this is only natural: "just like the pregnancy was gotten in private so too should the birth be in private." It does not make sense to her that people should have their deliveries naked and in the presence of others. She neither understands nor agrees with the practice that someone should see or put their hands inside "the secret of a lady." She asked rhetorically, why would she risk upsetting herself or exposing herself to ridicule when she could successfully give birth at home having done that more than ten times successfully. She believed that once you adhered to the traditions that elders taught, such as saying the appropriate prayers and taking rubutu ("writing" = is an ink solution prepared by washing a wooden writing board inscribed with therapeutic verses from the Qur'an) at the right time, then there would be no problems during delivery.

She, however, recognises that sometimes problems can happen during birth and that hospitals can be good at addressing these kinds of problems. Likewise, she conceded that hospitals are good at assessing the wellbeing of the baby during the antenatal period. Therefore, she always registered her pregnancies at the general hospital and made sure she attended at least one antenatal visit during her pregnancy to find out about the health of her baby. She knows that being registered at the hospital can work as a safeguard against humiliation in case problems that require hospital help arise. She explained that hospital staffs are particularly mean to women that have not registered their pregnancy with them. So when labour for her former co-wife's daughter-in-law, 'Wasila,' started just seven months into the pregnancy she was the one persuading her co-wife so she should be taken to hospital. As Halima said: "[I was waiting for Wasila's time to come] so I can nudge her so she will be bold enough to ask that [the men] take her to the hospital, because she is not as strong as our [other] daughter in-law. She also gave birth at seven months. When Babangida's wife gave birth to a preterm, I said let's go to the hospital. But the birth is already at hand. I touched her abdomen, and I know that she is about to deliver. And I said, now where are we going to get a car to go to the hospital? And [my co-wife] was worried that I am giving a lot of pressure to take Wasila to the hospital. She was worried about the responsibilities involved in going to the hospital, the going and coming."

With no access to transportation and concerns about pressuring their daughter-in-law, they decide upon an easier course of action and seek out a nurse that they know who lives nearby. "I said okay let me go and call a nurse. ... And I went out running and I went to Asibi's house. And I found that she had already gone to work. So, I came back. I took a motorcycle taxi and went to Fiddausi's house; she works at Dr Bello's (private hospital). So, I asked her to come. I told her to take the motorcycle taxi that I came with, and that she should come and attend to

Wasila. She asked …, have you bought gloves? I said no. We didn't buy gloves - if you have them then go with them. She said okay. So she took all the things needed for the delivery with the medicine that they give immediately when a woman delivers… As soon as she put on the gloves she checked and said that the mouth of the womb is fully opened. She is going to give birth now if Allah wills, and in less than 10 minutes she delivered."

Luckily it all ended well this time around both for Wasila and the new-born preterm baby.

Vignette 4: Open fracture (IP004)

Malam Audu is in his 50s and until his recent injuries was a builder. He is from Katsina, and he used to come and go as a teenage seasonal migrant worker trading wares in Zaria then a burgeoning railway station town. He later on started working as a daily-wage manual labourer in Zaria as a builder, and he eventually settled in Tudun Jukun over 30 years ago. He is proud of what he has achieved through hard work as he explained: "For us the burden that Allah placed on us and since he gave you the health you have to rise and make every effort. You cannot just lay back and depend on someone. Even in trading there was a time when we use to do it, and it was through it I built this house. But when it later failed we started manual labour. Through it I get what to eat and feed my family. Until this thing happened."

What happened was, about two years ago, Malam Audu was "pulling down an old building, they are going to build a new one." It was at a site located at Sabon Gari but owned by one of his wealthier neighbours in Tudun Jukun. It is the kind of work Malam Audu is familiar with but on that day it did not go according to plan despite all his preparations, as he explained: "and it is a thing of destiny if Allah bring such [there is nothing you can do] because I was very ready. I was knocking it down, knocking it down and watching when the wall shifted, and I run out and it followed my back. I got out, and it got me here [touching the leg that was hit by the falling wall]." He sustained an awful injury including crushing of most of his right leg below the knee. As he described: "it hit me here. One bone here broke. All these areas of scar are where it destroyed the leg. […] if you had seen the leg when it happened [you will be shocked]. It has been hit badly. If it were my destiny to die, that would have been it. [...] there will have been no way of escaping. It will have been it."

Immediately after it happened, the owner of the building site who was there at the time took Malam Audu in his car to the nearest general hospital. As Malam Audu explained: "Major [Abdullahi hospital], that was where we went first. When they saw it, they said no way that is beyond them. This one is beyond them. All they did was to strap it up and then asked us to move on […] from there we went straight to General [the university teaching hospital]." Again, it was "the person that we did the work for [that] took charge of the situation, he took me to the doctor and we were received quite promptly. [...] I was admitted at the hospital, and all that was needed in the form of medicines he [the owner of the site] was the one that bought them all they have to do is to do their work for me. I was there at General [the university teaching hospital], at the emergency [unit]." The severe nature of the injury, an open fracture with a lot of bleedings, meant it can only be managed by hospitals, as Malam Audu puts it:

"well it was necessary [to go to a hospital], since there was an open wound. If there wasn't a wound and it was just a fracture, I would have had it fixed at home. But since it involves open wound it must be taken to hospital. There at the hospital, they can assess and see, and they can wash and do different things. They can clean and fix it. But if it were [simple] fracture alone even at home [the traditional bone setters], they can fix it. But open wound must be [taken] to a hospital."

Malam Audu was, therefore, cared for at the university teaching hospital during the early stages of the injury. As he said: "I was there at General [the university teaching hospital], at the emergency [unit]. I spent four days there. At the time, they could not get a bed for me. […] afterward they got the bed and moved me upstairs [to the surgical ward] and gave me a bed. That's where I spent those [thirty] days. I was staying there peacefully. After every day or two they will dress the wound until [the time] I was discharged."

Things started deteriorating for Malam Audu as soon as his wealthy neighbour and the owner of the building site where he sustained the injury hands off the responsibility of financing the care. This happened while Malam Audu was still at the hospital. As he explained: "once he [the owner of the building site] finished buying the supplies and medicines that were requested when we presented at the [hospital] emergency [unit], I don't know how much he spent. Since that [time] at the hospital, even before I was given a bed, he handed over the responsibility to me. He never came to where I was again, and he lives in this neighbourhood. [Previously], any time he has any work, it was to us that he always came. So, he is not a stranger. After all that time till I was released, and I continue to suffer from this he has never showed up to say yaya aka ji da jiki ba (hey how have you been doing?)." Having no source of income and losing the support of his patron it becomes really difficult for Malam Audu to pay for his care at the teaching hospital, and he was discharged because of that. "When they discharged me they gave me a two-week appointment to return. When I returned, once he [the doctor] looked at it and saw this place [pointing at the healed discharge site] had raised the POP, he said, he gave an order and said the POP should be removed completely. He said they should remove it. [...] when they cut it off he stopped and looked at it. He held my big toe and shook it. He said surprisingly it was still viable, but the [fractured] bones are not fixed yet. He gave me another 2-week appointment to return again."

The cost of the trip and the lack of proper public transport made keeping to the follow ups very challenging for Malam Audu as he explained: "you see from here I have to board a motorcycle [taxi]. And anytime I am going I can't go alone I have to go with someone, so I have to get two motorcycles. I will pay the motorcycle [taxi] when we are going and pay for us to return. At least anytime we go I have to spend N200 (~80p)." Beyond the cost, riding on a motorcycle with part of the leg dangling brings considerable agony, as he explained: "even from there [the hospital] before we reached home on a motorcycle I was intolerably tormented. They have removed the POP. I came and left this leg like that for two weeks. I was worried about it not to get displace again." This has caused him to opt for the traditional bone setters even though as he explained earlier that is not the best for his injury. "So that's why they [traditional bone setters] put the corn stalk splint for me. So that was what was done, even though, I was going and get it dressed [at the hospital]." The poor and inconsistent care he got since then has resulted in prolonged suffering and poor healing of the wounds as he

said: "if this point heals another point opens. If that one heals it will then reappear here. That's how it keeps doing to me. It stopped draining pus just one and half years ago. That's why the leg became like this [all wriggly]." This continued for a while and at some point he was told by traditional healers that what he had was daji (a cancer). As he said: "I indeed tried traditional medicines. As they say, medicines related to daji have been tried a lot of times. That has been applied as much as I could." While trying all these different options, he still carried on with the hospital dressing even though he thought the hospital is too focused on making money than on addressing his problem, as he explained: "yes, everything. All they do for you is the dressing. That's all they do. And even that you have to pay. You have first to go and cut the paper (get a receipt) and pay and show them before they can do the dressing for you. […] now even the general [hospital] is all business. Everything that you do there [you have to pay] money."

Reflecting on successes and failures of all the measures he had to take to address the problem, Malam Audu said: "you see the matter of getting what you wanted is not a matter that you achieve at once. You try this, and you will see as if it will succeed and when it fails you look for another one. You keep on trying and trying and trying and then someone will come and tell that there is this other option and because of that it is difficult to say there is one particular one that was most satisfying. There is also no particular remedy that I will say it is the one that worked. At some point, I was frustrated with all the options and stopped everything and left everything with Allah. It kept on draining and draining, and all we could do is supplicate whatever we have learnt [ourselves] and blow the prayer onto the injury and gradually with time and Allah brought the matter to stop here."

Eventually, though, the wounds on Malam Audu legs got healed one after another as he explained: "it is now years. This continued until this one (pointing at one of the points that used to discharge pus) stopped. It is the last one. That was when I got a rest." Although this is still below what he wanted: "if I got what I wanted I would not be holding these things (crutches) I would like my legs to get healed and walk like everyone walks. But you see now. In short, the legs cannot bear any weight. Sai dai a hankali (we have to take it slowly). But what can we do? Even here now at home I can manage to walk with one (crutches) but if I am going a little further, I have to take the two. But in the past, even last year it was not possible I have to use the two." However, Malam Audu believes that if he had money, he would have achieved a better result. He said: "the problem is there is no money. Now, those that have money they actually go all the way to Kano." There is a national orthopaedic hospital in Kano located about 100 miles away from Zaria but for Malam Audu, that is beyond reach.