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***Ensuring the sustainability of DSS by making
scientific results available to lay persons:
case studies in Senegal and Burkina Faso***

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Introduction :

With this study we hope to initiate new thinking on the ethics of research in demographic surveillance systems (DSS). This work is based on well known aspects but which have not been the object of systematic researches yet. DSS activities are based on a longitudinal follow-up implying repeated visits to each household composing the site who are systematically asked the same demographic and also epidemiologic questions; these visits have often been occurring for years if not decades, and, over the years, the questionnaires have been further expanded with additional topics such as education or economic aspects. In addition to these activities, DSS sites constitute plate-forms for scientific research conducted by external research teams. As a result, DSS sites often become areas where populations are constantly solicited in various types of surveys and studies. This has led to the populations' increased weariness, sometimes exasperation as people have the feeling that they have been answering so many questions (and in general the same ones) over a long period of time without seeing clear improvements in their daily lives. As it is difficult for them to see the coherence in all the studies conducted, feelings of being exploited are also often expressed.

We argue that because people do not understand the purposes of the longitudinal follow-up and have difficulties to see the link between these routine survey activities with the temporary ones, they have increasing troubles to answer the questions whether they understand them or not. In other words, if they were made more aware of their interest of being part of such systems, not only their feelings of weariness and exasperation would be lessened, but also their answers would certainly be of better quality. As such, the research design common to all DSS raises the fundamental question of participants' rights to information and to the additional following questions:

- to what extent the communication established between the different actors (research teams, interviewers and interprets, populations) leads to the reproduction of social inequalities between these actors and within the studied society?
- To what extent this lack of understanding is likely to negatively influence the quality of the responses and ultimately lead to the stop of the DSS activities?

One solution to these problems could be the organization of a restitution of the results based on the DSS longitudinal data-bases. We use the word *restitution* on purpose, as it refers to "the restoration of something lost or stolen to its proper owner" (Oxford Concise English Dictionary, 1999). In this sense we argue that as long as people do not know or understand properly what the information they constantly provide lead to, feelings of being used by the system will remain and grow, thus jeopardizing the efficiency of research activities. At the same time, following Olivier de Sardan's view (1995b), we argue that populations more aware of the aims of the DSS activities illustrated by results (whatever the effect of these results on their daily lives) will help them better negotiate their future with development institutions. In that sense our approach goes a little bit further than "disseminating the results"; its aim is also to provide a pedagogic dimension to the whole operation. One main aspect of it is to involve the populations who are

directly solicited by the follow-up activities and not restrict such “restitutions” to local leaders and decision makers. Although this approach is strongly supported by most DSS research teams, in most cases, researchers have failed to put restitution activities in their agendas. This can be explained by two main factors: first, most researchers are trapped in a logic of publication and the agendas simply do not allow them enough space to include such activities; second, in most cases researchers do not have the communication skills to provide information and explain the results they reach to lay persons, especially when it deals with vulnerable and illiterate populations¹.

Our objective in the project was to identify the different topics that interviewed people were most curious about and thus wanted to be informed about. Further, different ways to communicate such information had to be discussed locally in order to understand what kind of communication channels and spaces were used within a given society. Ultimately this had to lead to a diagnosis on the appropriate communication tools to operationalize the future restitution activities. To get a deeper insight in the different perceptions populations have on DSS activities and which characteristics should be considered while designing these tools, a comparative study on five sites in Western Africa was undertaken in 2006, three in Senegal and two in Burkina Faso. Based on qualitative individual interviews and focus groups, a diagnosis was made for each site, highlighting which topics to be focused on in the restitution process, how to operationalize the restitution and why it should be designed in that way. This project has come to an end and the next step is to proceed to the restitution in order to evaluate our general approach. At the end of the whole process a protocol providing a description of the steps we followed and our recommendations will be available for all DSS part of the INDEPTH-network.

In a first section we will briefly describe each site under study, and then explain our methodology before getting to the more salient results. A discussion will follow, highlighting the main issues and the steps forward.

The DSS sites under study

At the time this presentation is written, two of the three Senegalese sites have been studied: the Niakhar site, located in the Senegal peanut basin and Bandafassi, in the South-Eastern part of the country. In Burkina Faso, the Nouna DSS site and the Ouagadougou pilot project sites have been selected for the project. It seemed interesting to include an urban site and Ouagadougou is of particular interest to us as it is a new DSS site. In this sense any information gathered on populations’ perceptions of the DSS activities could be used to prevent some of the problems mentioned above. Each of these sites are managed by different institutions which means that despite a similar research system we may find different working cultures between the sites which are likely to affect the relationships between the different actors involved in the longitudinal follow-up (for example in the interactions between the DSS leaders and the interviewers conducting the surveys; the presence of these leaders in the sites, etc.).

¹ For more information on the relationships between researchers, development institutions or operators and the population see Boiral, 1985 and Boiral et al., 1985; Lewis and Gardner, 1996, more specifically the chapter 2; and D. Mosse, 2005.

A brief reminder of the main aspects of DSS research device is needed here to better understand the issues at stake. Each DSS site refers to a group of villages or neighbourhood which has been selected on the basis of different criteria in order to follow its population's demographical and epidemiological changes. A preliminary census of the whole population has been conducted before starting the follow-up activities and in most cases, such censuses are up-dated on a regular basis. Longitudinal follow-ups are based on repeated visits (yearly, monthly, quarterly...) in each household included in the site. This general design has changed over the years since the creation of the DSS and can be slightly different between the sites. Such DSS imply a heavy and costly process which only well organized institutions can manage.

Each site part of this project has been constituted according to different criteria. For example, the Niakhar DSS site was formed based on the cultural, social and economic homogeneity of its population; Bandafassi and Nouna, on the contrary are very heterogeneous areas in terms of their populations' ethno-linguistic characteristics.

The case of Bandafassi needs some additional explanations. It is the only site of our sample where visits are yearly. Surveys are conducted by one of the managing institution's interviewers accompanied by a local interpreter. Only one person in each village is requested to answer the questions related to the demographic follow-up, usually the village chief or the health agent who constitute key informants on the demographic changes of the whole setting. Only if they report a death, the interviewer will directly visit the concerned family in order to perform a verbal autopsy. Hence there is no systematic visit to each household in each village composing the Bandafassi DSS.

Table 1 summarizes the characteristics that seemed most important for the design of communication tools: ethnic and religious belonging. In each site people or poorly educated or have had no education at all; only in one of the two areas covered in Ouagadougou are the levels higher as it is a socially and economically mixed area.

Table 1 : Main characteristics in the different sites

	Niakhar (Senegal)	Bandafassi (Senegal)	CRSN (Burkina Faso)²	OPO (Burkina Faso)³
Institution	Institut de recherche pour le développement/I RD (France)	Institut national d'études démographiques /INED (France)	Ministère de la santé (Burkina Faso)	Institut supérieur des sciences de la population/ISSP (Burkina Faso)
Start ⁴	1983	1974	1992	2002
Nb villages/areas	30 villages	42 villages	52 villages, 7 sectors in Nouna	2 neighbourhoods
Nb inhabitants	35000	11500	77000	5445
Ethnic group/religion	Sereer	Peulh, Bedik, Malinké	Marka, Bwaba, Mossé, Samo, Peulh	Mossé
Religion	Islam, christian, animist	Islam, christian, animist	Islam, christian, animist	Christian Islam
Types of systematic taking down	EV, AV, epidemiology, households, education	EV, AV, households	EV, AV, EM	Households' assets, EV, education, housing
Nb visits/year	Quarterly	Yearly	3 times/year	Quarterly
The interviewers	Permanent local interviewers	INED interviewer/ local interpreters	Permanent local interviewers	Permanent local interviewers

Note : EV = vital events, AV = verbal autopsies, EM = household surveys

Methodology and data

The methodology

The project design is structured by two main phases based on an exploratory fieldwork in which individual interviews and focus groups have been conducted. In the first one, the *immersion phase*, the goal was to “take the local temperature” (Olivier de Sardan, 1995a). Each site was visited and local key informants (local leaders, teachers, health agents, etc.) as well as inhabitants were interviewed, in most cases in focus groups. These interviews were aimed at identifying populations’ perceptions of the DSS activities, in particular their understanding of the demographic follow-up. Ultimately we hoped to get them to identify with us which topics covered by the follow-up they really wanted to have included in a restitution activity.

In this phase we also tried to evaluate people’s level of information regarding the various activities going on in the DSS in which they were part and whether they were aware of their belonging to such a system. In the second phase, or “eclecticism phase” (Chapoulié,

² CRSN : Centre de Recherche en Santé de Nouna

³ OPO : Observatoire de Population de Ouagadougou

⁴ We use the census date which after which the current DSS follow-up has been launched in each site.

2000), we looked for a confirmation of our first findings by collecting more systematic information on local communication channels and the spaces used by people to get together in various occasions. We also started to discuss with local people the most appropriate way of communication information and results to the populations according to the socio-cultural context. At the end of these fieldworks a diagnosis for each site was written highlighting a) the relationships between the populations and the DSS research process, b) their motivation to continue to answer despite their weariness, c) the results of which topic covered by the follow-up they would like to be aware of in priority and finally d) what would be the best way to communicate these information.

In each site, local research assistants have been hired and trained to do the fieldwork: 3 students in Burkina Faso, and 3 local interviewers-interpreters in Senegal. The interviews were all conducted by these assistants following the same interview guide covering different themes (perceptions on the DSS questions asked, information level, motivation to answer these questions, restitution format) and information were collected in the form of field notes. These notes were later computerized and analyzed: different categories were identified for the respective themes covered in the interviews as well as the regularities within and between each site under study. It is on the basis of these results that further recommendations will be made on the appropriate communication tools.

The data

In each site interviews were conducted among people who had answered the DSS follow-up questions at least once. Even if in the focus groups some participants had not gone through such process as it is only one person who is solicited to answer the questions, usually the head of the household, they nevertheless had an idea of the questions asked as they had been witnessing the visits for several years. As much as possible we tried to conduct focus groups separately between men and women but some naturally became mixed. Since the topic is of common interest and concerns the population as a whole, we felt that in some cases mixed focus groups were perfectly acceptable. In many cases men are overrepresented; this is mainly because our first move was to contact local leaders and representatives, and these people are in most cases men.

1) The Senegal data

The Niakhar data

Each village in the Niakhar study (30) area was visited. When it was possible the chief of the village (or his representative) was visited primarily. Depending on his views on the subject an individual interview or a focus group was conducted. In addition to the local leaders, inhabitants chosen randomly were interviewed. The three most important villages of DSS in terms of their size (from 2500 to 3900 inhabitants) and economic activity (weekly markets, ways for regional buses, etc.) are overrepresented.

Table 2 : Number of interviews in the Niakhar study area

	Individual interviews		Focus groups			Total
	Men	Women	Men	Women	Mixt	
In the whole area	27	12	11	12	15	77
3 main villages	12	6	6	7	6	37

The Bandafassi data

Out of the 42 villages composing the study area, 26 were visited. 25 focus groups and 4 individual interviews among key informants were conducted. Some villages can in fact be divided in two when their neighbourhoods correspond to different ethnic communities; when this is the case there are two chiefs heading their respective community.

Table 3 : Number of interviews in the Bandafassi study area

Ethnic groups	Nb villages visited	Nb focus groups			Total
		Men	Women	Mixt	
Peulh	11	3	2	7	12
Bedik	11	5	1	2	8
Malinké	3	1	1	2	4
Bassari	1			1	1
Total	26	9	4	12	25

2) The Burkina Faso data***Ouagadougou : the Wemtenga and Taabtenga neighbourhoods***

Wemtenga and Taabtenga are two contrasted areas of Ougadougou. Wemtenga is divided into plots, with urban infrastructures : drinking water, electricity, health centers, etc. Taabtenga is not divided into plots and has almost no basic urban infrastructures. Its population is poor and education levels are low. In these two areas 35 interviews were conducted (23 individual and 12 focus groups). Two additional individual interviews were conducted with a DSS supervisor and with an interviewer.

Table 4 : Number of interviews in Wemtenga and Taabtenga

	Individual interviews		Focus groups		
	Men	Women	Men	Women	Mixt
Wemtenga	9	6	2	3	1
Taabtenga	2	6	3	2	1
Total	11	12	5	5	2

The CRSN data (Nouna)

The Nouna DSS site covers 59 localities (58 villages and Nouna which is divided into 7 sectors). In terms of ethnic groups, the site is mostly inhabited by Marka, Bwaba, Peulh, Mossi and Samo. Because of the size of the site and limited amount of time we had to make a carefully thought out choice of the villages to be visited as they would represent the whole DSS. Three main criteria used to select them were: the number of years spent as being part of the DSS, the ethno-linguistic composition and the frequency of external interventions (for example health interventions). The fieldwork thus covered 19 localities (14 villages and 5 sectors in Nouna). All ethnic groups living in the area are represented in the study. 44 interviews were conducted (34 individual and 10 focus groups). 10 additional interviews were also conducted in the CRSN among the persons in charge of the DSS, interviewers and survey supervisors. In total 55 interviews have thus been conducted.

Table 5 : Number of interviews in Nouna and in the villages

Ethnic groups	Nb villages visited	Individual interviews		Focus groups			Total
		Men	Women	Men	Women	Mixt	
Peulh	2	1	1		1		3
Bwaba	2	10	1			1	12
Marka	4	7	1	2			10
Mossi	1	1			1		2
Samo	1			1			1
Peulh, Bwaba, Marka, Mossi, Samo	9	9	3	1	1	2	16
Total	19	28	6	4	3	3	44

Results

From the discourses in the interviews, we have identified several categories or sub-themes. In a first step we tried to identify the perceptions people have on the items they are routinely asked (those of the follow-up). We first asked them which were the questions that immediately come to their mind and from their answers, attitudes and reactions while responding to that question, we identified two additional categories: 1) the questions that embarrass or bother them and 2) those which do not make any sense to them. The border is often vague between these 3 categories but examined into detail each of them reveal its own importance. In sites like Niakhar where many additional surveys are conducted and where the DSS fully plays its role of scientific platform, many people find difficult to distinguish between the follow-up questions and those in a temporary survey. Some of these external surveys have strongly marked people's memories, especially when they were health oriented with concrete effects (like vaccinations, health care support, etc.).

For each site we will follow the order in which we asked the questions and synthesize the responses we got. When we quote it is from field notes which explain why the indirect style is often used.

1- In Senegal

The Niakhar study area

The questions remembered, embarrassing or making no sense.

Among the questions people remember immediately, those of the DSS come back most often. This is not surprising when we know that each household is currently visited four times a year and has been answering (or listening) to these questions for decades sometimes. The embarrassing questions refer to those concerning fertility and health. Several of these questions were part of surveys external to the follow-up, especially those related to reproductive health. Regarding the questions not understood because, to people's minds they make no sense, we find those related to population dynamics such as migrations, visits, departures, to the household composition (also: how many people live in the same room, how many share the same bed, etc.) and those which concern nutrition. The latter are not part of the DSS follow-up but people mentioned them as they had no idea why they were asked how much rice or millet they were preparing daily since no support came after they had answered.

In most cases, respondents wanted an explanation for each theme; many expressed their surprise regarding the repetitiveness of the follow-up process, wondering: "why do they always ask the same questions?" Underneath lays the other question: 'if nothing comes out in terms of support or at least explanation of some kind.'

The level of understanding of the DSS activities by respondents.

The issue here is to know whether respondents feel they are enough informed about the motives of the survey or not, and in the latter case if they have tried to understand it. In 31 interviews, respondents say they have never been informed. It is difficult to know to what extent they have really not been informed or if they have simply not understood the explanations. This can be the case when researchers take for granted that the way they present their study, even with simple words, is understandable. There are always concepts and ideas that are so culturally and socially embedded that it is difficult for someone completely external to it to understand what the purpose really is about. In respondents' motivation to continue to answer the questions despite their perceived lack of information and understanding, we find the role played by the IRD in terms of health interventions in the area. Their hope to see continuity in such actions is the strongest incentive for collaborating with researchers even if they do not see concrete effects immediately. Some, more patient, think that one day they will be given explanations about the purpose and results and continue to answer the questions. When asked - if you feel you are not informed enough why don't you ask for explanations? - their answers reflect an unbalanced power relationship between the actors of the DSS. First, several respondents said they had asked for explanations to the interviewers without getting any answer.

Interviewers admitted they did not really know ‘what the follow-up questions are used to’ (which suggest that the training interviewers get is not always adapted to local expectations). Other are surprised, admitting they never thought they could ask questions. A more general attitude is to stress the ‘sereer culture’ in which the stranger is welcomed and to whom people will do their best to satisfy his expectations (in other words the person coming to interview people cannot be rejected; this also raises the issue of our standardized consent forms in surveys mentioning that the person can refuse to participate or stop participating if he or she feels embarrassed by the questions). Another general idea is that the importance of the IRD in the area through the past decades also constitutes a strong incentive for the inhabitants to collaborate with its staff.

Many of our respondents expressed a real weariness and exasperation to the questions asked in the follow-up because they do not see any direct consequences. In this sense they highlight the gap they feel between their daily preoccupations and the nature of some questions which concern the same issues but do not seem to bring any change in their condition despite their collaboration to the survey/follow-up. For example, questions related to households’ assets are very badly perceived, one reason being that they recall people from the tax agents’ visits in the past, but more deeply because they feel they show their economic precariousness without seeing any solution coming from those who ask the questions. Such situation makes it difficult for them to give a meaning to these constant surveys and thus increases their lack of interest and wish to take time to answer ‘properly’. Several respondents admitted answering quickly without really taking time to think of the question because they cannot see the benefit of it. Hence, the more the weariness increases, the more the quality of the information collected is likely to diminish.

The restitution format.

Respondents prefer small scale meetings at the level of the neighbourhood or the village depending on its size. Ideally such meetings should include additional activities such as music and songs. In most cases the space where people get together is the village square under the trees. The best period to organize such meeting would be during the dry season when people are free from the agricultural activities. However as in the Niakhar area most of the young adults (men and women) migrate to the cities during this period it is important to plan restitution meetings very carefully in order to reach a majority of the villagers.

Conclusion for Niakhar.

Respondents have clearly expressed both a weariness and exasperation to the DSS research activities which they do not understand. The questions which do not make any sense to them are those related to population dynamics and some temporary surveys questioning about highly embarrassing aspects for these people: their assets and information in the reproductive health domain. In reality it is less the nature of the question that is a problem than the fact that it is not followed by a concrete effect aiming to improve their condition. In general respondents express a curiosity related to these research activities and in that sense the issue goes beyond organizing ‘simple’ result

restitutions; there is a pedagogic dimension to the project by which we should provide a deeper insight on the purposes and mechanisms of the DSS work that people need.

Main findings from the Bandafassi fieldwork

Main reactions to the DSS activities and to surveys in general.

The Bandafassi area is particular due to its geographical remoteness and the yearly follow-up set up by the DSS. When analyzing people's perceptions on the questions that embarrass them most we observe the generalised expression of very strong preoccupations concerning health issues: reproductive and maternal health, children's health, critical nutritional problems, etc. Such preoccupations, common to all inhabitants have the effect of increasing their expectations in terms of health support.

As a result, their rejection and complete lack of understanding is particularly clear with the verbal autopsies: according to one of our interpreters, it is indeed nonsense to "replay the whole film of one's child agony" when no concrete support follows.

Surprise has also been expressed to the follow up questions which come back year after year for several decades. Since all inhabitants do not have to answer, it is less a feeling of weariness which is expressed than a growing lack of interest.

In brief several dimensions of perceptions and feelings appear:

- surprise: why have the follow up questions been asked for 30 years as they do not see direct links between these activities and changes in their daily lives;
- annoyance, lack of understanding with the verbal autopsies;
- lack of interest despite a certain hope that they will get some help, especially in health; this lack of interest is mainly expressed by the fact that they see the visit of the interviewer as a 'habit': *When they come, there are the greetings and then they say they have come as usual to ask questions on demography. It has become a habit.* (Consensus among a group of young men in a Muslim area in a multi-ethnic village).

Such reactions can be related to the system itself which is based on the collaboration between an external interviewer and the local interpreters. All inhabitants are not visited systematically and the fact that it is a local leader who is in charge of answering to the interviewer's questions seems to be part of his functions. What really makes the difference are the verbal autopsies which are the only relation inhabitants will have with the interviewer who has to meet the closest person concerned by the death reported by his informant. Hence for the people in a household, seeing the interviewer approaching is associated to sad events. Some respondents mentioned the case of women running away to avoid going through their child's death with the interviewer because they know why he come to their place:

Some people hide in order not to answer to verbal autopsies (a young man, Muslim, focus group)

Problems with the verbal autopsies. Questions were asked to a woman about he child's death. She refused to answer. We had to ask the health agent to convince her. She said

she didn't want to remember. She finally answered but it was not her will (focus group, men, Christian)

A survey on health care use had been conducted in the area a few weeks before our own visit. The questions asked in this survey remained vivid in respondents' memories, typically those which were similar to those asked during a verbal autopsy.

In general people wanted to be informed on:

- all questions related to health and especially the verbal autopsies
- the questions related to population dynamics
- the institution involved in these activities (they remember persons not institutions and 'INED' did not mean anything to them)
- the principles of a longitudinal follow-up: why doesn't it provide immediate results?

The population's degree of knowledge and the motivations to answer.

Because of the research system design and the remoteness of the area, it was clear that people were far less informed compared to the other sites. For the same reasons people also expressed less weariness to the DSS activities as each household is not systematically visited.

In that sense, the geographical remoteness, the difficulties met in implementing modern communication channels, the very low levels of education, are elements that can contribute to ensure the continuity of research activities as it implies a contact with the 'other' who comes from elsewhere to talk and inform people (one can't refuse to answer his question). This unbalanced communication relationship between the different actors may increase when the interviewer is a Westerner. It is thus interesting to analyze such relationships in their respective contexts as it may provide explanations why in some areas people are more collaborative than in others (on the complexities of the relationships between researchers, institutions and populations in Africa see: Boiral, Lantéri and Olivier de Sardan 1985). We observed strong differences between the sites: in Bandafassi, in many cases, the coming of a stranger is an event; either people cooperate or they tend to withdraw. In Niakhar which is an area much more visited and better located in terms of communication, transportation, etc. people express a stronger feeling of weariness and exasperation. In this area the stranger is not an event; it does not mean he will not be welcomed; but the purpose of his visit will certainly be more scrutinized.

Therefore the relationships established with the local interviewers or interpreters are central to the system. In Niakhar people talked of the interviewers as "sons of our land", "we are from the same kin", "they do their job", and it often was an explanation why they would continue to answer the questions which they know are not *their* questions. In Bandafassi we found similar discourses, showing how people trusted the local interpreters who have been hired by INED for years in order to assist the interviewers. In other words, the populations implied that part of their continued cooperation to the DSS activities was related to their relations to these local interviewers/interpreters who at the

same time act as mediators. As a result, interviewers were also highly in demand for restitution as they are the first to whom inhabitants ask questions and they cannot provide satisfying answers to them.

To the questions related to their knowledge of the process, several respondents said they thought that they were provided no explanation because they were illiterate, and that researchers considered it was thus useless to explain the whole purpose of their work. Again, such attitudes reflect the unbalanced relationship between researchers, interviewers/interpreters and local people.

An idea we found several times was that if people understood better the purpose of the DSS activities they would answer 'better':

If we have explanations it will make things easier to answer. The work will go quicker. We could give more information if we find some interest (a man in a Bedik village, catholic)

There are no embarrassing questions but the questions surprise them because during years they come and ask you these questions. But they never say why they come. That's why some people do not want to waste their time to answer (young man in the same village, Muslim area).

Clearly these two men refer to other surveys. However what is symptomatic to all DSS sites is the feeling that people are constantly surveyed and they do not understand why. At the end it generates a lack of interest in all the activities and thus loose attitudes when answering the questions.

The restitution format.

The format varies depending on the local socio-cultural characteristics (for example Bediks and Peulhs suggest slightly different formats like in Nouna between the Peulhs and Bwabas); however the general frame remains the same in all villages we visited: get people together, no sexual division, either at the village level or at the area level (in villages mixed ethnically); in all cases the place mentioned was the village square and suggestions to include activities to entertain people were made. A consensus was reached regarding the best period to organize such meetings: like in Niakhar it is during the dry season as people are free from the agricultural work.

Conclusion - Bandafassi.

In Bandafassi respondents were less exasperated against the DSS activities, especially the follow-up than in Niakhar. This is explained by two factors: the nature of the research system and the remoteness of the area. On the other hand, these factors increase the unequal relationships between the different actors and the feeling of inferiority people have to strangers. These feelings are aggravated by the population's vulnerability especially in terms of health as their reactions to questions related to health show. Regarding the restitution format, like in Niakhar, respondents suggest an interpersonal and interactive approach with entertaining activities. Thirst of knowledge and entertainment are related and this is certainly a signal we should not neglect.

2- The Burkina Faso DSS sites

The CRSN (Nouna) site

The questions people remember, embarrassing questions and those which do not make any sense.

The questions people remember when they think of the follow-up questions are those related to the source of income, for what people use the money, the household's assets, entries and exits of the household's members, births, deaths, education, and prevention care.

Imagine, your harvest is not good because of a lack of rain; you have no ox and no plough and someone comes to ask you how much you spend every day; it becomes embarrassing (an old man in a Bwaba village)

The questions people do not understand are those related to the household's income, the household's assets and the verbal autopsies. Beyond these questions, it is above all their usefulness, their interest which people wonder about.

Really, they [the questions] do not make any sense if they are not accompanied by interventions that respond to the immediate needs of populations (a man, association leader in Nouna).

Some particular questions give rise to embarrassment as they touch secrets and family memories. These questions are mainly those asked in the verbal autopsies which collect detailed information among the parents of the deceased.

Respondents' degree of knowledge

In general the populations have a good knowledge of the various topics covered by the DSS. However people seem to ignore the reasons for the follow-up questionnaires and they asked: why such repeated surveys? What will the collected information be useful for? What are the objectives of the DSS?

Despite these questions people continue to participate to the follow-up survey and this can be explained by what we refer to as the "symbolic violence" made to respondents.

Symbolic violence to respondents

The follow-up surveys constitute a hope for the populations. Even if they do not understand the purpose of the questions, people hope that these surveys will contribute to the improvement of their life conditions. It is one of the reasons why they continue to answer despite a clear weariness. Other more subtle but fundamental factors must be considered in order to understand respondents' "passive attitude". First, in an environment where populations are vulnerable, the collaboration between interviewers and interviewees are based on domination relationships. The interviewer represents a

powerful institution. Second, interviewers, like in Niakhar, are often the “sons of the land” who conduct the interviews in their own land. This situation creates other kinds of relationships based on the familiarity and gratefulness between interviewers and interviewees. The obligation to answer the questions for the latter becomes a moral and social obligation. The following quote from a young Mossi man in Nouna illustrates this feeling of being marginalised from the research process:

What is the use of all these data you are collecting?

All these questions to which we are answering, what will they be used to?

What are you looking for with your questions? What are your objectives?

In fact it is the meaning of your work we do not understand. We answer (to) your questions without knowing what you are looking for with us.

Tell us clearly, all these questions, what is it for?

Another dimension of “symbolic violence” made to respondents is related to the feeling of inferiority and powerlessness people who are not or poorly educated have when they see the interviewer mastering the skills of reading and writing in their job:

Interviewers come, they write, and they leave. We do not understand anything of all this.
(a young man in a Bwaba village)

In general people want to know what all the different types of questions lead to in terms of results, whether the questions deal with health (and particularly the verbal autopsies), the vital events or the households’ characteristics. In all groups health issues are at the core of people’s preoccupations, whereas the other aspects may be ranked differently in their interests.

The restitutions format.

In the CRSN study area, men and young people insist on the use of the local radio, traditional artistic troops for entertainment; for women, smaller group meetings seem to be more appropriate. The spaces people mention to organise such meetings are religious places, the residency of influential people such as the village chief’s compound. The dry season, like in the other areas in Senegal is the period all respondents suggested to organise the restitution activities as it is the period when people are least busy.

Conclusion for Nouna

Populations continue to participate to the DSS follow-up even if its goals are not clear. Answering to the questions is respecting the other; it is also hoping that the DSS will progressively contribute to improve people’s daily life conditions, especially regarding health. The questions which annoy respondents most are those related to the household income, expenses and the verbal autopsies. It is not really the questions in themselves that are problematic but more the assumptions underlying the DSS. People really want to know, to understand what is going on and why. The appropriate restitution design would

be a combination of personal and interactive approaches associated with traditional practices (local entertainment activities) as well as modern (radio).

The OPO site : the Wemtenga and Taabtenga neighbourhoods

The questions people remember, embarrassing questions and those which do not make any sense.

The themes which mainly retain people's attention are health and education. The questions which are perceived as embarrassing are those related to the household income, its assets and expenses.

The interviewers, who visit us every three months to talk to us, also ask us questions about what we possess in the house. They ask us if we have a television, a radio, a motorcycle, a bicycle, cattle, if inside the house it is cemented or not. Really I must say that these questions annoy us a lot. You know, we have to give all this information without knowing what will be done with it, where it will go (a man in Wemtenga, leader of an association).

Respondents' degree of knowledge

Respondents seem to have a relatively low degree of knowledge regarding the DSS. People know the themes, but do not understand the objectives, the goals and principles of the DSS. They also feel they have not been sufficiently informed about these dimensions when the DSS was launched.

We do not understand the importance of these data. Nobody has ever explained to us the reasons why you do this work of data collection. We answer to please the interviewers. Since they need it we cannot refuse to answer. By answering we also hope that we will get something one day (Focus group, young men in Wemtenga).

In both neighbourhoods there is an important need for restitution as stressed by the supervisor of the Ouagadougou DSS :

I think that all the inhabitants concerned by the DSS need to be informed. We can see two categories of inhabitants: on the one hand there are those who want to know the objectives and the goals of the data collection; on the other hand there are those who are looking for potential concrete effects of these activities. In brief, people want to know the objectives, the goals and the effects.

In Taabtenga, men insist on the household's assets and children's school trajectory. Women focus more on questions related to their matrimonial situation. Young people are more curious to understand why questions are asked about the presence of strangers in the house and the household's expenses. It is important to stress that questions related to housing strongly interest the Taabtenga inhabitants. This area is not divided into plots;

therefore people hope that the DSS activities will contribute in one way or another to improve their housing conditions.

Currently in Taabtenga, inhabitants only think of issues related to plot division in their neighbourhood. All those who come and do not pay attention to this issue are not listened to and people do not give much interest in what they say. (a young man in Taabtenga)

In Wemtenga women pay attention to the questions related to pregnancies, births, attendance to health centers and children's vaccination. Younger respondents are more interested in topics such as hygiene, income, job while men mention the questions related to the household's assets.

The restitution format.

In both neighbourhoods the best way to organise the restitution activities would be in the form of training and information workshops, forum theatre, and radio diffusion. The appropriate spaces for such meetings would be in schools, close to water fountains, associations head quarters (especially for women) and video clubs for young people.

Conclusion for Wemtenga and Taabtenga

In both neighbourhoods, populations continue to answer the questions even if certain weariness appears. In Wemtenga, an urban area, the population's weariness is clearly expressed. Like in Nouna, the questions which do not make any sense are those concerning the household income. In Taabtenga, extremely poor area, populations expect concrete effects for their daily lives from the DSS follow-up. In this area it seems almost impossible to think of doing research without including means that will improve the populations' life conditions. In both areas, populations need to understand what the information they provide to researchers is used to, what are the final goals in the use of these data.

Discussion : the interviewers' perspectives

It was very important to us to get the perspectives of the local interviewers and/or interpreters working permanently in the DSS. They usually have years of experience and were often born in the study area. Therefore they are able to sensitise researchers to problems related to the questionnaires and are also confronted to difficulties in communicating with surveyed people.

In all the discussions we had with the interviewers and interpreters in the different sites, they insisted on the strategies they had to deploy to convince participants to answer the questions whether these were part of the follow-up or of temporary surveys. We are touching here an interdisciplinary field mixing psychological, sociological and anthropological dimensions: how to manage the fact that strategies must be developed to convince people to answer questions? What meaning can be given to the questions asked and how can the quality of the answers be assessed? Interestingly, in most sites (Niakhar,

Bandafassi and Nouna) interviewers told us that as long as there were health care interventions in the area, whether related to the DSS follow-up or not, their work was much easier because the populations could see concrete outcomes of the researchers' presence in their environment. As these interventions started to diminish, their interest also decreased and questions started to rise as their daily living conditions got worse or stagnated.

In Bandafassi one of the two interpreters told us that in the beginning of the DSS activities there were many diseases in the area; therefore any research activity that was medically related was positively perceived by the inhabitants. His problem is that he now participates to surveys which provide no medication; this is partly why people are so reticent to the verbal autopsies. According to him, respondents have lost their interest because no care is provided anymore and they do not understand the goals of the questions. The second interpreter adds :

You can be face to face to a person whom you do not know and you have to ask him an embarrassing question. You have to talk in a certain way, you have to turn around. The problem in such cases is that you must not be in a hurry, people need time to think, they hesitate to ask why they are asked such questions. But interviewers are always in a hurry so they push the interpreters.

We found similar problems and strategies in Niakhar :

Interviewer C (Niakhar) : *...sometimes you are blocked by people's education level, but once you are there with your question you have to deal with it, find a way out. You tell yourself: 'you got me' and finally you push the person to provide an explanation even if he does not want to (...). People have become familiar to the questions. But do they only know what demography is? The questions related to deaths, the verbal autopsies are problematic. People do not understand that they are asked to summarize the death of their child.*

The nature of the relationships interviewers have with locals help them to develop these strategies: either they have kin relationships or simply they were born in the area; and in some cases they play a specific role, like in Bandafassi where the two local interpreters working with the INED interviewers are also two community health agents.

Interviewer A (Niakhar) : *There are familiar relationships with the interviewers which make their work easier with the interviewees.*

Interviewer B (Niakhar) : *Health aspects are now lacking so people say now you are bothering us with questions and you do not bring anything. People are pushed so they do not answer well to the questions. But thanks to the relationships existing between interviewers and interviewees they can get the answers... since there are no returns [he thinks of the health surveys which included free health care and vaccination] the questions are useless to people.*

Their training was another important issue raised by all interviewers and interpreters. They felt that they needed more training, more information about the research process of the DSS in order to better understand what they were doing and why. More profoundly they wanted to be able to answer the respondents' worries and questions about the DSS. This is particularly the case when they interview people with some educational background. In such cases people are less cooperative and ask more questions to which interviewers or interpreters do not always know what to answer.

The second interpreter in Bandafassi mentioned how the slightest changes in the general design of the follow-up (like the coming of a new interviewer) could be disturbing for the people especially if no clear explanation to these changes is provided. Like the interviewers in Niakhar he feels he is not able to provide explanations to the DSS activities and as an interpreter he admits never have had any training to participate fully to the interviews. Also like in Niakhar he suggests that in households where people have had a few years of schooling there is more dialogue and negotiation to get the answers compared to the more remote villages where the populations are less educated.

Such discussions with the interviewers showed their need to express their perceptions about their daily work and the problems encountered. Among these, the feeling of guilt because they are taking the time of vulnerable people without providing any concrete support or at least explanation was often expressed. In Niakhar the discourses were quite radical, interviewers using words such as: *prise d'otage, réquisitionner, pourchasser, s'infiltrer [dans la concession]*.

Interviewer A (Niakhar) : *For example, a woman was collecting water, they came to interview her; when it was finished, the water fountain manager had closed the tap so the woman was left without water [and problems when she came back to her compound].*

Interviewer C (Niakhar) : *In some compounds there can be many people (he mentions one with 200 people). It takes the whole morning, so the person whom you have "réquisitionnée" for the demographic follow-up has lost his morning.*

All interviewers and interpreters admitted that inhabitants had started to feel exploited as they feel they have been spending so much time answering the same questions for many years, some of these being embarrassing as they force people to describe their poor conditions. Therefore, a consensus appeared in our discussion in Niakhar, interviewers saying:

The real problem is not there. They do not care for explanations. We must show with the explanations that the population is gaining something with the surveys. The populations associate the demographic survey with health surveys which have a more immediate and visible effect.

Conclusion :

We should never neglect the fact that individuals are usually curious to *learn*; restitution experiences have already shown it, in particular in the Bwa country with the work of Hertrich and Lesclingand, and in our conversations in the different sites, inhabitants always showed an interest when we provided some simple explanations about the existence of other DSS sites in the world and what could be learnt from the data collected.

In this study we allowed people to talk freely about their experience of a research process (the DSS) they do not understand which at the same time touches different dimensions of their daily lives. We are aware that this increases our exposure as investigators to a series of requests related to the topics of the researches they are involved in (e.g. health care or material and financial support in their daily activities). However our interviews with local people enabled us to raise fundamental questions on the issue of the articulation between research and action. In particular in a context of vulnerable populations, is it logistically and ethically acceptable to ask the same questions over the years through repeated visits without any concrete and direct effect on populations' well-being? Do these "concrete effects" need to be directly related to the research? Indeed one issue with the demographic and epidemiological follow-up is the gap between the long term process of such a data collection and the short term time frame in which populations are embedded. Also, the fact that there is a continuous presence on the DSS site make local people feel that the teams must be aware of their problems and thus should do something, even if it is not related to the aim of the follow-up. It is this paradox that engenders people's uneasiness and exasperation: the fact that research teams are present and, according to them, seem to be blind to their needs.

Respondents' motivations to continue to participate to the surveys can be seen as indicators of the importance of their needs and of their vulnerability. Respondents feel "trapped" by these needs to the point that they continue to answer questions which do not make any sense to them, and sometimes make them angry (the verbal autopsies in particular). Also populations' weariness of being constantly surveyed and asked similar questions seem to increasingly lead them to answer superficially, sometimes in an erroneous way to quickly get rid of the interviewer. It may be objected that statistically factual events can easily be checked and control mechanisms can be developed. It is at this level that the ethical dimension must be considered: is it a good reason – the technological control of potential errors and inconsistencies – to continue the research process without considering the growing uneasiness of the populations? Another issue is to what extent such a situation can worsen in the future. With no systematic evaluation of interviewees' perceptions on the DSS activities across time it is difficult to assess to what extent attitudes to these activities have actually changed. We can certainly rely on the positive discourses of some respondents who have in their memories the improvements in health within their community whatever the reasons of these improvements (they can be the result of the DSS activities as well as of NGO interventions). Many of our

respondents were worried because of the decrease in health care support and interventions and were thus less interested to collaborate in the interviewers' work.

In general the populations in each site – to a lesser extent in Ouagadougou which is an urban site and as such bring together people of various backgrounds and levels of knowledge – are equally interested in knowing the results of the different researches conducted in their area and getting more information allowing them to better understand the meaning of the DSS research process. Regarding the restitution format, restitution in a personal and interactive mode is clearly favoured. They suggest bringing the whole village or neighbourhood together after an official announcement several days before. These meetings must be informative and entertaining. Among the communication tools which are known to combine such characteristics and usually succeed in stimulating interactions the following were mentioned: sketches in forum theatre activities, commented slide shows, traditional music activities, etc. In some areas where the radio is intensively listened to (in Niakhar for example), announcements are possible including special interviews with the research leaders. In all cases to operationalize restitution activities in the near future, it is necessary to:

- establish a collaboration with the researchers who are responsible for the different components of the DSS activities so they can communicate their main results to the team involved in the restitution process
- get back to the different sites in order to determine in a definite way which communication tools should be designed;
- operationalize these tools: the logistic, training, scheduling;
- conducting the restitution activities
- evaluate this work before writing a final document intending to be a protocol to be followed by the research teams in the future

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