

# Study of the treatment costs of HIV/AIDS patients in Niger

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## 1. Introduction

The seroprevalence rate in Niger is 0.7%, a figure that is relatively low in comparison to neighbouring countries. Nonetheless, the government has put in place an extensive programme of treatment. Two points of note within this programme are the emphasis on decentralisation of treatment programmes and the availability, in theory, of free medication and examinations across large swathes of the therapeutic process. Despite these steps, much expenditure remains at the charge of the patient, notably the cost of transport, the opportunity cost of lost income and the cost of certain examinations and medications that are not covered by the government's programme. These costs undoubtedly have a strong effect on patient behaviour as the level of expenditures that fall upon the patient could potentially be an indicator of future observance.

Between September 2007 and February 2008, I undertook an internship with the French NGO, SOLTHIS, with the aim of evaluating the level of these supplementary costs relative to patient income, across three sites in Niger. At the same time, I intend to calculate the cost for the state of providing free treatment. This document presents an overview of the work undertaken in Niger – the aims of the study, the research undertaken and some preliminary results. In order to clarify the background of my research, I will briefly outline the epidemiological context of HIV/AIDS treatment in Niger and the organisation of HIV/AIDS treatment within the public health system.

## 2. The epidemiological context of HIV/AIDS in Niger

Despite the relatively low rate of seroprevalence, certain epidemiological tendencies of HIV/AIDS are worth emphasising. While the official national prevalence rate is 0.7% in

the adult population between the ages of 15 and 49, it is estimated that the actual prevalence rate may be considerably higher.

Already, the epidemic is more established within certain at-risk populations. As would be expected, the prevalence rate among sex workers is much higher than within the general population, at 34%. Other populations that appear to be at particular risk are miners (2.1%), the military (3.8%), long-distance drivers (1.7%) and prisoners (2.8%).<sup>1</sup>

Similarly, there are significant differences between the urban (1.5%) and rural (0.5%) domains, and between men and women. Amongst the uneducated population, there is a rate of seroprevalence of 3.8% amongst women, compared to 2% amongst men.<sup>2</sup> This reflects the particular vulnerability of women within Nigerien society. Apart from the Tuareg ethnicity, which is traditionally matriarchal, the status of women is very low in Niger. Rape is not uncommon and female circumcision is widely practised (the official rate of 2.2% in 2006 is thought to be a gross under-representation). Similarly, women suffer disproportionately from stigmatization as they are frequently the first members of the family to be tested. Nigerien society is polygamous and the use of contraception is rare, so seropositive men frequently infect three women and numerous children before accepting that they themselves may be the cause. Similarly, many people are either ignorant of the illness or refuse to accept it. This has a significant impact on expenditure as many prefer to invest in traditional healers to purge themselves of 'bad spirits' rather than attend modern medical facilities. This aspect of patient expenditure is very evident in my results.

The government's national coordination committee states that the principal reasons for the spread of HIV/AIDS are the movement of population between the major urban centres and the countryside, whether for seasonal work, commerce or military service, and the movement of at-risk populations. This last category consists of migrants from West Africa to the Maghreb and by extension to Europe, but also a considerable number of sex workers who left northern Nigeria after the adoption of Shari'a law. Similarly, the dry season sees a considerable rural-urban migration between the months of October and June.<sup>3</sup> Therefore, while the national rate of seroprevalence is relatively low, Niger's status as a fragile state and her position at the crossroads of West African migration combines to put the country at great risk of further spread of the disease.

### 3. The organizational context of HIV/AIDS treatment in Niger

#### 3.1 National organisation of treatment

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<sup>1</sup> Comité National de Coordination des activités de lutte contre le SIDA, la Tuberculose et le Paludisme du Niger (CCM) (2006) *Programme de Renforcement, de Décentralisation et d'Amélioration de la Réponse Nationale face au VIH/SIDA au Niger*

<sup>2</sup> WHO CCS Niger, 2006

<sup>3</sup> Comité National de Coordination des activités de lutte contre le SIDA, la Tuberculose et le Paludisme du Niger (CCM) (2006) *Programme de Renforcement, de Décentralisation et d'Amélioration de la Réponse Nationale face au VIH/SIDA au Niger*

The ministry of health, and more specifically, the *Unité Sectorielle de Lutte contre le SIDA* (ULSS) is charged with coordination of HIV/AIDS treatment across the country. The ULSS is attached directly to the office of the Prime Minister, while the *Première Dame prime* (there being two 'first' ladies in Niger) is the patron of the national *Lutte contre le VIH/SIDA*. ART treatment started in Niger in 2004 and there are currently 12 treatment centres, of which five are to be found in the capital, Niamey. Of these five, 3 are public hospitals, one a military hospital and one is the *Centre de Traitement Ambulatoire* (CTA), a public structure created with the technical and financial assistance of the French Red Cross. The CTA accounts for roughly half of all patients treated. With the exception of the CTA, which is entirely dedicated to the treatment of HIV/AIDS, consultations are integrated within the treatment of all pathologies. While there is no private mechanism for HIV/AIDS treatment, there are private laboratories and pharmacies which provide biological and radiographic services, and supply the drugs necessary for the treatment of opportunistic infections (OIs).

A major element of the strategy for universal access to ART (80% of patients to be treated by 2012) consists of decentralisation of treatment programmes. This poses a major problem as provision of HIV/AIDS treatment, as it stands, suffers from great inconsistency across the country. Harmonization of the quality or cost of treatment is neither attempted nor applied. As a result, the quality and cost of treatment is not the same in all of the public treatment centres.

A second major element of government policy is the gratuity of treatment. This gratuity was formalized by law in April 2007, but without setting concrete limits to the extent of gratuity. In theory, ARTs, biological, immunological and viral monitoring, contraceptives, and the diagnosis and treatment of principal OIs are all free of charge for the patient. However, due to supply problems this is often not the case.

Free treatment is now an internationally recognized strategy for improving access to health care, and there are a number of principal arguments put forward in its favour:

- Improved motivation to attend formal health structures
- Improved equitability of the health system
- Improved observance, leading to the improved efficiency of the health system
- Reduction of delays to treatment linked to a lack of finance

In the precarious economic and social context of Niger, and in the presence of strong discrimination against patients living with HIV/AIDS (PLWHA), the provision of free treatment is undeniably a strong element in the strategy of prevention as well as that of treatment. Only a very proactive dissemination of information regarding access to

treatment can develop the public health imperative of voluntary testing, and by extension the increased reach of the public health service.

A part of treatment of seropositive patients is therefore financed by the Nigerien government (thanks to the principal international donors: the Global Fund and the World Bank). Nonetheless, in reality, many patients see their budgets affected by the need for therapeutic observance (transport, accommodation, hospitalization), not to mention by the failure of the government to guarantee gratuity (costs of medication and analyses).

The smooth-functioning of the health system is therefore integral to the efficiency of the national programme for free treatment. It is impossible to evaluate the costs which fall to the state and to patients without an appreciation of the structure of the Nigerien health system, as well as the decentralization programmes put into place by the government.

### 3.2 The therapeutic itinerary

In broad terms, there are two aspects of treatment that must be taken into account once a patient has been tested seropositive. The first is the Anti-Retroviral Treatment (ART), which involves the administering of ARTs and, due to their significant side effects, regular biological monitoring. The second is the treatment for OIs, which are treated as they would be for a patient without HIV. At the early stages of treatment, patients are frequently tested for TB, which requires a pulmonary X-ray and potentially further scans. Similarly, patients can also be tested and treated for Hepatitis and a host of other co-infections. Depending on the gravity of the HIV infection, there are therefore numerous potential therapeutic itineraries, ranging from monitoring immunological levels on a quarterly basis in the absence of symptoms, to hospitalisation.

Typically, patients in Niger arrive at a relatively advanced stage of the illness and therefore require ART treatment straight away. Adults are given ART according to clinical (WHO stage 3 or 4) or immunological (less than 350 CD4 lymphocytes per mm<sup>3</sup> of blood) criteria. The first step in the treatment process consists of a clinical and biological survey and complementary exams are prescribed. The second consultation allows discussion of these tests and it is at this moment that the doctor proposes ART if necessary (a trial half-dose is administered).

This second consultation is followed after 15 days by a third consultation, when a full dose is prescribed provided that there have been no adverse side-effects. Between the second and third consultations, the patients are advised to attend psycho-social consultations related to their acceptance of the disease and therapeutic observance. Finally, thirty days after the third consultation (forty-five days after the first ART prescription, the patient returns for biological monitoring and a renewal of the

prescription. This is then repeated roughly every three months.<sup>4</sup> Needless to say, this standardised itinerary is not always adhered to, whether because of the patient's stage of illness, problems of observance or the availability of drugs, doctors or test results.

All of the patients interviewed as part of this study were on programmes of ART treatment.

#### 4 Aims

The principal aims of the study were twofold. Primarily, the aim was to evaluate the repartition and weight of expenditures at the charge of patients seeking treatment at four sites across the country. The second aim was to evaluate the cost to the state (and partners) of providing this treatment to the patients interviewed.

The question of the cost-efficiency of decentralised treatment programmes was considered too complicated given the short time-frame and limited resources available, but will nonetheless remain an important factor to consider over the course of the analysis that remains to be carried out. Nor is the analysis presented here a study of the costs implied by a high-quality treatment programme. Rather, the questionnaires and study of patient notes permit an analysis of whether patients receive the same quality of treatment regardless of the location of their treatment centre. It may be possible to compare the costs evaluated over the course of research with a theoretical model of the cost of a treatment programme of high quality.

More broadly, it should be possible to suggest strategies for improving the organisation and provision for HIV/AIDS treatment. For example, how much would it cost for the government's donors to put in place a truly free treatment programme? Would this have a significant effect on patient behaviour? Should certain mechanisms be put in place to provide direct subsidies to patients in the event of prohibitive treatment costs, or should the government focus on improving the quality and reach of the health system? Should the state focus on assuring the *real* gratuity of treatment programmes before it considers rolling out an imperfect treatment model? Are there aspects of treatment for which the state can proceed with decentralisation, and others for which the government should consider other strategies? These problems go beyond the realms of economics and will require a delicate balancing of short term humanitarian needs with long term development aims.

#### 5 Methodology

##### 5.1 Questionnaire

- Content of questionnaire

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<sup>4</sup> See appendix

The questionnaire consisted of five parts<sup>5</sup>:

i. Explanation of the study and consent form

Given the subject matter, it was essential to explain clearly the nature of the study and the fact that participation in the study was voluntary and anonymous. To this end, I included a two page summary of the objectives of the study and the conditions under which subjects would participate in the study. Emphasis was placed on the voluntary nature of the questionnaire, as well as the fact that unwillingness to participate would have no effect on the quality of health care that the subjects receive. Subjects were also informed that data pertaining to their treatment would be taken from the national database, FUCHIA, and from their patient notes held at their treatment centre. Subjects were also given the option to opt out of individual questions.

At the end of this explanation, conducted either by myself in French or by my translator in a local language, the subjects were asked to sign or mark the paper, to demonstrate that they had understood the conditions of the study and that they agreed to take part. Roughly 40% of patients approached refused to take part, the majority among them being men. The questionnaire was tested with a group of patients belonging to the patient association at the National Hospital in Niamey.

ii. Open question

The first question was an open question asking patients to relate the difficulties that they had experienced over the course of their illness. This question was not always entirely successful, some patients being less expansive than others. The intention was to see whether financial matters occupied an important place in the minds of patients without having just discussed their income and health expenditure for ten minutes.

iii. Personal data

Subjects were asked for their unique INAARV identification number, as well as their age, sex, marital status, schooling and profession, before and after the illness. They were also asked the reason for which they were tested and the time since their test and their first consultation.

There were very few complications with these questions. The INAARV number was either taken from memory or from a prescription, and in some cases the number proved to be incorrect when cross-referenced with FUCHIA or patient notes. Frequently, patients could not remember exactly when they had been tested or when they had first attended a consultation. This is not necessarily a problem, however, as the aim of these

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<sup>5</sup> See attached document

questions was to see whether income level had an impact on the readiness to seek treatment, so it was only necessary for subjects to remember the time period between testing and consultation.

#### iv. Income and household data

The next part was intended to measure the income of the subject and the household. This posed a particularly difficult task as few Nigeriens have a fixed income. Where it applied, subjects were asked to estimate their income per day, week or month, although many could not. Subjects were also asked whether they could estimate total household income – this question did not work: wives did not know their husbands' incomes, and neither husband nor wife could account for the casual labour that children frequently undertook. More successful was the question asking whether income was constant, slightly variable, or completely variable.

Subjects were also asked details about their households, in an effort to estimate their socio-economic status (source of water, material of the house, number of dependents, proprietor or tenant, number of HIV+ members of the family). Finally, subjects were asked to evaluate their own financial status – indigent, poor, middling, or comfortable.

#### v. Health expenditures

The final section consisted of questions relating to health care and related expenditures: medication and exams, transport, hospitalisation, food and housing (if from a different town to that in which they sought treatment) and companions. They were also asked to specify how they had paid these costs. They were then asked if health expenditure had had an effect on other household expenditures, whether they had had to sell property to cover health care expenses, and whether they had missed an appointment or delayed collecting a prescription because of a lack of funds. Next they were asked if they had made expenditures on traditional medicine, both before and after testing positive for HIV. Finally, they were asked to evaluate the relative importance of four common problems for PLWHA: financial problems, problems of discrimination, anxiety and decrease in health levels.

- Choice of sites

Four sites were chosen to carry out the interviews: the Centre de Traitement Ambulatoire (CTA) in Niamey, the National Hospital of Zinder, the Regional Hospital of Maradi and the National Hospital in Niamey. The sites were largely chosen out of convenience – SOLTHIS works closely with the institutions in Niamey and Zinder, allowing easy access to the doctors and patients, and Maradi lies on the Niamey-Zinder access, roughly two-thirds of the distance from Niamey to Zinder. Ideally, a more remote treatment centre would have been chosen, but due to the security situation in Niger this was not recommended.

i. Centre de Traitement Ambulatoire (CTA)

The CTA is an in-patient centre dedicated to the treatment of HIV/AIDS. Patients come for regular consultations to pick up prescriptions or in the case of illness. There is also the facility for in-patient hospitalisation for cases that require more intensive care. The most serious cases are referred to the Hôpital National de Niamey for hospitalisation.

The Ministry of Health pays the base wages of the staff at the centre, but the French Red Cross supplements these wages and in addition funds a wider range of medication and exams than are provided by INAARV (*Initiative Nigérien à l'Accès aux ARV*). As a result, the treatment received by patients at the CTA is more comprehensive and should involve less expenditure by the patient than elsewhere. Similarly, the patients at the CTA tend to be more open about their status and were far readier to talk to me than those at other centres.

In order to approach patients, I was advised by the chief medical officer of the CTA to wait in the pharmacy. As patients came to collect their prescriptions after consulting with the doctors, my translator and I would approach them to ask if they were willing to take part in the study. A number preferred not to take part.

ii. Hôpital National de Zinder (HNZ)

The National Hospital in Zinder is one of three national hospitals in Niger (the other two being in Niamey), acting at the 'strategic' level of the health pyramid. There are three prescribing doctors at the HNZ; two based in general medicine and one in infectious diseases. The HNZ also benefits from an integrated treatment centre (*cellule de prise en charge globale*) which provides a counselling service to patients. It also administers a fund set up by UNICEF to cover the cost of medication and exams that are not covered by INAARV.

I spent a total of two weeks in Zinder, the first week in mid-December, the second week in mid-January. I was based in an office next to one of the prescribing doctors, who would introduce my study to the patients and then allow them to come and see me or not, giving them the choice.

During the first spell, only one of the prescribing doctors was present, which allowed greater access to patients as they were concentrated in one area. Additionally, more patients made the journey into Zinder in the period leading up to the festive season. During the second spell, all three doctors were present, meaning that the patients were more dispersed around the hospital and less inclined to make their way across the hospital to be interviewed.

iii. Hôpital Régional de Maradi (HRM)



The Regional Hospital in Maradi is one of eight regional hospitals in the country, operating at the 'technical' level of the health pyramid, and is dependent on the local *Direction Régionale de Santé Publique*. There are four prescribing doctors at the hospital, three of whom treat internal patients or patients with appointments, and one of whom treats walk-in patients at the entrance of the hospital. I spent two weeks in Maradi, much of which was spent dealing with cumbersome administration. Although I had the agreement of both the director of the hospital and the regional public health director, there was a delay in transferring the document of approval from the regional director to the hospital director, during which time I was barred from entry to the hospital by the military security.

As in Zinder, I contacted the prescribing doctors, who introduced my study to patients coming for consultation. The patients then decided if they wanted to come and take part in the study or not. Additionally, I contacted the president of the local patients' association. In return for paying his taxi fare each day, he came to the hospital and made contact with members of his association to encourage them to take part in the study. This will undoubtedly lead to a bias in the results, as the members of patient associations are by no means typical of patient body as a whole.

#### iv. Hôpital National de Niamey

The National Hospital in Niamey has by far the greatest number of prescribing doctors of any of the HIV/AIDS treatment sites – twenty-seven in all. The doctors treat a mixture of outpatients and inpatients and HIV/AIDS treatment is integrated, as with the other non-specialist treatment centres. Additionally, there is an anonymous treatment centre which is run by a patient NGO, *Mieux Vivre avec SIDA*. The treatment itself is largely the same as within the hospital, but the psycho-social services are much more comprehensive. Frequently, the patients themselves did not distinguish between the two different sites.

Initial efforts to contact patients for interviews were very unsuccessful. The chief doctor put aside a meeting room for me, and introduced me to the doctors present at the time. The intention was for the doctors to tell the patients where I was and to ask them to come to me for the interview. Unsurprisingly, this did not work, whether due to the unwillingness of the patients or the fact that the doctors simply forgot about me. Finally, I decided to base myself at the INAARV pharmacy, reserved solely for patients picking up HIV/AIDS prescriptions. I was therefore able to interview patients in much the same way as at the CTA, while preserving their confidentiality. At the HNN, therapeutic educators worked in the pharmacy as well, and whenever a patient wanted to consult with the educator, I would leave the room until they had finished.

- Translation

Throughout the study, I used the same translator. The questionnaire was written in French, and where possible I conducted the interviews myself in French (and even in English for one patient). The majority of interviews required my translator, who conducted interviews in Zarma, Hausa, Peul and Beriberi. My translator was a member of the therapeutic education team at the CTA, as well as a prominent member of the patients' network RENIP+. This greatly aided when approaching patients requesting participation in the study, although she was not a trained translator and this had a certain effect on the effectiveness of the open questions. Similarly, the fact that she was a member of a patients' association introduced a selection bias as she had more success persuading other members of associations to participate. Nonetheless, she had a good understanding of the issues at stake so was willing and able to explain questions in more depth if a subject did not understand something.

## 5.2 Patient notes

To evaluate the overall cost of treatment, I complemented the data gathered over the course of the interviews with data from the notes of the patients I had interviewed. Data was gathered on the total number of consultations attended, and the exams administered. Unfortunately, this was not always possible, for a number of reasons.

Where patients could not remember their INAARV number, or where the INAARV number was incorrect, recourse to patient notes was impossible. There were also a number of practical constraints to examining patient notes. In all of the centres other than the CTA, patient notes were kept in the office of the consulting doctor. This precluded the study of patient notes during consulting hours and when the doctor was away from the hospital. This was a particularly problematic in Maradi, where the prescribing doctors were dispersed around the hospital. Equally, at the National Hospital in Niamey, there are twenty seven prescribing doctors and patients moved from doctor to doctor according to which ones were present on the day they arrived for treatment. At the CTA, patient notes are stored centrally, and I was granted permission to consult them after the hours of service.

## 5.3 National data base (FUCHIA)

In theory, all paper notes are transferred to a centrally administered database, FUCHIA, which has been put in place by Epicentre and MSF. In practice, the computerised database is a number of months out of date, and where it is up to date, the data entry is very incomplete and inaccurate. It remains to be seen what use can be made of the data available on FUCHIA.

## 5.4 Cost data

At each site I visited the pharmacy, laboratory and radiology departments to collect data on the machines and consumables used for the various exams applicable to the

treatment of HIV patients. I collected data on the prices of medications and exams as charged to the patients. I also collected information on the model and make of machines, their age and the number of examinations performed on each. Finally, I collected information on the reagents and other consumables used, the amount used for each examination and the life expectancy of each unit supplied. The accuracy of the information supplied depended heavily on the technician interrogated and their level of involvement in the exams.

I now propose to contact the companies responsible for supplying these goods with a view to collecting cost data and life-expectancy in the case of the instruments. Eventually, I will calculate the real cost of each exam per patient, with the aim of calculating the real cost of exams and medication administered to each patient within the study.

6 Preliminary results

	CTA	HNN	Zinder	Maradi	All sites	
<b>No.</b>	82	32	35	37	186	
<b>Mean no. consultations per patient</b>	10.53		3.86	7.44	7.28	
<b>Mean no. tests per consultation</b>	1.46		1.67	0.56	1.23	
<b>% able to give personal income</b>	51.2	90.6	77.1	81.1	75	
<b>Average income (F CFA)</b>	68845	30603	33759	27277	40121	
<b>Average expenditure on medication and tests once within INAARV (F CFA)</b>	27447	24229	33983	18569	26057	
<b>Mean patient expenditure on medication and tests, per consultation (F CFA)</b>	2606.6		8803.9	2495.8	4635.4	
<b>% of patients who use their personal income to support these costs</b>	36.6	18.8	20	40.5	29.0	
<b>% supported by family</b>	25.6	43.8	17.1	37.8	31.1	
<b>Mean cost of transport (one way, F CFA)</b>	1509	2236	2396	422	1641	
<b>% hospitalised</b>	29.3	46.9	31.4	48.6	39	
<b>Average duration of hospitalisation (days)</b>	11.07	28.8	9.15	21.51	18	
<b>Average total expenditure on hospitalisation (F CFA)</b>	102438	249545	37700	89933	119904	
<b>Average expenditure on hospitalisation per day hospitalised (F CFA)</b>	9254	8665	4120	4181	6555	
<b>% having consulted traditional practitioners</b>	29.3	37.5	51.4	70.3	47	
<b>Average expenditure on traditional practitioners (F CFA)</b>	241367	268416	478083	186333	293550	
<b>% having sold property to cover treatment costs</b>	43.9	28.1	60	94.6	56.7	
<b>% having reduced household expenditures due to cost of HIV/AIDS</b>	73.2	37.5	80	75.7	66.6	
<b>% having missed a consultation</b>	6.1	6.3	14.3	2.7	7.35	
<b>% having delayed a test or prescription because of lack of finances</b>	40.2	37.5	17.1	64.9	39.9	
<b>Nature of financial difficulties</b>						
	<b>Perpetual</b>	52.4	34.4	51.4	67.6	51.5
	<b>Temporary</b>	15.9	18.8	22.9	10.8	17.1
	<b>Non-existent</b>	31.7	46.9	25.7	21.6	31.5
<b>Relative importance of principal problems (1 = most important, 4 = least important)</b>	<b>Finances</b>	2.28	2.28	1.83	1.65	2.01
	<b>Health</b>	2.43	2.38	2.26	3.38	2.61
	<b>Discrimination</b>	3.52	3.34	3.29	3.19	3.34
	<b>Anxiety</b>	2.93	2.31	3.11	2.84	2.80