

An evaluation of the Sinan health information system as used by the Hansen's disease control programme, Pernambuco State, Brazil

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Summary

Background Since the introduction of the national notifiable diseases information system (SINAN) in Pernambuco State, Brazil, in 1994, many problems have been encountered. The aim of this study was to evaluate the SINAN software, quality of data input, the transfer of the computerised data from the municipality to state levels, human resources and other factors associated with the health information system infrastructure (HIS).

Methods A cross-sectional study was carried out in Pernambuco state, North-eastern Brazil, in 2005. A sample of health regions and municipalities was chosen. SINAN forms from those municipalities were analysed and the flow of notifications followed from municipal level to the regional and finally to the state. Professionals from health units, district, municipal and regional Hansen's Disease Control Programme (HDCCP) and Epidemiological Surveillance System (ESS) coordinators, health secretaries and managers of the municipalities and health regions selected were interviewed.

Results SINAN software is functioning up to expectation. However, at all levels of the health system, serious weaknesses not related to the SINAN software were found, varying from lack of human resources (limited number of staff and staff

development), lack of infrastructure (office space, computers, supplies, etc.) to an absence of effective coordination, management and supervision of the HIS.

Conclusions Lack of reliable, complete and timely information, and especially the lack of widespread analysis and use of available information in planning and management of health services were the main weaknesses found. Many areas need urgent attention: the quality of patient examination, recording and reporting, the timely processing of quality data, the coordination and management of disease control programmes, and the use of HIS reports by the health services and health managers. Regular feedback, supportive supervision visits and annual reviews are essential to monitor the system and make sure that essential information is decentralised and used by the primary health services and HDCP coordination. Assessing the quality of services from a client perspective would give additional information for the identification of strengths and weaknesses of the Hansen's disease (leprosy) services.

Introduction

Standardised information systems and the availability of reliable information are essential for monitoring the quality and coverage of health services.¹ The effectiveness and sustainability of a disease control programme depend upon the existence of detailed and accurate information to support decision making and resource allocation. In the past, national health information systems (HIS) were often considered the weak link in health systems: data were often not up to date and therefore did not truly reflect the situation; information was not readily available and not always complete or comprehensive; and decisions were taken without evidence and, as a result, did not have a targeted impact on the health sector.²

The Brazilian government began development of a national notifiable diseases information system (*Sistema Nacional de Agravos de Notificação* – SINAN) in 1990 and the system was introduced countrywide in 1994.³ It was subsequently stated by the Ministry of Health in 2004 that:

1. Its effective use permits a vigorous diagnosis of the occurrence of an event in a population; can provide information to explain causality; indicates the risks to which people are subjected; and contributes to the identification of the epidemiological situation of a determined geographical area;
2. Its systematic and decentralised use contributes to the democratisation of information, permits that all health professionals have access to information, and that this can be made available to the community. Therefore, it is a relevant instrument for health planning and defining priorities for intervention, in addition to permitting the measurement of the impact of interventions.⁴

The law that established the National Epidemiological Surveillance System also regulated the compulsory notification of infectious diseases like Hansen's Disease (HD), cholera, meningitis, measles, tuberculosis and many others.⁵ The Epidemiological Surveillance System (ESS) functions at three levels: municipality, state and federal government. The input of the system is based on the notification and investigation of the diseases listed for compulsory notification. Each disease has its own specific notification form. In the case of HD and some other chronic diseases, an individual notification form is recorded at diagnosis with additional information collected over the course of treatment, *via* a

patient monitoring report. The notification forms and monitoring reports are completed at the health unit, sent to the municipality (ESS section), where the data are transferred to the SINAN computer file. Those files are then transferred either by Compact Disc (CD) by post or sent directly *via* internet to the health region (formed of several municipalities) and subsequently from the health region to state level. Data from all the municipalities are consolidated and sent from the state to the federal level by internet (Figure 1).

Brazil has the second highest number of Hansen’s disease patients in the world, following only India in total caseload, and is one of the six countries that did not achieve leprosy elimination in 2005. Pernambuco is one of the 27 states of the Brazilian Federation and is located in the north-eastern region of the country. It is highly endemic for HD with more than 3,000 new patients a year and detection rates around 4 per 10 000. Most patients are found in the Recife metropolitan area, as 68% of the HD patients were registered in the capital city.⁶

SINAN was introduced in Pernambuco State, Brazil, in 1994. Since then, systemic differences between databases at state and federal levels have been found, such as: problems with the transfer of data from one level to another, loss of data, and the failure of the system to automatically check if fields are left blank or if there are inconsistencies. Other problems exist related to the quality of the basic data included on patient forms and the transfer of these data from the patient forms to the computer file. In addition, hardware problems have been registered in municipalities where computers with too little capacity were being used to process large amounts of data. Many health professionals working with the Hansen’s Disease Control Programme (HDCP) have claimed that the problems encountered with SINAN are due to its software instead of operational factors.

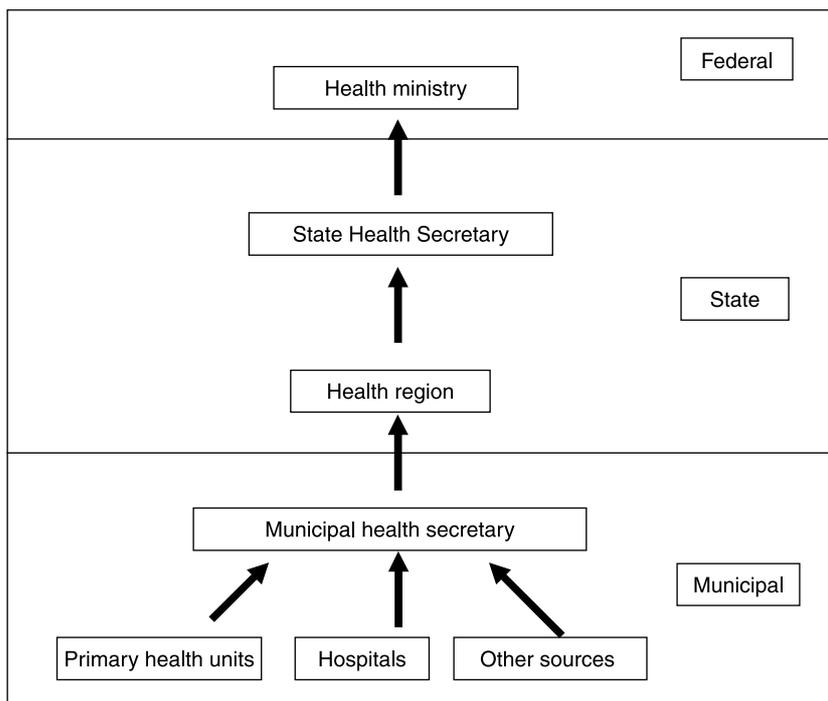


Figure 1. Flow of notification forms and patient monitoring reports.

Four professionals from the State Health Secretariat of Pernambuco, two of the HD Control Programme (HDCP) and two of the ESS Section, were invited to participate in a series of Health Systems Research (HSR) workshops in 2004 and 2005. HSR aims to collect the data necessary to provide the most relevant information to policy makers and health managers to take more informed decisions.⁷ The research proposal on the SINAN health information system (HIS) was developed during the HSR workshop in 2004 and carried out in the field in 2005. The aim of this study was to evaluate the quality of the SINAN data input, the transfer of the computerised data from municipality to state levels, human resources and factors associated with the system infrastructure and the SINAN software.

Methodology

A cross-sectional study was carried out in Pernambuco state, North-eastern Brazil, in 2005.

SETTING

Pernambuco consists of 184 municipalities and the district of Fernando de Noronha, and is divided into 10 Health Regions. Each health region covers several municipalities. The health regions are under the responsibility of the State Health Secretary. In 2005, the population was 8,238,849, making it the 7th most populous state in the country. Indicators related to health, education and socio-economic development leave much to be desired. For example: in 2003, the state had an infant mortality rate of 39 per 1,000 live births, a maternity mortality rate of 71 per 100,000 live births and an adult illiteracy rate of 23%.

STUDY POPULATION

A sample of health regions and municipalities was chosen representing areas with the highest numbers of new patients diagnosed during the period of March – September 2005. Of the 10 health regions, 5 were selected, and from each of those regions two municipalities were chosen – a total of 10 municipalities. From each municipality one referral centre and one primary health unit were selected except in case of Recife where, because of its size, the study focused on two of its six Health Districts, and again two health units (the referral centre and one primary health unit) of each of these districts were selected. Therefore, a total of 22 health units were selected for inclusion in the study. If it turned out that only one health unit from a given municipality was diagnosing HD and notifying new cases in the SINAN, then only that one centre was visited. Professionals from the health units, district, municipal and regional HDCP and ESS coordinators, health secretaries and managers of the municipalities and health regions selected were interviewed. One of the health districts was used to test out the questionnaires, but its results were included in the overall results.

DATA COLLECTION

SINAN forms and flow

All selected municipalities that had new cases of HD notified during the period of March – September 2005 were invited to send copies of their notification forms to the state. In order to

analyse the quality of the entry of the forms into the electronic patient information system the following variables were compared: number of forms with blank spaces; number of blank spaces per form; inconsistencies between operational classification (PB–paucibacillary or MB–multibacillary) and Madrid classification (I-Indeterminate; T-Tuberculoid; D-Dimorphous; V-Virchowian); between operational classification and therapeutic schedule (MDT-PB, MDT-MB), operational classification and skin smear result, Madrid classification and therapeutic schedule, Madrid classification and skin smear result, therapeutic schedule and result skin smear; and time interval between diagnosis and notification. In order to analyse the flow of information from municipality to state level, 61 notification forms were randomly selected from five municipalities during the period from January to May 2005, and the information flow from municipality to health region to state level was followed regardless of the means of transfer (CD v. internet).

Human resources and infrastructure related to SINAN

To interview the health professionals from primary health units, HDCP and ESS coordinators of health districts, municipalities and health regions, health secretaries and health managers, three different semi-structured questionnaires were used. The following variables related to the health professionals were studied: number of health professionals (medical doctor, nurse, assistant nurse) trained in HD control; period of their most recent training; steps taken when a space on the notification form was left blank; time interval between diagnosis and notification; and the issuing of patient monitoring reports. Variables related to actions taken by the municipal ESS unit, which may have an effect on the quality of the data were: number of patient monitoring reports submitted over the past 6 months; availability of epidemiological publications (e.g. epidemiological bulletin) by the municipality, health region or state. Variables related to the physical structure and human resources of the municipal ESS unit were: number of professionals receiving training in HD control; number of typists at the CDC unit who transfer patients' data to the computerised SINAN file, and of these, number of typists trained in SINAN; number of computers at the health office and number of computers used specifically by CDC.

DATA ANALYSIS

For the analysis of the notification forms (spaces left blank – incomplete data; inconsistencies) a special programme was developed in Delphi by the main author. The data collected from the different questionnaires were analysed and frequencies, proportions, means, median and amplitudes calculated (SPSS13, EPIINFO).

COMMITTEE FOR ETHICAL RESEARCH

Approval for conducting the research was requested and received from the State Ethics in Research Committee.

Results

COMPLETION OF THE NOTIFICATION FORMS – SPACES FILLED IN VERSUS SPACES LEFT BLANK

In total 4,671 notification forms were received. On each form, 37 spaces were selected to be examined and compared. None of the 4,671 had all spaces completed. On the first part of the form, which focuses on demographic and socio-economic information, an average of 7 out of 21 spaces were left blank. On the second part, which contains disease-related information, on average 1 out of 16 spaces was left blank. Twenty-five percent had two or more spaces not filled in. The listing of household contacts on the patient was left blank in 46% of the forms.

INCONSISTENCIES BETWEEN INFORMATION PROVIDED IN DIFFERENT SPACES OF THE SAME FORM

Comparing the operational classification (PB, MB) versus the Madrid Classification (I, T, D, V; with the understanding that: I and T = PB; D and V = MB) inconsistencies were found in 6%; comparing operational classification with initial chemotherapy course inconsistencies were found in 2% (Table 1).

TIME INTERVAL BETWEEN THE DATE OF DIAGNOSIS AND DATE OF COMPLETION OF THE NOTIFICATION FORM

The mean time (in months) between the date of diagnosis and the SINAN notification was 0.5 (15 days). Excluded were 1,232 forms (many of those were not of new patients never treated before, but were notified for reasons like transfers in, defaulters beginning a new course of MDT, relapses; some forms were completed incorrectly; and in case of 43 forms the time interval was more than 1 year).

THE FLOW OF INFORMATION FROM MUNICIPALITY TO STATE LEVEL

All the 61 forms that were randomly selected from five municipalities in order to follow the information flow from municipality to health region to the state level reached the state ESS without fail and without loss of data.

Table 1. Number and percentage of the inconsistencies and blank spaces in HD notification forms, Pernambuco, Brazil, 2005

Variable	Blank (%)	Fields evaluated for inconsistencies	With inconsistencies (%)
Operational x Madrid Classification	936 (20)	3735	207 (6)
Op. Classification x Initial chemotherapy	689 (15)	3982	81 (2)
Op. Classification x result skin smear	2066 (44)	2605	107 (4)
Madrid Classif. x Initial chemotherapy	1030 (22)	3641	230 (6)
Madrid Classif. x result skin smear	2159 (46)	2512	131 (5)
Initial chemotherapy x result skin smear	2139 (46)	2532	97 (4)

HD CONTROL ACTIVITIES, NOTIFICATION AND MONITORING REPORT AT THE PRIMARY HEALTH UNITS

In eight of the 10 municipalities selected, only one health centre actually confirmed the diagnosis of HD and was the only one that completed the notification forms. The other health units in these municipalities were involved in control activities, but did not diagnose patients. Of the 22 basic health units selected and visited, only 14 questionnaires (only those involved in notification) were completed (eight municipalities with one health centre involved in each one; one municipality with two health centres; and in Recife all the four health centres involved).

Of the 14 professionals who answered the questionnaire, most were nurses (57%) or physicians (21%), who had been working in a basic health centre for an average of 7 years, graduated 14 years before and been involved with the HD control activities for 6 years (Table 2). In regards to the completion of the patient monitoring report, it took on average 9 days to complete this report and another 2 weeks to send it to the municipal health office.

DISTRICT, MUNICIPAL AND REGIONAL COORDINATORS OF HDPC AND ESS

Of the 10 municipalities, two health districts (Recife) and five health regions, there were a total of 17 ESS sections of which the ESS and the HDPC coordinators were interviewed. In total 27 questionnaires were completed; in some ESS section the roles of ESS and HDCC coordination were carried out by the same professional. Two-thirds of the professionals responsible for the coordination of the ESS unit and the HDPC were nurses. On average, not including the capital city Recife, a municipal coordinator is responsible for 35 primary health units, of which 66% would be involved in HD control activities. It was claimed that almost all of these units also confirm HD diagnosis (Table 3).

MUNICIPAL AND DISTRICT HEALTH SECRETARIES, AND REGIONAL HEALTH MANAGERS

Of the 10 municipalities, eight health secretaries were interviewed; additionally two managers of the health districts of Recife and four out of five managers of the health regions also provided

Table 2. Evaluation of HD control activities at the primary health units

Questionnaire health professionals	14 professionals
1. Had training in HD	10 (71%)
2. Had training in SINAN	4 (29%)
3. Completion notification form:	
- does always	10 (71%)
- sometimes	3 (21%)
4. When not sure about the data:	
- to contact the one who examined the patient	9 (64%)
- to look into the patient record	5 (36%)
5. Objective data collection:	
- for disease control	9 (64%)
- for the sake of reporting	5 (36%)
6. Experience with the patient monitoring report	12 (86%)
7. To know the criteria to remove a defaulter from the register	11 (79%)
8. Does the unit receive feed-back from the municipal ESS section	5 (36%)

Table 3. District, municipal and regional coordinators HDCP and ESS

Questionnaire coordinators HDCP and ESS of health districts, municipalities and health regions	27 coordinators
1. Notification forms checked for completeness and consistency	
- checked	19 (70%)
- not checked because of lack of time or skills	8 (30%)
2. Patient monitoring reports	
- collecting and processing every six month	22 (81%)
- forms are complete and correctly filled in by health units	6 (22%)
3. Having typist at HDCP and ESS section for digitalisation of data notification form and patient monitoring report:	All sections
- More than 1 typist	50% of sections
- Typists received special SINAN training	41% of typists
- Having computers specifically for HDCP and ESS	71% of sections
4. Coordinators knowing the epidemiological situation of HD in their area:	
- Claim to know	24 (89%)
- Coordinators who had a fair idea of the detection rate	12 (44%)
5. District, municipality or health region producing epidemiological bulletins about HD	13 (48%)

Hansen's Disease Control Programme (HDCP).
Epidemiological Surveillance System (ESS).

information. In sum, 14 people were interviewed, nine of whom are medical doctors. Many of those interviewed have occupied their position for a very short time, on average 1.6 years, and they indicated that only one quarter of the primary health units under their responsibility implement HD control activities. Thirteen out of 14 (93%) claimed to know the epidemiological situation, but only two (14%) had an approximate idea of the prevalence and detection rates. Only 10 (71%) knew about the SINAN notification system for infectious diseases. Asked about financial means to implement HD control, most thought these were insufficient. All health secretaries and managers confirmed that the high turnover of health professionals was a serious problem. Many professionals stay only a short time in a municipality, subsequently moving on to other places; as a result, new teams had to be trained frequently.

Discussion

The hypothesis that part of the difficulties encountered with the SINAN health information system in Pernambuco was due to software problems could not be confirmed. According to the findings, the SINAN software is functioning up to expectation. However, at all levels of the health system serious weaknesses unrelated to the SINAN software were found, varying from lack of human resources (limited number of staff and staff development), lack of infrastructure (office space, computers, supplies, etc.) to an absence of effective coordination, management and supervision of the HIS.

This study only looked at a part of the HIS, more specifically at the flow and factors influencing this flow of information from the municipal health centre to the state level. In regards to the flow of information, only the flow of notification forms was looked at, not the transfer of the monitoring reports. During supervision visits in 2006, it was found that

occasionally data from the monitoring report, when sent to the state level, were not accepted by the higher level and therefore some updates (not the whole report) were not incorporated into the state database. This happened rarely and did not always occur within the same municipalities. The most likely explanation is that this was due to memory limitations (overload) of the computer used at municipal level and not to software. However, what has been a bigger problem is the transfer of monitoring reports from the state level to the federal level (but not part of this study). In 2006, in the case of Pernambuco, the federal database contained almost twice the number of patients undergoing treatment compared to the state database, even though updates were regularly sent. Other states faced the same problem. It may have been due to software, but others claim incompatibility between the (different) databases used at state (InterBase) and federal levels (Oracle).

NOTIFICATION

The highest percentage of incomplete information relates to demographic and socio-economic data, which is similar to other disease notification forms. It shows how little importance some professionals ascribe to the notification process in general and to the socioeconomic variables in particular. Although the disease-related section of the form had fewer spaces left empty, there were various inconsistencies: e.g. MB patients treated with paucibacillary MDT, skin smear positive patients treated as PB patients, etc. It was not checked if this was because of errors in recording, reporting or typing or whether these patients indeed received the wrong treatment. The fact that the space most commonly left blank (46% of the forms) related to the number of household contacts registered did not come as a complete surprise. In reality, this activity receives limited priority; contact tracing and examination are generally weak points of the programme.

The notification forms which were selected at the health unit and subsequently monitored to check data flow to the state level in fact arrived with all information intact. The average delay between date of diagnosis and date of notification by the health unit was 15 days. This is a serious problem as clinical information on the patient record card is often minimal. The prompt processing of the notification forms at municipal level is another weak point noticed during supervision visits. However, the study did not check the time delay between diagnosis and the inclusion of the notification data in the SINAN system at municipal, regional, state and federal levels. Every week, notification data must be sent from: (a) the municipality to the health region; (b) the regional level to the state; and every two weeks, from the state to federal level. Each step in this process allows for the delay of essential data, which merits further study.

Professionals at the health centres who fill in the notification forms are not always trained to do so, and many have no idea of the flow and importance of the information system. Most of the medical doctors who examine patients delegate the responsibility of notification to other professionals, who often, because of incomplete recording, have problems compiling the necessary data. Ideally, it is the medical doctor who is and should be responsible for the notification and the correctness of the information.

The basic qualifications of the municipal health professionals should be more than sufficient for basic understanding of a health information system. Besides that, most of them have been working in the same position for several years and should have had, in theory, ample opportunity to gain experience of the notification system (and not just related to HD). However, some of them still did not know the importance of the SINAN and the transfer of data. One of the factors that contributed to this situation was the lack of feedback from

municipal authorities and other officials. This lack of feedback does not stimulate the professionals to give greater weight to the HIS.

MONITORING REPORTS

The majority of the health unit staff claimed to have experience with the patient monitoring reports, as well as how to complete and send them to the municipal health office. In practice, more problems are encountered with the completion of these monitoring reports than with the initial notifications. The municipal coordinators complain that only a few complete the monitoring reports regularly. For many patients on the active prevalence register, no follow-up data were available in the SINAN system. Sometimes information about a patient dated back several years, resulting in highly inflated prevalence rates. A considerable number of health professionals did not know the criteria and national guidelines to delete a defaulter from the active registry. Of those who claimed to know these guidelines, only a few have actually followed them. Apparently, the importance of this information for monitoring the epidemiological situation of HD is not fully appreciated by staff members.

HDCP AND ESS COORDINATORS

A majority of the coordinators claimed to check each notification form before being typed into the database. The other 30% confessed to not even checking the forms because they were not trained to do so or had no time. The fact that none of the forms had all spaces filled in points to a lack of understanding of the importance of the HIS. The observation that only a few coordinators knew the main HD epidemiological indicators of their area of responsibility requires attention. This casts serious doubts on their awareness of the HD problem and their ability to coordinate and direct the activities of the HDCP. Only a small percentage of the staff responsible for data entry received specific SINAN and HD training. Because of this, it is assumed that incomplete forms or forms with inconsistencies were not returned to the municipal coordinator and simply entered into the computer. Typing mistakes could lead to additional inconsistencies as well.

HEALTH SECRETARIES AND MANAGERS

Most municipalities selected had a considerable number of primary health units under their control. Officially, the HDCP was deemed to have been decentralised in many municipalities and the majority of primary health units involved in HD control activities. However, in reality, among the nine municipalities studied (not including Recife) only one municipality had more than one health unit providing diagnostic services. The definition of decentralisation states that each unit should diagnose and notify new cases and not merely provide MDT or trace defaulters. All health secretaries and managers interviewed stressed that they knew about the HD endemic in their area, but most of them had no idea of the extent of the HD problem. Nevertheless, they were convinced that special attention should be given to HD control. Several managers mentioned operational problems, particularly that only a few health units implement control activities. This was blamed largely on the lack of staff, especially highly-qualified staff, high turnover of personnel and lack of financial resources. As was observed in case of the HDCP and ESS coordinators, serious doubts are raised as to the awareness by the health managers of the extent of the HD problem and their ability to plan

and manage the health services based on objective information. Mutemwa states that the success of decentralisation depends significantly on the capability of the municipal health managers to exercise their assigned functions.⁸

SINAN SOFTWARE AND DATA PROCESSING

Even though many claimed that the SINAN software itself was a constraint, in this study no such failings could be found. However, some other problems were encountered. The management system of the database (INTERBASE 6) has some characteristics which could lead under some circumstances to a loss of information, like the clause 'forced write on.' When WIN32 'forced write on' is encountered, the SINAN software is disabled. In the case of problems with the computer or of sudden loss of electricity, this can lead to the corruption or loss of data in the 'buffer'.⁹ Instead of the most recent data entered, the system will restore copies of a previous database. If one is not aware of this and does not correct what has been lost, recent updates will not be reflected in the file sent to the higher level. For a proper and robust functioning of the SINAN software, up-to-date equipment is required. Most municipalities seem to have sufficient equipment, but often other information systems (e.g. mortality, live births, etc.) besides SINAN are installed in the same computer as well. This leads to data overloads and slows down computer data processing considerably. Computers with a low memory (RAM 128 MB) in conjunction with processor of a capacity of 700 MHz or less will not be able to pass on updates of patient information with any degree of confidence.

HEALTH INFORMATION SYSTEM

Social and economic inequalities aggravate health problems, and impose on the state the need to provide quality and accessible health services. To increase the planning and management capacity of services, a strategy of continuous evaluation of the quality of the health information is essential. The decentralisation process in the health sector should include decentralisation of information to allow the division of political and technical responsibility between the three spheres of the government – municipal, state and federal.¹⁰ The availability of information in an understandable and meaningful format for the general public, council members, health professionals and health managers to understand is a prerequisite for a functioning democratic process and social control.¹¹ One has to realise that indicators for control programmes are defined by the government and can become important strategic tools.^{10,12} In recent years, examples of such have been seen from some endemic countries driven by the pressures of elimination targets.¹² In a typical organisation HIS is only one of the information systems used by health managers. For decision making, besides the HIS other forms of information are brought to bear, like human resources (health managers, coordinators programmes, health professionals) and management organisational processes (e.g. meetings, supervisory visits, task forces, consultation with local communities).⁸

CONCLUSION

Although the sample of notification forms analysed, municipalities and health units selected, as well as the numbers of professionals and managers interviewed, was small, some general conclusions can be drawn. No fault could be found with the SINAN software. However, the lack of reliable, complete and timely information, and especially the lack of widespread appreciation and use of available information in planning and management of health services

were the main weaknesses found. Even though much has improved in recent years, there are still many areas that need urgent attention: the quality of patient examination, recording and reporting, the timely processing of quality data, the coordination and management of disease control programmes, and the use of HIS reports by the health services and health managers. Regular feedback, supportive supervision visits and annual reviews are essential to monitor the system and make sure that essential information is decentralised and used by the primary health services and HD/PC coordination. One should realise that SINAN is just one of the information systems on which the coordinators and health managers depend. Assessing the quality of services from a client perspective would give additional information for the identification of strengths and weaknesses of HD services.

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