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Paper: "Reporting back results in Health and demographic surveillance systems (HDSS): an ethical requirement, a strategy for improving health behaviours or both?" (by Nathalie Mondain, University of Ottawa, Valérie Delaunay, IRD, Valérie Ouédraogo, University of Ottawa)

Reporting back results in Health and demographic surveillance systems (HDSS): an ethical requirement, a strategy for improving health behaviours or both?

Final paper

The context of the study

In 2014, the Niakhar Health and demographic surveillance system (HDSS) celebrated its 50 years of implementation. A scientific symposium was organized in Dakar, the capital city, which brought together researchers, technicians, interviewers and invited guests to share their respective professional experiences as well as more personal stories. Following this meeting, 3 days dedicated to report results back from the core research themes addressed during the past decades – population, health and environment - were scheduled to take place in the HDSS site with local representatives of the population. Researchers, fieldworkers and local key informants gathered together during four months to design the event. Beyond its ethical dimension, this first experience of organizing a major event to report results back at a larger scale than solely local authorities and decision makers appeared as a unique opportunity for both populations and researcher to talk about the research projects conducted in the area for over 50 years and the related findings. More specifically, we argue that reporting back scientific findings is likely to have two main effects. First it may improve (or create more) collaboration between researchers and participants (here HDSS residents) in the process (preparation, planning, implementation) of designing the research projects. Second, for the populations included in the demographic longitudinal follow-up or directly concerned by a more specific research project , the exposure to understandable information about the findings may be an incentive for them to integrate those to their daily lives, in particular when related to health.

Main issues

Why report research findings back? Several objectives can be followed, all, to some extent, related to ethics. However, before exploring both theoretical considerations and empirical studies addressing this particular issue, it is necessary to provide a brief description of what is a HDSS and how it works as it raises both methodological and ethical issues by its specific and unique research design before exploring the different avenues that ground the efforts made in reporting scientific results back using a participatory approach.

What is a Health and demographic surveillance system (HDSS)?

The main objective of a HDSS is to conduct a longitudinal demographic and health follow-up within a geographically circumscribed population in a rural or urban area. At the implementation of a HDSS, a census is conducted to identify each household as well as the number of residents composing it. Once this baseline established, the longitudinal demographic and health follow-up starts, with regular visits (usually one or more per year) in each household where one member, generally the head of the household, is mobilized to update the demographic and health information since the last visit. The frequency of the visits depends on the objectives of the project as well as on the financial means available, both being usually related. In addition to the demographic follow-up, a HDSS also constitutes a research plate-form open to various projects under the approval of the coordinating team and in collaboration with the HDSS research staff. Consequently, the residents of such sites are solicited to answer the standardized questions of the demographic follow-up on a regular basis as well as to participate to surveys and other studies on related issues conducted among a sample of the HDSS population.

HDSS have started to be implemented since the early 1960s (mostly in Asia and sub-Saharan Africa) as is the case for the Niakhar site (Delaunay et al, 2013). The main motivation to implement a HDSS is to measure the impact of health interventions among the population under study, so most of the scientific approaches used are health oriented with demographers or other social scientists collaborating with physicians and researchers in public health. However, some sites, due to their long lasting existence (for example Niakhar in Senegal or the Navrongo HDSS in Ghana), have opened to other fields of research to explore more socio-anthropological aspects of the populations at stake in order to provide more depth in the understanding in demographic and health behaviors and change (Madhavan et al, 2007).

Several actors are involved in a HDSS, and beyond the residents and the researchers, interviewers and other field workers constitute a key group if not ***the*** key informants and facilitators. In rural HDSS such as the Niakhar site, most of the field workers in charge of the demographic follow-up are natives from the villages and in any case live there with their families. Other research staffs – interviewers for punctual projects, facilitators, interpreters – are generally hired locally based on their reputation gained by working with various research teams across the past years. Therefore the usual design of research projects lead to the following relational dynamic within the sites: a researcher visiting occasionally the site or the population sampled for a more specific study, one or more local fieldworkers directly in touch with the participants of the study. Of course the researcher's presence and frequency of visits will depend on various factors, including the discipline at stake (an anthropologist is likely to choose a constant immersion with the population compared to a physician for example), the researcher's status in the project (is the researcher alone or is the project based on a team where collaborators can share the tasks for example?), etc. In any case, unless the researcher masters the local language, the local field-staffs remain key intermediaries between him-her and the participants. This leads to a paradoxical situation where research activities are constantly present through various forms of data collection but not necessarily the researchers themselves. We argue that this lack of immersion from the people leading the projects is likely to shed confusion in residents' perceptions of who is responsible for the activities in which they are involved and thus can lead to misunderstandings regarding certain research practices. One regular example provided by the Niakhar field workers is the blood sample undertaken in some medical projects which has been interpreted as "the white man is taking our children's blood to sell it".

Therefore, HDSS face complex methodological and ethical challenges. Among the latter, an issue that has started to be explored extensively in different settings relates to the reporting back of results to the communities. One motivation for these initiatives is based on the argument that participants express weariness and sometimes reluctance to participate due to the constant solicitation they are submitted to with no clear understanding of the purposes of such intense data collection processes. Therefore a preoccupation has emerged among HDSS researchers in the mid-2000s to go beyond the Health Ethical committee board's agreement regarding medical oriented project and improve the respect for ethical principles for all kinds of research, among which the respect for justice and inclusiveness. In this paper we will address the specific issue of ethics in HDSS and show that beyond the application of the principles set by the ethic committee boards, a more contextualized and thus participatory approach should be used to ensure that the participants will be respected as research subjects. We hope that our reflections on this topic will set the base for a more open and enlarged discussion on the ethical dimensions of research practices in the social sciences and how reporting results back to participants may constitute a way to reconcile the problems related to informed consent, participation to a research and its potential benefits. In the case of HDSS in particular but more generally in the context of developing countries, one challenge is to address the contradiction between "fundamental" research, "applied" research, and participants' expectations or experiences.

Reporting scientific results back to lay people: beyond the exclusive ethical requirement

A project conducted in 5 HDSS sites in Senegal and Burkina Faso in 2006-2007 focusing on the ethical issues raised by these particular research platforms, showed the need for residents to have more information on the whole research process, from data collection, management to the final results, and a better understanding of their gains in participating to such systems (Mondain and Bologo, 2009 and 2010). For example, blood samples involved by some medical studies or clinical tests are often not well accepted by the populations leading to intense negotiations between them and fieldworkers. Verbal autopsies[1] also constitute an important issue with respondents being extremely reluctant to participate and fieldworkers often emotionally moved by the distress of some respondents, especially when they have to conduct a verbal autopsy with a mother whose baby or young child has died. Hence, reporting results back could fulfill an important ethical requirement by clarifying the misunderstandings or feelings that may occur first at the implementation of a HDSS or at the start of new survey when participants are asked to give their formal consent, and second, during the following years while the demographic follow-up is ongoing. Addressing populations' expectations and understanding may thus be a key issue for the continuation of these programs especially as HDSS provide researchers with a longer time frame to plan their agendas along the lines of global health and development objectives aimed to be applied locally.

In the specific case of HDSS, reporting results back have two major advantages. A first one is that it may improve the contacts and to some extent the collaboration between researchers and participants. As

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[1] Verbal autopsies are used to identify the cause of death of a person in countries where such information is not systematically collected, thus complicating the tasks of health actors to better target groups at risks and specific illnesses. The procedure consists in interviewing a close member of the family or any other person who had a close relationship with the dead and get as much detailed information as possible on the context and conditions of the symptoms and agony.

mentioned earlier, in a HDSS, residents are likely to have high expectations from the long lasting presence of research teams in their environment. However, it is not the purpose of HDSS to translate their results into action; rather, the findings are usually transmitted to decision-making actors. Therefore a misunderstanding of the researchers' role by the population is common and opportunities for these two groups to share ideas and questions could be beneficial for both: for the researchers as it may give them new orientations to local preoccupations they hadn't considered; for the populations as their better understanding of the research process may motivate them to participate and even provide other insights to researchers. Hence the ethical requirement of obtaining the informed consent through *a posteriori* information on projects could be reached: more aware people will make them more active for the next project, ask more questions, etc.

Another advantage of reporting results back is that participants, by being informed about the findings and implications of those in their daily lives may actually modify their attitudes and behavior accordingly. In that sense, reporting results back may act as a sensitization workshop even if it is not officially its purpose. In that sense the ethical principle of justice could be achieved. This being said, health practitioners and researchers would argue that this is the scope of knowledge transfer. However, knowledge transfer is mostly meant to target practice settings and decision makers even if the ultimate objective is to reach the greater public (Siron et al, 2015). Our perspective is both less and perhaps more ambitious: less ambitious because we are not claiming that reporting scientific findings back are meant to inform decision makers in order to influence their choices and actions; some of the findings at stake do not necessarily lead to concrete applications. Our ambition is first and foremost to inform research participants directly since the usual design of knowledge transfer activities often does not include this group. This seems to us a more ambitious approach in terms of logistics and of how to formulate things in such a way that it becomes both understandable and socio-culturally appropriate to the majority. By reaching the populations "first" we are nevertheless influencing their attitudes and perhaps behaviors regarding the fields concerned, mainly health but also environment and population change. In that sense, reporting scientific findings back to participants may complement knowledge transfer activities with which it should be articulated.

Madhavan et al (2007) had already pointed to the need of a more participatory approach in HDSS. However, adopting a participatory approach may represent a challenge in a context where the key research actors are often not skilled in that type of methodology and thus reluctant to use it. In addition, both field staffs and local residents may not be active in that process at first since they are not familiar to it either. However, by reporting findings back to a wider range of actors involved in the research and not only local authorities and decision makers, and by involving field workers and key informants within the population in the design of these activities, researchers can get a better insight of how their activities are perceived by the participants and thus how it may influence the way they answer to questions. Getting these perceptions could thus offer the opportunity for researcher to improve their explanations of the research process and in some cases to adapt their project design and analytical framework (Massé, 2003; Olivier de Sardan, 2014). In this perspective reporting results back could be seen as a pedagogic approach where all actors can share their ideas and understanding of the research process

(Bergier, 2000). As such we argue that reporting back results to a broader audience contributes to a better appropriation and use of research findings by all actors at different levels: individual, household, local authorities and decision makers.

Such a perspective refers to a certain extent to what Olivier de Sardan (2014) formulates as the "citizen argument" where reporting research findings back in more politically oriented research brings the topic to the public debate. We argue that this could also work for health and even environment oriented research: by "citizen" we consider the capacity and desire for any individual (local teacher, health worker or any other key informant) to inform and advocate for a change in behaviours, new policies or programmes because of this person's sense of citizenship beyond his-her social or political status. This perspective could be seen as the extension of the idea of information exchange rather than transfer of knowledge related to health behaviour and attitudes to research practices in that particular domain (Gravois Lee and Garvin, 2003). Therefore, reporting back findings from studies that address central dimensions of people's daily lives such as health and environment, should involve the larger population in a participatory approach so that the actions implied by the research become better integrated to the local socio-economic and cultural realities.

This being said, several questions arise: to whom should the results be reported back? If targeting the entire population is a good idea, when it reaches over 40,000 people spread over 30 villages as is the case in the Niakhar HDSS, it can become complicated. In that case who should be selected to participate to such activities and by whom? Another issue relates to what should be reported back: this is especially salient in the case of long lasting HDSS where research projects in addition to the longitudinal demographic follow-up have led to a huge accumulation of data. Clearly not all the results can (and even should) be reported, but on the basis of which criteria and by whom the selection of results should be done? Finally, what are the appropriate communication channels and tools that will contribute to make research findings understandable to socially and culturally diversified actors?

Drawing from a recent experience in the Niakhar HDSS where three days in February 2015 were dedicated to report scientific findings back accumulated over the past 50 years since its implementation, we address these questions and open the discussion on the outcomes of this innovative way of interacting between the various actors involved in the site. More specifically we are examining to what extent the communication tools used to reach the population were adequate, whether the content covered topics that interested them or if some themes were missing. We also look at the participation to these days has modified participants' perceptions and understanding of the research undertaken in the site and the scientific process overall from data collection to diffusion. Finally we are attempting to assess the extent to which participants are themselves trying to disseminate the information and as such contribute to the sensitization of non-participants.

The design of the "Journées de restitution"

Both the designing and the running of the successive activities during each day have to be understood as a process. A process in building a frame for the activities and what was meant as a pedagogic process of making the "path to results" understandable, from data collection to the dissemination of results and potential interventions. After briefly portraying the Niakhar HDSS, we describe the process followed to select the participants to the days, the findings to be reported back and design the communication tools as well as the main issues we encountered during that process.

The Niakhar HDSS located South East from Dakar in Senegal was implemented in 1962 by ORSTOM which became IRD (Institut de recherche pour le développement) in 1998. In 1962 the HDSS was composed by 8 villages only. Since 1983, the site was enlarged to 30 villages, its population reaching over 44,000 residents in 2014. The frequency of the visits has varied across time from periods of weekly follow-ups when important health projects were ongoing in association to large vaccination programmes in the end of the 1980s-early 1990s to periods with fewer visits (3 times to once a year). This highlights one of the main limitations of these scientific plate-forms as activities are increasingly depending on external funding.

In 2014, the Niakhar HDSS leaders with the collaboration of the IRD's local staff organized a scientific symposium to celebrate 50 years of research in the study area. This symposium was followed a year later by three days *in situ* where researchers in the three main domains covered by the HDSS follow-up and additional studies - population, health and environment - shared the findings identified as most important with various representatives of the population.

For logistic reasons tightly related to the contemporary scientific research system constraints, namely researchers' agenda and funding, it was agreed that these days would constitute a first step in a general process aiming to report research findings back in each village and to all the residents. In this first step a sample of participants representing various socioeconomic domains related to some extent to the topics addressed during the days was selected in each of the 30 villages of the area with the assistance of the local fieldworkers in charge of the demographic follow-up, living in the area and most of them native from there. So in a way, these days appear as a compromise between the conventional knowledge transfer activities gathering together decision makers and practitioners and a more participatory process of knowledge exchange between all actors, including first and foremost the populations subject to the research projects. Each day took place respectively in one of the three main villages of the study area gathering approximately 100-120 persons, and covered the three topics through the following communication channels: a theater performance, a slide show commented in the local language (Sereer), and a period of discussion between the audience and the researchers, moderated by a researcher and a local fieldworker.

To organize these days an organizing committee was set up with a coordinator, five IRD researchers including the HDSS leaders, and two of the local field workers in Niakhar in charge of the demographic follow-up.

Get back to the different dimensions that have led to the specific design of these three days - who (i.e the sample), what (the themes), and how (the communication tools) – we discuss the limitations of what was supposed to be a participatory process and the difficulties to use such an approach in a research environment still strongly marked by a domination of quantitative and often positivist postures (Riley, 2003).

The sample.

The participants were selected based on their occupation and status in the community and according to their belonging to one of the three main health dispensary located in each of the three main villages of the HDSS area. Local field workers in charge of the demographic follow-up were asked to participate in this selection and two of them in a team of 7 people were included in the organizing committee. So participants were identified a priori on the basis of researchers' own criteria discussed with the field workers. To complement their advice, one key informant was identified in each big village where one of the days was to take place to assist the coordinator in identifying more localized personalities and contact them. Hence, a series of consultations took place during the 4 months prior to the event where the coordinator, assisted by the key informants and the demographic follow-up team visited as many villages as possible and set up a list of guests. In addition meetings were organized in each of the three main villages where chiefs from the neighbouring villages and other representatives of the participants were invited to get the information and also share with the coordinator their preoccupations, what they wished to see covered by the reporting back activities and also who else should be invited. On the basis of these information, the coordinator with the field workers after sharing with the other members of the organizing committee were able to improve the design of the days pointing to some key issues that had to be covered in addition to the formal considerations which will be detailed below.

As expected, all health occupations were represented, which means in this particular area: the head of each dispensary, community health agents, midwives, nurses, and *bajenu gox*[2]. Teachers from the primary and secondary schools were also represented with their respective directors. Women's groups were identified and a number of them represented by one or more of their members. Also, farming associations specialized in agriculture and animal breeding were contacted. Finally all village chiefs with one or two of their councillors were invited. Most of the field workers hired on a temporary base by IRD staff or their collaborators were also asked to participate. Finally, religious leaders were also invited.

The themes and findings covered.

Through the preliminary consultations with the local representatives a consensus emerged that people needed a better insight on the "path to information": what are the different steps from data collection to the findings and potential actions? Interestingly, despite the fact that there was a consensus among the organizing committee members that these days were a first step towards a more direct share of information with the populations rather than exclusively the local leaders and authorities, inevitably,

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[2] A bajenu gox (sereer) is usually a woman who is in charge of sensitizing women in her village or neighbourhood depending on the size of the village on various reproductive health matters. Each bajenu gox has to write a report and hand it to the midwife of the dispensary she depends on regularly and these reports are sent to the health district.

each researcher wanted to highlight findings that were important according to *them* with little considerations whether these would interest people or not. However, everyone agreed, and it was also under the pressure of the local field-workers, that "problematic" topics such as blood sample procedures should be included in the themes covered during the days. Indeed, one of the main motivations with the days for them was that it could facilitate their daily work by making residents more willing to answer the questions and participate as they become more aware of the reasons why certain research procedures are undertaken.

Clearly the task for the researchers in health was the easiest: everyone in the area, like elsewhere in the country, is preoccupied by health issues. Interestingly, during the consultations, one idea that was expressed by several people was that researchers were neglecting adult health and remained too focused on children's health despite its significant improvement noticed by all villagers across years. People who expressed this perception and preoccupation were encouraged to keep this issue for the discussions during the day and bring it up during the period dedicated to questions at the end. Clearly this preoccupation is related to the phenomenon of population aging due to the improvement in children's and adults' health and the related decrease in mortality.

One challenge in presenting the various findings was to highlight the relationship between many of them. The example above speaks for itself: health improvement and spectacular decrease in the under-five mortality since the implementation of the HDSS, in other words a reconciliation between demographic data with findings related to causes of deaths in this case. However, and this is another challenge, how should the role of the HDSS be presented? In fact such improvements are only indirectly due to the scientific work accomplished by generations of researchers in the area; interventions are not under their responsibility although by their results they influence these. Beyond the findings this is one of the main mechanisms that was aimed to be clarified during the day.

Finally, regarding environment oriented findings another challenge appeared when selecting them and trying to build pathways with the other domains. Contrary to most of the health oriented findings and more like demographic patterns, these results tend to describe the current situation in Sahelian rural areas and how locals adapt to it by cultivating new or older crop, devoting more time to cattle rearing or market gardening. In general these findings refer to changes and adaptations that are part of local peasants and farmers' daily strategies and constraints. This being said, it is of course always interesting to share such findings as it could lead to discussions where new research avenues could emerge, simply by letting people express their preoccupations. For example many representatives of peasants and farmers in our consultations mentioned their wish for more research on diseases attacking crops or animals.

Were these issues taken into account by researchers while designing the synopsis for the three days? The evaluation conducted a month later provides some guidance to discuss this point.

The communication tools.

From the beginning a consensus emerged within the organization committee that forum theatre shows should be used. Usually performed in sensitization programmes, forum theatre can be an extremely powerful tool to both disseminate a specific message and to make people react (there is an extensive literature on the use of interactive theater in health and development. See Morrison et al, 1991 for a more general reflection on the use of that media in West Africa and more recently research undertaken in different contexts and on a variety of topics from aging to reproductive health, addressed to service providers, teachers and populations). In other words it is an incentive for the audience to participate actively to the performance by expressing one's opinions and sharing one's experiences in the domain at stake. As such it could be extended to other purposes, not only sensitization. In the specific case of HDSS for example, where many participants, residents, wonder about the longitudinal follow-up and the additional punctual surveys on more specific and often health oriented matters, forum theatre sketches were seen as an opportunity to illustrate the questions participants have during the interviews and how the task of the field worker could be complicated by residents' attitudes. The purpose of the theatre performance was thus to make the atmosphere lighter, remove some of its formality, encourage a dialogue between the main actors – populations, field-workers and researchers - and also ease the transition to the slide show where findings are described.

The slide show was designed following a detailed synopsis (appendix 1) and almost entirely composed by photographs taken in the area, some older and representing past projects, other more recent showing the main changes occurred since the HDSS implementation. More than 60 photographies sampled in the IRD database and also taken for the purposes of the three days by a professional photographer were gathered in a power point file to present de main results in demography, health and environment. For each slide a small text written in French and then translated into Sereer, the local language in the Niakhar area (see appendix 1). From the start, a gap appeared in this way of presenting the results that could not be addressed due to lack of time and funding. Indeed, the comment for each slide should have been recorded in the slide show rather than being said *in situ* by the two field-workers participating to the organization of the event. Because it put a lot of pressure on the two commenters who were not used to that tool, the comments were said very quickly while at the same time one fieldworker decided to add more concrete explanations thus lengthening considerably the whole show. However, as the evaluation will show, what appeared as not appropriate for skilled researchers embedded in their own communication biases, seemed highly appreciated by the audience.

Finally, after the slide show a period open to questions from the audience was scheduled. This period was meant as an incentive for participants to directly address their preoccupations and questions to the researchers present in the audience. The consultations that had taken place during the 4 months prior to the event were supposed to have prepared the participants to formulate their questions and convinced them of the importance to ask them. However, that dimension of the reporting back process was disappointing with few people taking the floor to question the researchers, at the exception of village chiefs somehow feeling obliged to have a word in public. The evaluation will shed some light on the reasons why participants were not inclined to intervene.

A month after the event, three groups of participants totalizing 80 people were asked to evaluate the whole process. These groups were: 1) the researchers who were part of the organization and those who were invited for the event; 2) most of the fieldworkers involved in the design and organization of the days; and 3) a sample of participants to each day. Using a qualitative design we addressed three main dimensions: first, what were the questions and discussions the participant had before the day about the research conducted in the area on similar topics? Second, were the topics addressed during the day of interest for the participants? Third were the communication tools appropriate and able to feed or awake participants' interest? Finally, did the participant have discussions with other people about the event once over and did they disseminate some aspects addressed during the event?

The 50 qualitative interviews and 30 open-ended questionnaires that were conducted to cover this evaluation by a local fieldworker and transcribed from Sereer to French by the same person are currently being analyzed, using the NVivo software. In the following section we present some preliminary results.

Context of the evaluation

Our evaluation process was designed to capture the perceptions and suggestions from a sample of participants to each day. Three interviewers were hired, respectively in charge of one sector, each sector corresponding to one main village and those depending on its health dispensary, usually around 10. The table below describes the characteristics of our sample in addition to the different approaches we used to gather similar information. All interviews and questionnaires were further typed by the same person based in Dakar.

Table 1: sample characteristics

	Ngayokhem sector (24th February, 2015)	**Diohine sector (25th February, 2015)**	**Toucar sector (26th February, 2015)**
Approach used	Qualitative interviews Recorded and transcribed by the interviewer	Qualitative interview Written notes and transcribed by the interviewer	Qualitative questionnaire filled by the interviewer and handed for typing[3]
Village chiefs and their councillors*	2	5	8
Teachers, school heads, etc.	3	2	4
Health agents**	6	6	9

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[3] 4 additional qualitative interviews were conducted by another field-worker with two of the organization committee researchers.

Religious leaders***	1	5	1
Women's groups representatives	1	4	5
Agriculture and farming groups representatives	1	4	2
ASC – Association culturelle et sportive (youth, cultural and sports activities)	2	1	3
Local political advisers	2	1	1
Total	18	28	33

*Among this group we also included field workers hired by IRD and living in the area and people working for administrative although non political institutions

**Within this group we find different actors: heads of dispensaries, nurses, community health workers, and bajenu gox a sereer expression referring to women doing sensitization in their community on reproductive health matters essentially.

***Both Muslim and Christian. If the Muslim religion is dominating the Senegalese religious landscape, the Sereer are characterised by a significant Christian influence dominated by the Catholics and more recently new religious communities such as "Les Assemblées de Dieu". However, this fairly traditional society (in the sense that despite people's mobility and access to modernity, they remain strongly attached to the land and their kinship ties) still cultivates its strong animist beliefs and practices leading to an interesting mixture with the monotheist religions.

Each sector has its own characteristics despite the fact that it is located in the same area referred as the Sereer-Siin region where an ancestral agricultural and farming tradition and culture has lasted until the contemporary period. Another common feature of the whole area is the intense circular seasonal migration to cities, mainly Dakar for young and older adults in search for additional income as agriculture is not sufficient to sustain a whole family anymore. These circular migrations have considerably modified individual behavior, especially regarding marriage and family building. However, perhaps due to deep affective ties to their homelands, Sereer people keep their traditions and ways of life ongoing as much as they can; for example in the Diohine sector where Christian religion is dominant combined to animism, the rituals surrounding boys' circumcision remain vivid. At the other corner of the spectrum the Toucar sector appears as more diversified with a significant Wolof community or Sereer who have embraced the Wolof culture. Toucar is also at the crossroad of different routes leading to close towns and cities in addition to the main road to Dakar. Finally Ngayokhem seems to be the sector more concerned with agriculture and environment, which could simply be related to the focus of researchers specialized in these fields for a long time and who have spent extended periods in the field with peasants and farmers. In other words, each sector has its own 'history' which may constitute one key of interpretation should any significant difference within the discourses of the residents be related to their respective belonging to one sector or the other.

It is important to consider how each day went on. In Ngayokhem, the first day, the process was somehow tested. The theatre performance faced some logistic difficulties, the slides and the comments said in Sereer were not well articulated to each other as the commentators were not sufficiently trained yet. So the final parts, the question-answer period was used extensively to clarify points and thus generally well appreciated by participants. As the days went on, the theatre performance and the slide show were considerably improved and had a great success as the question-answer period became less dynamic and essentially expressed either acknowledgments by the local authorities of the work accomplished by IRD or participants' complaints and expectations from IRD's current and future activities. It is worth noting that the third day that took place in Toucar was disturbed by a sand storm which made it necessary to move the whole meeting in a closed building rather than being held outside. As a result many people who wanted to assist didn't find space in the room and had to stay outside; trying to capture what was going on from the windows.

In addition to these 79 interviews, 10 interviews were also conducted among local field-workers, those from the demographic follow-up team and some hired on a more temporary basis for other studies, and 6 researchers, 4 who were part of the organizing committee for the 3 days and 2 who were external.

The interviews are analyzed using a thematic content analysis framework based on a codification grid entered in an NVivo project.

Participants' perceptions of the content and the communication tools

The content.

The results show that for most of the participants the fact that the content covers the three domains (health, demography, and environment) is what made the three days exceptional.

In particular, participants were extremely satisfied with the fact that the issue of blood samples and clinical trials in certain research projects was addressed. These activities have conducted to strong opposition from several residents and continue to do so despite intense sensitization from local field workers and increased education among the population. Because most people do not fully understand the research process, from data collection to final results and in addition consider findings as being individual thus expecting more personalized reports, a rumorregarding blood samples is that IRD is selling them for lucrative reasons. Such a belief in addition to the symbolic meanings of "taking blood out of the body", especially from children is so embedded that researchers and physicians still face huge difficulties to convince the populations and their authorities to accept to participate to the tests. Clearly, the fact that this issue was clearly and directly addressed improved participants' understanding of these research and medical processes. This came out almost in all interviews and in the three sites. This illustrates the gaps occurring when reporting findings back solely to local leaders and decision makers, excluding the 'average' population and/or its representatives. During these days, what was innovating was that the local village residents were represented by a variety of people in various fields, health, education, women's groups, youth associations, farmers and agricultural groups, all directly concerned as well by these tests since they are residents in the HDSS.

Another innovation was the inclusion of research findings in the environmental field. Despite a huge amount of activities conduct by the IRD research staff for decades; most residents were simply not aware of these, unless they were part of the project. This can be explained by two reasons. First, populations were and continue to be preoccupied by health and particularly children's health. And in fact, HDSS were initially essentially focusing on child mortality and health before including a wider range of research areas both in the longitudinal follow-up and by welcoming a diversity of research teams from different disciplines. With the significant improvement of child and under-five mortality levels and consequently population's aging, preoccupations are increasingly turning towards adult health which has not yet become a main focus of health researchers. Second, findings in environmental studies is so embedded in people's daily lives that it does not necessarily appear as "research results" but more "facts" that the majority is aware of. For example, the lack of rain leading to droughts and bad harvest and as a consequence, peasants' strategies to innovate and find new ways of surviving is well known by most residents. However, becoming aware that IRD researchers are interested and conduct an increasing number of research in these domains has clearly surprised participants and has led to their hope that IRD would "find solutions" for their farming problems as they think it has for their children's health. In that sense, reporting findings back to the populations must be done with great caution as the risk for increased expectations from people might put researchers in delicate positions. However, on the other hand, because it also encourages a dialogue between populations and research teams, it might also contribute to lower or clarify populations' expectations with the explanations they get as well as provide new or more precise research orientations for the environmental scientists.

Other reactions were more common to IRD staff such as the acknowledgement of children's health improvement and the direct link between that and the projects conducted in the site by the residents. This has always been a complex issue as in fact IRD is essentially producing health and demographic (and more) data that is meant to guide health decision makers but it does not intervene directly. For people having witnessed the teams circulating around in coordination with vaccination programs it is extremely difficult to disentangle the respective roles of the various actors at stake. Therefore, for some of them, it came out that they appreciated to get some clarification of who IRD actually is and what is its 'real' mission.

The communication tools.

From the three communication tools (theater, question-answer, and slide show) most of the participants have found the theater as a good tool because this was understood as an interactive tool. So like one participant said "it is an ice breaker tool and it gives the message that IRD is looking for a way to communicate <u>with</u> the population". The slide show is seen as a tool which permits participants to remember about some studies, so like some historical event that the actors are sharing together.

However some participants have found it as well as the question-answer model a little bit 'too pedagogical'.

Table 2: Appreciation of the different communication media by the participants

	Theater performance	**Slide show**	**Question-answer period**
Positive appreciation	Very informative Ice breaker	Remembering some studies Showed the environmental studies	Complemented well the questions they still had after the theater and slide show
Neutral to negative appreciation	Somehow a unidirectional tool which doesn't allow the participants to be involved so they can express their critics about their experience of being permanent "research subjects" of IRD for such a long time	Too long Not always easy to follow	Everything was clear so not useful Too shy to talk in front of many people Lack of time to ask questions and talk
Observation	Consensus in all interviews and sites	Recalls investigators' presence in the research processes	Case where several women did not dare to intervene – some asked for separated events

Interestingly, the appreciations participants from the three sites had on each of the communication tools used were generally very different from those the researchers present in the audience had, including the members of the organising committee. This remark is important because it somehow confirms our hypothesis that often, despite efforts made to report scientific findings back to 'lay' people, or at the start of a research informing participants to get their consent, the information are not understood as such by those to whom they are addressed.

Hence, for example, the theater performance was essentially seen by researchers as an ice breaker because it was showing well known situations by residents in a funny way: the field worker entering a compound with his questionnaire and being asked silly questions, reactions to blood sample tests, etc. The theater performance ***was not meant*** to inform or explain anything, on the contrary it was supposed to highlight the questions populations have and thus make the transition to the more explanatory purpose of the slide show. Unexpectedly, the theater performance was in fact almost systematically considered as being very informative, making clear what the IRD is doing and that blood samples in particular are not meant to be sold and are made for populations' well being. Thus, surprisingly to most of the scientific organizers, it was through the 4 sketches that the audience could better grasp the research objectives and pathways from data collection to the final results and potential action although no explanations were provided during the performance.

The slide show, on the other hand, was designed to clarify some findings in particular the 'path' from data collection to the results. While designing it, researchers made efforts to avoid graphs and tables, exclusively using pictures from the villages and selected situations and projects that were supposed to shed light on the worries and questions populations had on their purposes. They also tried to follow the usual rules of not 'talking too much' on each slide in order to not overwhelm the audience with information. After the first day where both a researcher and two Sereer fieldworkers were involved in the dissemination of the slide show, it was decided that the two Sereer speakers would take more control of the whole presentation. Consequently they spent much more time explaining each slide with lots of details and highlighting the role played by IRD insisting on its scientific rather than intervention purpose. Through informal discussions between researchers these comments appeared far too long, overwhelming for the audience who seemed to lose interest after a long period of listening to the comments while watching the photos. In fact, after examining the different interviews, it appeared that a majority was extremely satisfied with the explanation provided during the slide show; these constituted an "added value" to the theater performance and clearly highlighted the importance of environmental studies which was a discovery for a majority of the audience. In other words, the more time was spent explaining in their own language the purpose of the various types of projects and researches conducted for decades in the area, the more people understood and the more satisfied they were.

Finally, regarding the question-answer period, a significant difference in researchers and participants' perceptions also appears. For researchers this part was expected to be the most "participatory" where participants would be able to share their preoccupations and ask questions directly to the researchers, something fairly unusual for both groups. However, researchers felt it was the most "disappointing" part, where few questions showing participants' curiosity on the results and need to deepen their understanding were asked. Rather, it seemed to them a long litany of either acknowledgements for the "wonderful work" accomplished by IRD for decades and/or requests to provide some assistances in specific domains, especially agricultural or to start projects on other topics such as adult health and also animal breeding. Nevertheless, in the interviews, most respondents said that they liked this possibility for exchanging ideas with the IRD staff, but that in general the theater and slide show had been so informative that they didn't have any questions or that the questions asked by others complemented well what they wanted to know. It is worth noting that several women said that they were not comfortable to talk in front of a big audience and that they would have preferred to be in smaller groups, just among other women. Finally, other respondents said they felt they were lacking of time to ask their question. This could be understood in different ways. It is true that some questions were in fact long comments said by local authorities such as village chiefs or religious leaders. Also, some 'real' questions led to long answers by the concerned researchers. And both the theater and slide show took a quite long time and it is very likely that without expressing it, many participants were just tired and so not willing to extend the period.

This tells us two things. First that expecting an active participation of the audience by making comments and addressing their questions to the research staff might be, at least in this context, unrealistic. In this society like in many other in sub-Saharan Africa and elsewhere in the world, talking in public is a 'men's thing'. So despite the fact that during our preliminary consultation no women with whom we discussed said anything about separating groups by gender, it might be more appropriate to schedule "causeries" with different groups separated by age and gender. Also it is worth considering the 'fatigue' of keeping the focus during a long period (approximately 2 to 3 hours) for people who are usually active in farming, domestic tasks, etc. This format may be too long. However according to most of our respondents, none of the different tools used should be removed. They were complementary and should be kept as such although perhaps with some modifications. Also it is likely that researchers' initiative to be more accessible to local residents, ready to answer any question, was perceived by the audience as a positive sign of openness towards them and that it was enough for them. In other words, as researchers, we should not have too high expectations regarding the question-answer period but rather keep it as a good way for locals to have an opportunity to address their concerns publicly to the IRD staff and schedule parallel discussion groups or "causeries" with a sample of the participants soon after the day they watched the theater performance and slide show.

Overall a consensus was met that such an event should occur more regularly to keep the population updated on what was going on in terms of research and also the future they could expect from the presence of IRD.

How have the "days" contributed to modify participants' orientations in their activities and daily lives?

Questions were asked about the usefulness of the days for local professionals such as health workers, teachers, or authorities such as village chiefs and religious leaders.

First, especially for local health workers, but at a general level also, the days helped them to better understand some projects relying on clinical trials and/or blood samples which have led and still lead to the hostility of a large majority of the residents whether sampled or not by the research. Therefore, they acknowledged that after the days they felt more comfortable because more knowledgeable to explain the reason and importance of such projects.

For others who considered that they already knew enough, such as nurses or heads of dispensaries, these explanations were seen as very useful to sensitize their own staff on how to convince sampled patients to participate to such studies.

Several participants spontaneously told us that they shared what they had learnt with other residents during ceremonies or meetings they had (associations representatives for example). As this was not insisted on by the organizers, it is interesting to note that people shared the information on their own initiative thus showing how important the information disseminated was for them and their awareness that non participants would be interested.

Another interesting finding relates to some participants' request to be more involved in the process if it were rescheduled. In particular health workers such as *bajenu gox* who are extremely engaged in their community and know particularly well the realities faced by women regarding reproductive health, insisted that they should have been involved in the organization of the days, both logistically and by informing the potential participants. According to those who participated to the first day, which was perhaps the least structured, many people attending to it did not really get the meaning of it and why it had been organized.

Finally the field workers hired on a permanent or regular basis like the DEMO team[4] or temporarily by IRD had strong expectations on these days as they perceived it as the best way to ease their work when explaining to local participants the purposes and significance of a study to which they are solicited.

In addition to these positive reactions, several participants had an interesting request which goes beyond asking for any support or assistance. Due to the long lasting implementation of the HDSS in their area, people having specific social and professional position in the community asked for certain types of information. For example, teachers were requesting to get some didactic documentation on the demographic changes in the area they could use for their classes. The head of the catholic primary school in one of the 3 main villages asked to have the number of children of school age depending on their religion to plan the classes of Catholic schools in the area. Village chiefs asked to have access to the lists of residents in their respective villages with basic socio-demographic information in order to be more aware of the potential needs they may have. Heads of health dispensaries wanted to have more information on the prevalence of certain diseases in the area and so forth. These expectations clearly show that people are aware of the long lasting presence of researchers producing data on the population and able to provide basic characteristics on the inhabitants. . Of course some of these requests are not feasible for obvious confidential reasons. However, they highlight the awareness people have of the existence of detailed data on themselves and their community and the questions surrounding the lack of availability of this data.

After attending the days, it is likely that these needs become increasingly expressed which will lead researchers to get more involved in the sharing of results and information on the area.

Suggestions to improve the process of reporting research finding back in the Niakhar HDSS: avenues for generalization?

After discussing with the various groups represented, several avenues for improvement were discussed.

A first one clearly relates to the local key informants who should be involved in the design of the whole reporting back process. The activities were organized by a team composed by researchers and by the

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[4] The longitudinal follow-up is conducted by a team of 7 field workers, all men, who live in the area and for most of them are native from there. Two of them are permanent whereas the others are on contract depending when the follow up takes place: once a year, every three months, or any other time each year.

local field workers most familiar with these researchers. This inevitably created a bias in both the subjects to be addressed as well as the design of each activity. In addition, as already mentioned, these field workers, part of the DEMO team, were all men, and despite their extensive experience of the area and having witnessed many different situations, it is clear that the gender bias appears through the reactions gathered among the participants interviewed. This bias appeared in the content: very little on reproductive issues, social changes that affect women's lives such as new patterns of marriage, girls working in the cities, etc. Most of the content was oriented towards the visible scientific activities related to children's health and, increasingly, to farming and climate change. Also, in the design: as mentioned previously, the public sphere essentially belongs to men so it was unrealistic to hope that women would participate actively to the question-answer period at the end of the day.

Another issue relates to how participants were recruited. Clearly the team neglected certain dimensions although this is almost unavoidable and some gaps were noticed. In the main villages for example, where the days were taking place, some neighbourhoods had been neglected and thus poorly or not at all represented. None of the organizing team members had thought in terms of space but rather in terms of social status and role in the community. However, it is also true that none of the respective village key informants hired to help the organizing team to recruit had mentioned that either.

More importantly, a consensus emerged through the participants' interviews, that the whole population should have been informed about the days even if not invited. Obviously, the team feared that everyone would want to participate and that they would thus not be able to provide a satisfying space for sharing and discussing the results. However, most participants, affirmed that with clear explanations that the activities would be held in a closed location for a sample of people, the local population would have accepted this (with a few exceptions) and waited for feedback from participants. This is the key idea: they would have preferred to know about the event before it occurred being, and be aware that even if not invited they could expect a feedback from the participants. Getting the news of the event afterwards was not well perceived by most residents. This could increase the effectiveness of how participants would appropriate the information for themselves and for the other as they would know that their community expect a feedback from them. Clearly this means more reflection regarding the participatory dimension of the process.

Logistically a little "commotion" occurred with a misunderstanding regarding the transportation of the participants. First, people were informed that IRD would pick people up in the villages with their own cars and buses. Then, realizing that it would be far too costly and complicated, the team changed and decided that people would come using their own means but would be reimbursed. Despite the efforts of the organizing team, some people were not informed of that change and as a result never arrived as they were waiting for the cars.

Beyond the anecdotal aspect of this misunderstanding, it tells us that it can be very easy to create small conflicts or frustrations. The fact that Niakhar is such a long lasting HDSS and that IRD has been present for decades both eases and complicates things: eases because in general people are more tolerant as they see the institution as contributing to progress in terms of health in the area; complicates because expectations are high and people are likely to increasingly see researchers as 'using' the information they gather for their own professional purposes. Therefore, people can be fairly sensitive to the way researchers and HDSS leaders behave.

The other 'lesson' we can draw from these reactions is that there is a slight contradiction between the way some researchers address the whole process: for some the idea is clearly to manifest their good will in order to ensure a constant and better participation by residents to their successive projects and thus solicitations. For others, the main preoccupation is to prevent the process to create high expectations in terms of interventions and assistance. Therefore they are often reluctant to inform at a wide scale fearing that they will be overwhelmed by too many people hoping to participate to the activity. In other words, researchers, because relatively isolated from the field despite their long lasting commitment to the HDSS, can end up with a fairly mistaken view and perception of how people may react. Therefore it appears essential to diversify the key informants who will be involved in the organization of the activities as well as introduce a new culture of participatory approach in a field where medical and demographic research practices have dominated for decades.

In fact some frustrations were related to the gap between the intentions shown while designing the activity and how it came out concretely: during the preliminary phase, people were consulted and asked to mention the topics they were interested in/preoccupied of. Among those, adult health was a key issue that was hardly addressed during the days. Therefore the intentions shown while designing the activity and its actual content must match to a certain extent in order not to disappoint participants and to ensure a sustained credibility of the organizers.

Discussion: the challenges of a participatory approach in such a context

Confirming the findings in the 2006-2007 project, participants' evaluation demonstrates that using a participatory approach to select the results that should be reported back and how they should be reported, could facilitate the identification of gaps between people's understanding and researchers' perceptions of what is a research priority. The evaluation process also allowed participants to address certain critiques to the way the event was designed thus providing the opportunity for researchers to improve the design of a future similar event; however, there was a consensus that such an event should occur on a more regular basis and be addressed to all residents (see Hertrich et al, 2011).

Participation or participatory approaches are part of the increasing number of international development buzzwords (Cornwall, 2005). In many cases one limitation highlighted regarding such approaches is that participation is never really achieved and lack of epistemological critique: who are the actors involved, how do they build their methodology and on what theoretical and methodological grounds, and how is it operationalized? In any case such an approach is not familiar to typical research conducted within a HDSS which ends up in the lack of "savoir faire" of the local field workers who have never been trained to use it.

Should a more participatory approach be used in the design of reporting research findings back to the community, a change in research culture has to be internalised by the different actors involved whether they actually use it or not. After the experience in Niakhar several avenues for improving the whole process can be identified:

- About the recruitment of participants: this is certainly where the participation of a diversity of actors is essential. For example had the bajenu gox been more involved in the process, some neighbourhoods would not have been neglected and in general, having the input of a diversity of key informants is likely to lead to the identification of "less visible" key informants; these may not have a particular professional or social function but may nevertheless have a certain authority and leadership in the area. We clearly missed that although we knew some key people, well appreciated and respected in the area.

- About the content: taking into account people's preoccupations can lead to identify new avenues for research. In the case of Niakhar these are essentially related to adult health and animal farming.

- About the communication tools: if all tools have generally led to the enthusiasm of participants, the theater appears as a 'must'. Unfortunately we couldn't get a Forum theater company to perform but the fact that the company hired was local, spoke the same language was essential. However, more work hand in hand with local field workers and also perhaps a sample of the populations' representatives could considerably improve the performance and lead to more reactions and potential discussions among the participants.

It is essential to be clear on the expected outcomes and explain to people what such activities are for and how they can contribute to improve the information through the area by participating.

The last issue to be addressed is how to ensure that such a process will be re-conducted, updated, and how often should it occur? In the case of HDSS, if such events occur on a regular basis and are evaluated it could allow researchers to assess the extent to which the information is not only disseminated at various levels but also how it is appropriated by individuals and groups. As such the impact of reporting scientific findings in health, environment and other key development issues could be measured with reliable data.

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