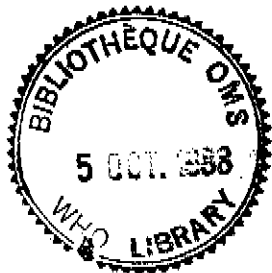


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REPORT OF A MEETING ON METHODS FOR THE
RAPID ASSESSMENT OF THE LEPROSY SITUATION

Geneva, 15-16 April 1988

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1. INTRODUCTION

The meeting on methods for the rapid assessment of the leprosy situation was held at WHO headquarters in Geneva on 15 and 16 April 1988. There were participants from eight countries, as well as representatives from the WHO Regional Offices for Africa and the Western Pacific and staff of WHO/HQ (see Annex A).

The meeting was opened by Dr G. Torrigiani, Director, Division of Communicable Diseases, WHO. Dr Torrigiani said that the experience gained over the last five or six years of MDT implementation has shown that proper planning and preparation of control activities are critical if a substantial impact is to be made in areas/populations covered by MDT. Up to now the collection of information on the magnitude of the problem, required for the initial planning exercise, has been considered possible only through elaborate and expensive random sample surveys and, in certain circumstances, by total population surveys in the area of operations. The sample survey approach is too expensive and impracticable in countries with integrated leprosy control programmes and poorly developed health infrastructures. Such is the situation in most African countries where leprosy is endemic and, perhaps, this could be one of the reasons for the delayed commencement and slower implementation of MDT in this continent.

2. SCOPE AND OBJECTIVES OF THE MEETING

Dr S.K. Noordeen, Chief of the Leprosy Unit, WHO, stated that leprosy was still a serious health problem in Asia, Africa and Latin America. In WHO documents the number of cases generally referred to is 10 to 12 million estimated cases and this number has been repeated for 20 years and more. However, the basis for this is very weak and the only reasonably reliable number available is that for registered cases which has been around five million for the last few years. Here too there are problems relating to the definition of a case of leprosy and the updating of registers etc., but the last Expert Committee on Leprosy, which met in November 1987, has been able to produce a clear operational definition of a case of leprosy which should make things easier in the future.

At the national level, the information-base on leprosy is directly proportional to the quantity and quality of the leprosy services available. Wherever there are vertical leprosy services the information is more complete and reliable but such services are few and in most countries do not cover the entire country. In certain situations sample surveys have been undertaken to define the problems but these have been few and far between. The high cost of undertaking sample surveys is further compounded by the relatively low frequency and the very uneven distribution of the disease even within limited geographic areas. Thus, the current situation, particularly at the national level, is quite unsatisfactory and needs to be rectified so that leprosy control programmes can be better planned and evaluated.

The need for simple, rough and ready methods to assess the leprosy situation has been felt for a long time but has become more urgent over the last few years, particularly after the recently introduced new technology of multidrug therapy (MDT) for leprosy control. The WHO Study Group 1981 recommendations on MDT made it possible, for the first time, to treat leprosy patients for finite periods of time. This meant that it was possible to reduce the prevalence of leprosy within reasonable periods of time and also reduce incidence after appropriate lag periods. Experience over the last five to six years has shown that this has indeed happened. In good MDT programmes the prevalence of registered cases has come down as much as 80% within a period of four to five years. Such results have created a greater interest at the country level, an increased political commitment to leprosy control, and has attracted more funds from donor agencies. While the overall progress of implementing MDT at the global level has been reasonably good (currently over 1.1 million leprosy patients are either on MDT or have already completed MDT), the progress is very uneven. Also, even though in several countries MDT coverage is over 75%, there are many countries which introduced MDT to only a limited number of patients. In many of these the leprosy problem is not even recognized as important. It is for this reason that it would be desirable to develop and promote methods for rapid assessment, not only to ensure reliable base-line information but also to monitor the

progress of leprosy control. It was hoped that, as a result of this meeting, it would be possible to provide at least some of the answers sought so that not only the current situation but also the progress being made towards the goal of eliminating leprosy as a public health problem could be assessed.

The specific objectives of the meeting were:-

1. to develop methodology for rapid assessment of the leprosy situation in countries where this information is inadequate;
 2. to discuss the feasibility and approaches for the application of such methods in a number of selected countries;
 3. to discuss the use of the information thus collected for planning, monitoring and evaluating control services.
3. INTRODUCTION TO SOME STATISTICAL ISSUES ON ASSESSMENT OF LEPROSY SITUATION AT COUNTRY LEVEL

Mr T. Sundaresan, WHO/LEP Consultant, brought to the attention of the participants the existing problem of inaccurate statistical information concerning leprosy.

In most countries where leprosy has been identified as a health problem there is no reliable estimate of its magnitude. The standard scientific method of estimation is by sample surveys. However, the national prevalence rates of the disease in endemic countries are very often of a low frequency and sometimes as low as 0.1%. In these situations, statistical sample surveys require a very large sample size, i.e. a population of 50 000 and more, and tend to be very expensive.

After all, the objective of obtaining an estimate is to get an approximate but unbiased idea of the order of magnitude of the problem so that the planning of a control programme may be realistic and the measurement of the epidemiological impact more meaningful. When the expected prevalence rates are as indicated above, the factor responsible for demanding a large sample size is the desired precision for the estimate. For example, when the prevalence rate in the sample is around say 1%, we would like to be able to say that the prevalence rate in the population is between 0.8% and 1.2%. In statistical language this means that we would like the confidence limits to be within a sufficiently narrow range. There is, therefore, an urgent need to explore other ways of estimating the total case-load in a community in a relatively inexpensive way and with enough precision to form the basis for resource allocation and planning of an appropriate control strategy.

In view of the above, Mr Sundaresan proposed that the group consider the use of one or more of the four rapid methods below. These were discussed later in the meeting after the presentation by each participant of his personal experience on the estimation of the leprosy problem.

1. Extrapolation from prevalence rates in children:

Examination of children in the 5-14 age group and a knowledge of the age distribution of the disease could help in estimating the total prevalence. Schools are best for covering this age group but school attendance may only be partial. Other methods for ensuring a good coverage of children should be explored.

2. Extrapolation from registered cases

Where leprosy services and registration of leprosy patients exist, the study could be designed to estimate the proportion of cases that are on the register. Practical difficulties in this procedure were mentioned with suggestions for resolving them.

3. Extrapolation from cases with disability and deformity:

The detection of cases with deformities is generally easier than the detection of all cases. If only an approximate figure could be established for each community for the proportion of cases with deformities, this could perhaps present another possibility for estimating total prevalence.

4. Extrapolation from rapid village surveys:

The rapid village survey, where the leprosy team visits villages after an intensive leprosy education programme, is another possibility but one has to devise ways to get over the stigma problem if it exists.

4. COUNTRY REPORTS

A summary of the presentations made by the participants is given below.

Dr J.L. Cartel gave a brief description of French Polynesia and its public health service. The Territory consists of 130 small islands with a total surface area of 4000 square kilometres scattered in a large ocean of more than four million square miles. It is divided into five archipelagos, with only 60 of the 130 islands inhabited. The total population in 1986 was 180 000, 75% of which live in Tahiti, the largest island where the administration is based. There is good medical and public health coverage in French Polynesia. Excluding the medical and paramedical personnel working in the six main hospitals there are 909 health agents working in 91 public health clinics.

Since the population is very small and there is a good health service coverage, the chances of all leprosy patients being detected are high and, consequently, the estimation of the total number of leprosy patients in French Polynesia is based on the number of those already registered.

An interesting immunological study is in progress in the isolated archipelago of the Marquesas islands where, during the last 20 years, the annual detection rate for leprosy was eight times higher than that for the whole of French Polynesia. The study tries to identify the serum levels of Phenolic Glycolipid (PGL) antibody by the ELISA technique and to correlate them with disease endemicity.

It is possible that in the future the PGL antibody may be of use to estimate the leprosy disease prevalence in a given population.

Dr Daumerie, in his presentation, referred to the steady decrease observed in known leprosy prevalence during the last 20 years in eight French-speaking West African countries. Currently, the global mean prevalence for these countries is close to three per 1000 population with a range from 0.36 to 4.24 per 1000. Dr Daumerie then referred to the three methods used for estimating leprosy prevalence in those countries, indicating the advantages and disadvantages of each of them.

The first method was the direct analysis of available data on patients' registration. The advantages of this method were: (a) low cost, (b) the possibility of getting a global view of the magnitude of the problem at national and sometimes at local levels, and (c) the possibility of following-up those patients. The disadvantages were: (a) the length of time required before all data is collected (about two years), and (b) difficulties in utilizing the information for calculating the epidemiological indices.

The second method was based on cluster sampling survey and household surveys. A household total population survey was carried out in 1986 in the urban area of Bamako (Republic of Mali), and a cluster sampling survey is underway in a rural area in the Republic of Togo. The advantages of the Bamako household survey were: (a) the results were available quickly and the whole survey lasted only six months; this was due to the easy accessibility of the population and the existing facility of data analysis by

computer; (b) the utilization of an existing sample framework, shortened preparation time and reduced total cost; (c) results are accurate and reliable, and (d) the total cost of the survey was acceptable (US\$ 17 000 only). The drawbacks of household survey were: (a) the risk of underestimating the prevalence of known cases because the household sampling did not take into consideration hospitals, public offices, jails, etc., (b) the difficulties of conducting surveys in rural areas with scattered populations; (c) examination of the whole group may be unnecessary for just estimating known cases; and (d) possible psychological and cultural constraints to physical examination in some areas. Concerning the cluster sampling survey in the Republic of Togo, it is being carried out following the classical procedures. It will last eight months and the cost will be around US\$30 000. Even if this method yields very reliable results, it takes a long time and is very expensive.

The third method was based on the assessment of the leprosy situation in a limited area before implementing MDT. All patients registered in the area were examined clinically and bacteriologically and usually only one-third of them required treatment with MDT; this results in a dramatic drop in the leprosy prevalence rate when the numerator is made of all cases eligible for treatment. As the MDT programme progresses, the improvement of control activities and the increase in patient confidence in treatment results in an impressive increase in the detection rate. The use of indices like the case detection rate greatly assists in estimating the endemicity of the disease and in measuring the long-term effects of MDT. The advantages of this method are: (a) it provides continuous assessment of the problem through an integrated process; (b) it involves the whole team in the assessment, and (c) It is inexpensive. The only disadvantage of this method is the length of time it takes to set up.

Dr Daumerie concluded by saying that it was extremely important to clearly define the objectives for assessing the leprosy situation in a given area and that, in his opinion these should include at least: (a) determination of the number of cases immediately eligible for treatment; (b) determination of the number of patients suffering from deformities from leprosy; and (c) determination of the annual incidence (detection) rate. Since the number of cases eligible for immediate treatment in Africa is relatively small (about five per thousand inhabitants), it would be very difficult to estimate such a small number by means of rapid and low-cost surveys, particularly on a large geographic scale, even after stratification. It would be more realistic to use these methods in areas where leprosy prevalence is higher.

Dr G. Groenen presented the various aspects of the leprosy problem in Zaire which has adopted the primary health care approach as the national health policy. The country is divided into 306 health districts of approximately 100 000 inhabitants each and leprosy control is to be integrated into the general activities of each health district. This creates problems when the district is not yet operational, while in operational districts, leprosy is often not considered a priority. The National Leprosy Office of Zaire issued the following data:

1. Historical data. In 1959, mass medical multipurpose surveys yielded a leprosy prevalence rate of 27.5 per thousand and an incidence rate of 3.0 per thousand. These figures are probably too high and they cannot be extrapolated to today's population.
2. Annual report 1986. In 1986, the National Leprosy Office registered 30 908 patients, 23.9% of whom were multibacillary (MB). It is not possible to get an accurate estimate of the prevalence from this report since there was an incomplete population coverage, the numerator was not clearly defined, the denominator was often unclear and the reports received were not standardized.
3. Annual report 1987. It is expected that data from this report, based on the standardized OMSLEP form, will provide more useful information. By April 1988, 45% of the districts had responded and, based on the data so far received, the following conclusions can be drawn:

- (a) In the tropical rainforest the annual detection rate is 0.3 per thousand;
- (b) In the mountainous areas, the annual detection rate is between 0.06 and 0.09 per thousand;
- (c) The MB proportion is 10 to 15% except for Northern Kivu (30%);
- (d) Prevalence rates vary from area to area (from 0.3 to 5 per thousand). This seems to be related to differences in case detection methods and to variations in the introduction of MDT.

Dr Groenen concluded by saying that there is no need for large random population surveys since they would be difficult to organize, and are very costly and time consuming. Rapid assessment methods would be of some interest but at this time the National Leprosy Bureau feels that the existing information system should be strengthened and the existing health services personnel should first receive additional training and logistic support. For the time being the existing leprosy services can provide sufficient data for planning purposes. Special surveys may have a role to play in validating the data provided by the health services.

Dr Haider Abu Ahmed from Sudan stated that Sudan was the largest country (2.5 million square kilometres) in the African continent and had a total population of 22 million. Health services, though provided free, are unevenly distributed throughout the country and are of poor quality. Despite being a serious health problem, leprosy is not considered a priority by the Government. Different methods have been used to assess the leprosy situation in the country.

1. Basic information was needed before deciding which area was to be given the higher priority. Since there was no information within the country itself, the prevalence of leprosy in a corresponding area in neighbouring countries was applied, i.e. i.e. Egypt (in the north), Zaire, Kenya and Uganda (in the south), Chad and the Central African Republic (in the west) and Ethiopia in the east.
2. In areas of higher endemicity in certain parts of the country, some quick surveys were carried out by health workers and community leaders. Information about the original habitat of patients residing in leprosy settlements has helped to map areas of endemicity in the country.
3. School surveys were undertaken in some towns in Wau in the south. The method is also relatively quick, cheap and easy. The main drawback, however, was that many children of school age do not go to school. This is more noticeable in rural areas where school attendance is even lower.
4. Sample surveys were also carried out in one of the known high endemic areas. This is an expensive method that could not be used later for monitoring purposes. However, it was of great help for planning control activities.
5. More recently, attention has been given to the utilization of primary health workers by the health units. These workers can undertake small surveys to find cases in the communities where they work and, in this respect, more importance is given to their training.

Dr G. Steenbergen, in his presentation on leprosy and leprosy control in Zambia, mentioned that, although a declining trend in leprosy has been observed, it is still a public health problem in many parts of the country. With the progressive implementation of MDT, many patients are discharged contributing to the decline in the active case load. At the moment MDT is fully implemented in 24 of the 57 districts, covering approximately 25% of the total case load. In assessing the leprosy situation, the operational management of leprosy control is guided by the statistical returns from the districts that are sent quarterly, biennially and annually. The reliability and completeness of these figures are questionable. It is planned that the statistical feedback be reorganized and

simplified to ensure a more practical system that can help to adapt the programme on a much shorter term basis. Besides the sporadic activities of some rural health centres, very few efforts are made to assess the true leprosy situation beyond the registered case load. Prevalence and incidence estimates are based on registers. No systematic epidemiological assessment has been carried out, taking the current logistical and material constraints into account. New methods that can give reasonable estimates of the true leprosy situation and that can also be carried out by the general health staff of the rural health centres are highly desirable. Any of these methods will derive significance from the linkage with an effective control effort but the results must be sensitive and specific as operational tools for the district health management team.

Dr M. Zuniga, in his presentation, referred to the current leprosy problem in Latin American countries. Though information concerning leprosy in general is limited it is possible to make an epidemiological diagnosis of leprosy in the Latin American countries. By means of appropriate statistical methods and utilizing previous available data, (i.e. detection rates), it is possible in most of these countries to establish the evaluative characteristics of the leprosy endemicity. In Venezuela, there has been a steady decrease in the annual case detection rate from 16 cases per 10 000 in 1951 to 2.4 cases in 1985 (a reduction of 85.2%); there has also been a reduction in the prevalence rates from 1.73 cases per 1000 in 1960 to 0.7 cases in 1985 (a reduction of 59.5%). The distribution of cases by clinical type, age and sex is consistent with the declining trend in the disease: an increase in MB cases and a shift towards the older age groups. However, different trends could be observed in other countries. There is a clear increase in leprosy prevalence and incidence in Brazil, a decrease in Mexico and alternative increases and decreases in Peru. Dr Zuniga stated that it should be possible to develop simple tests that can be used in field conditions, similar to tuberculin, in order to identify the infection rates in the community, from which the prevalence of the disease could be easily estimated. He also mentioned that at the level of leprosy endemicity in Venezuela, the prevalence rates among children were so low that its extrapolation to establish the total prevalence rates is not acceptable.

Dr N. Chitimba, currently in Nigeria, referred to his own country Malawi where he has been working in leprosy control for several years. In the leprosy control programme in Malawi no random sample surveys have been undertaken since its inception in 1965. However, periodic school and contact surveys have been undertaken. Great importance is given to the village meetings for "sensitization" health education purposes and to establish contact with staff for the leprosy control programme. Also in Malawi, in the Leprosy Evaluation Project (field study), a conventional mass survey was undertaken for research purposes. It is very expensive, but in terms of results, has produced 50% more cases than was registered. However, early cases were not motivated enough to present themselves to the leprosy control programme staff.

In Nigeria, the situation was quite different. In the short time that Dr Chitimba was assigned to Nigeria (11 months), there was only time to go through records and reports on registered cases and registered prevalences as determined in various previous house-to-house and contact surveys. To accomplish this, visits were made to the Epidemiological Unit of the Federal Ministry of Health, the State Ministry of Health and the Local Government Areas where leprosy supervisors were consulted. Even more important were the visits made to various leprosy clinics to determine what proportion of registered cases actually were required to continue chemotherapy. In this way a correction factor of up to 50% was found necessary to apply to figures from some states to allow for patients who should have been discharged from registry. The registered number of cases was thus reduced from 285 000 to 165 000 as a base-line prevalence for the national plan, although the mean national estimated prevalence rate of 5 per thousand was not correspondingly reduced. Also there was a need to obtain information on detection rates and distribution of cases by type of disease, (MB and PB) by age and sex. With the available information a national plan with a time frame was worked out.

Dr J.W. Lee of the WHO Regional Office for the Western Pacific reported on the method used to estimate the prevalence of leprosy in South Korea. The first step was to conduct a whole population survey between 1963 and 1965 in a high endemic county, Wolsung-Kun,

with a total population of 189 995. At the end of the survey, 95.3% or 181 084 people were examined and 375 new cases were detected. It was also known that the number of cases already known in the area surveyed was 678. From these figures, the estimation proportionate (E.P) of 0.61 was obtained.

Estimation Proportionate (E.P.)

Total known number of cases by place of birth at Wolsung-Kun: 678.

Prevalence rates based on the known cases

$$\frac{678}{189\ 995} \times 1000 = 3.36 \text{ per } 1000$$

Newly detected cases as a result of the population survey: 375.

Rate of newly detected cases

$$\frac{375}{181\ 084} \times 1000 = 2.07 \text{ per } 1000$$

$$\text{Estimation proportionate} = \frac{2.07}{3.36} = 0.61$$

All known cases, i.e., 33 531, in Korea were classified according to the place of birth and distributed by province. By multiplying the number of known cases from each respective province by the EP (0.61), estimates of undetected cases were obtained for each province. Finally, by adding the estimated undetected cases with the actual number of registered cases, the total estimated cases for each province were obtained. By adding the cases from nine provinces and two special cities, the total estimated cases of 60 157 was obtained for Korea. With a total population of 30.7 million in 1968, the estimated prevalence rate was 1.95 per 1000. The design of this study assumed that leprosy services in the different cities and provinces differed little in quality.¹

Dr P. Feenstra, in his presentation on the rapid village surveys, referred to the protocol prepared earlier on a similar subject for the Multidisciplinary Research on Leprosy Project (MURLEP). An abstract of his presentation on the procedures of rapid village surveys as implemented in Indonesia and Thailand, is given below:

With Rapid Village Surveys, survey teams estimate the leprosy prevalence both of disease and of leprosy-related disabilities among the general population through the examination of persons with possible leprosy symptoms who present themselves or are specified by members of the community after public meetings at which there is extensive discussion about the signs and symptoms of leprosy. As currently practiced in various leprosy control programmes, this active case-finding method may involve the participation of community health workers, (e.g. in Thailand). It is quick, comparatively inexpensive and has the added advantage of involving health education. Its usefulness in obtaining information about the magnitude of the leprosy problem may, however, be affected by the degree of stigma and fear of stigma attached to leprosy in the population concerned.

Dr E. Declercq, in his presentation on experiences with sample surveys, referred to two programme situations; one in Polombakkam, India, and the other in Indonesia. In Polombakkam, the data obtained covered the whole area of the control programme from 1955 to 1982. This data did not come from random sample surveys but from all the clinically active cases registered in the area. A total of 47 068 patients were detected during the 27-year period. There could be some under-registration but there is no reason to believe

¹ More detailed information may be obtained from the Korean Leprosy Bulletin, Vol. 6, No. 1, 1969. K.H. Kim, et al.

that the rate of under-registration is different from year-to-year. A very strong correlation was found between the prevalence rate for children (either 0-14 or 5-14) and the total prevalence rate and between the prevalence of multibacillary leprosy in children and that of the total population. Twenty random sample surveys were carried out in 19 different areas of Indonesia during a ten-year period. Two of these surveys (South Sulawesi 1 and South Sulawesi 1 Evaluation) concern the same area of South Sulawesi Province but with a ten-year interval. The precise age of the patients was known; of the 1422 cases examined during the surveys, only ten were of the 0-4 age group. A very strong correlation was found between the prevalence rate for children and the total prevalence rate, but the regression equation was quite different from that observed in Polambakkam. The relationship between the prevalence rate for children and total prevalence rate was very similar for the two surveys carried out in the same area of South Sulawesi with a ten year interval. No relationship was found between the proportion of MB patients among children and among all patients. No relationship was found between the registration rate of disabled cases and the total registration rate. If five surveys are excluded (East Nusa Tenggara 2, South-East Maluku, South Sulawesi 5, North Sumatra and Bali) for which either the number of people examined or the number of patients found was very low, there was a good correlation between the registration rate of MB cases and the total registration rate.

In conclusion, it can be said that: (1) there seems to be a strong correlation between the prevalence rate of leprosy for children and the total prevalence rate if studied in different areas of the same country; (2) the prevalence rate remains stable over the years within one area; (3) this relationship is not similar in different countries. This should be studied further by comparing these results with those from other areas; (4) it is not possible to estimate the total number of disabled patients from the registration rate; (5) if the prevalence rate is high enough, it seems possible to estimate the total number of MB patients from the registration rate.

5. CRITICAL ISSUES RELATING TO THE PROPOSED METHODS

5.1 Extrapolation from prevalence rates in children

Rationale: From past experience we can prove there is a relationship between prevalence in children and total prevalence. It is relatively much quicker and less expensive to examine children, e.g., school surveys, where a large sample of schoolchildren can be surveyed. However, the extrapolating factor, i.e., the ratio of total prevalence rate to child prevalence rate could vary from one place to place depending upon the endemic level of the disease in a community, the proportion of multibacillary cases, socio-economic or cultural causes, etc. It is therefore important to establish this quantitative relationship for each zone. It is understood that a zone is an area with a large population, such as a state in India or a province in Nigeria.

However, the following points need to be considered in depth in each context:

1. What proportion of children attend school?
2. If only a proportion attend school, what are the reasons for school attendance or non-attendance? In other words, do the children attending school represent a "selected" segment of children in that age group?
3. In the above case, is there any mechanism, e.g., cooperating with another health programme, that would enable one to secure good representation and good coverage of the child population?
4. The possibility of suggesting appropriate age groups for this purpose was considered at the meeting.

Ages 0-14: Very few cases are seen in the age group 0-4. Many infants will be examined and very few cases seen. Furthermore, examination of infants necessitates other operational arrangements such as house visits.

Ages 5-14: This is the usual school-going age in many countries. In the past in many highly endemic areas, the prevalence rate in this age group was almost equal to the prevalence rate for all ages. However, the school age may not necessarily start at five years of age, but if it does, a proportion of those attending school may start to improve only after six or even seven years of age.

General: For operational purposes, it may be more convenient to include in the survey all classes in the primary and secondary schools, or specified classes corresponding most closely to the selected age group. Alternatively, if grades 1 to 10 correspond approximately to the 5-14 age group, it may be an advantage to include grade 11 also so that the 5-14 age group may be more complete. In any case the actual ages of the children should be noted.

5.2 Extrapolation from registered cases

Rationale: In the absence of other types of information, the number of cases on the register is the only information available in many countries and serves as the data base for planning. It is usual to estimate the actual prevalence from registered cases using well-informed opinions as the basis. The merit of the approach is that one is looking at registers and not at patients. Hence, if a meaningful quantitative relationship can be established between the rates based on registered cases and true prevalence rates, the method would be useful to provide quick first approximations to prevalence.

Points to be considered in each context

1. There should be a leprosy service in the area with reasonable registration procedures.
2. There should be a mechanism to control or estimate the extent of multiple registration in different services.
3. When cases have reported voluntarily coverage by leprosy services would depend on (a) the quality of the service; (b) the accessibility of the services; passive case-reporting is more likely to be from nearby areas than from remote areas; (c) the severity of the disease: it is likely that most patients on register are those from patients with advanced disease, especially disabilities. However, from past experience, there does seem to be a fairly constant relationship within an area between the number of cases on register and number of active cases needing treatment in the community.

The Group was of the opinion that this relationship should be explored more in depth to see if the numbers on register can be used to provide approximations in limited areas.

5.3 Extrapolation from cases of disability and deformity

Rationale: Disabilities and deformities are easily perceived and much easier to enumerate. There appears to be a consistency in the proportion of cases with disabilities, at least in the older age group in situations where leprosy services have been minimal in the past. However, general opinion at the meeting was that to extrapolate from disability rates could be very difficult as the proportion could be altered considerably when leprosy services improved. Wide variations between countries, and even within countries, could be expected. Furthermore, the data on disabilities suffer from historical accumulation and many uncontrollable errors.

5.4 Extrapolation from rapid village surveys

Rationale: Rapid village surveys are easy to carry out as they do not involve house visits. Briefly, the team visits are preceded by an intensive effort to educate the village population on leprosy symptoms and the possibility of cure, etc. After such an effort, and with the help of influential people in the village such as the village headman, people with symptoms are invited to present themselves. With minor variations

this is the practice adopted in many situations. However, in each situation the relative efficiency of the method should be evaluated for its efficiency in comparison with the random population survey by household visits. If the efficiency is high and reasonably constant from one area to another, this method could be an alternative to the population survey. However, if there is a high degree of stigma against leprosy in the community the response can be expected to be poor. It is a matter for consideration as to what can be done under the circumstances. One option is to include it as part of a "dermatological" survey and to provide minimal treatment for all dermatological conditions. However, the prevalence of dermatological conditions in many societies can be very high and this may put a strain on the team's capabilities. The merit of this method was that it is truly community-based and can be fruitful if the community is friendly. However, the extrapolation factor will need to be appropriate for each local situation.

The methodology for the conduct of rapid village surveys needs to be standardized and general guidelines should be worked out to suit different socio-economic or cultural settings.

6. SUMMARY AND RECOMMENDATIONS

The meeting recognized the need for rapid assessment of the leprosy situation especially in relation to the introduction of multidrug therapy.

Various methods were proposed for the rapid assessment of the leprosy situation and their validity, feasibility and adequacy was discussed.

Based on the various options discussed, the Group recognized the need for, and recommended the development of, protocols geared to different situations in various countries based on the general outline developed at the meeting.

Using such protocols, the need to test the proposed methods for; (a) their scientific validity, and (b) their adequacy for planning purposes was endorsed.

The potentialities for future use of the sero-immunological tests presently being developed were also discussed.

APPENDIX A

SOME SUGGESTED METHODS, THEIR RATIONALE AND A STUDY DESIGN
FOR TESTING THEIR ADEQUACY AND VALIDITY

Mr T. Sundaresan

Sample surveys

Population based sample surveys are the recognized standard methods of obtaining epidemiological indicators such as prevalence rates and even incidence rates. However, sample surveys of the size and type necessary for estimating leprosy prevalence are extremely expensive and require experts in such surveys. Financial resources and expertise are very scarce in many countries where leprosy has been identified as a problem and where at least an approximate but objective estimate of the magnitude of the problem is necessary.

As an example, if the expected prevalence of the disease is five per 1000 inhabitants, one needs a sample size of some 50 000 to be able to say with confidence that the true prevalence rate is between four and six per 1000. This large size is necessary because clusters of communities, or even whole villages, are adopted as the sampling units. The mere increase in sample size does not guarantee the accuracy of the estimates. Inability to secure adequate coverage because of the stigma associated with the disease and inter-observer variations in the diagnosis of the disease are some of the "non-sampling errors" that do not improve by merely increasing the sample size and can very well distort the conclusions. For example, with a sample size of 50 000 one would expect 250 cases. If only 50 cases are missed the sample estimate of prevalence would be four per 1000 with perhaps confidence limits of three and five. As a general rule it is better to strike a balance between securing good precision for the sample estimate (as by increasing the sample size) and reducing such non-sampling errors (by adequate training of personnel for diagnosing cases, and intensive efforts to trace the non-respondents or a sample of them and study their characteristics in relation to leprosy).

The foregoing is an illustration of the expense and difficulties inherent in population based surveys. Some are of the opinion that even if the resources and expertise are available it may be better to divert these resources to the control of the disease.

Information needs for planning

It is taken for granted that information on the magnitude of the leprosy problem is very desirable for managers. Information of some sort, for example, subjective impressions, are usually available. The crucial question that has enormous resource implications is how objective and how precise the information need be. Managerial decision making is a continuous process. Objectivity of the information is always necessary. On the other hand, information with a high degree of precision may not be crucial for immediate planning and allocation of resources. For example, it may be sufficient to be convinced that the prevalence rate is below 1 per 1000 or between 5 and 7 per 1000 etc. The planning process should normally indicate the order of precision crucial to decision-making.

Alternative approaches for estimation

The relationship to child prevalence: The high correlation between child prevalence rates and total prevalence rates for leprosy has been noticed in the past (vide Bechelli et al).¹ A limited analysis of the data from population-based random sample surveys in

1 Bechelli, L.N., et al. Proposed method for estimating leprosy prevalence rates in children. Bull. WHO, (1975) 148, 502-503.

nine different situations appears in Annex 1. Also the correlations have been examined over a period of 17 years in Polambakkam, an area of India where intensive leprosy control work has been and is still going on (Annex 2). The interesting feature that emerges from these data is that there is indeed a very high correlation between child prevalence and total prevalence. However, the actual ratio, i.e. child prevalence rate/total prevalence rate, can have variations from one place to another. From any one place such as Polambakkam, in South India, the ratio is not seen to vary very much in spite of the fact that the total prevalence rate has registered a sharp decline over the years. Thus, at least in one place, the ratio has not changed with total prevalence rates. It is not clear whether the differences in the ratios observed from one country to another are real differences or can be accounted for by differences in the age-specific coverages in the sample surveys; the sample surveys were not primarily designed to study the relationship and at this stage it is not possible to study in depth the reasons for the variations.

It would therefore seem worthwhile to explore, by a well designed study, how child prevalence rates reflect the total prevalence rates and whether such child prevalence rates can be used to derive the total prevalence rates with enough precision for planning purposes. It is generally much easier to examine a large number of children, e.g. school surveys, etc., and if extrapolations from such surveys are proved to be scientifically valid and reasonably precise, the method would seem to be worthwhile adopting, at least for obtaining base-line information on leprosy in communities where very little is known about the magnitude of the problem.

Relationship to cases on register

Most official information on leprosy is based on cases on register. It is generally agreed that cases on registers are gross underestimates of the actual magnitude of the problem. However, an examination of the data obtained from some sample surveys in the past reveals that there is a good statistical correlation between the cases on register and the actual numbers detected in the surveys. The pattern of cases on the registers, such as proportion of advanced cases, etc., can be quite different from that observed in population based surveys, but there is a suggestion that the crude number of cases on the registers, irrespective of their make-up, bears some relationship to the number of cases discovered in surveys; a relationship that could, of course, vary from one area to another depending on the quality of the leprosy services. Nevertheless, if extrapolation from registers can yield an approximate indication of the size of the problem, the method has much to recommend itself as it saves the effort and expense associated with population based surveys.

Rapid village surveys

A method very often used for case-finding is first to launch an intensive public information on the symptoms of leprosy, the possibilities for cure, etc., and then follow it up by visits to villages. Instead of making house-to-house visits the population with symptoms suggestive of leprosy is invited to report to a trained team visiting the village. The number of cases that can be discovered in this way would depend largely on the attitude of the population towards the disease, the sort of key village personnel collaborating with the visiting team and other socio-cultural factors. Nevertheless, if in any one area the number of cases detected in this way from village to village bears some reasonably constant relationship on the average to the actual number of cases as could be detected in the course of standard sample surveys methods, this could again provide another measure of the prevalence.

Some of the methods suggested above are from past experience in sample surveys. There could be others such as extrapolating from cases with visible disabilities. Before being recommended for general adaptation all these methods would need to be tested in typical situations for their validity and adequacy. A limited study is therefore proposed which, apart from providing evidence of validity and adequacy, can also highlight the operational problems in field studies of this nature so that, if necessary, the procedures can be modified and applied on a large scale if the initial results warrant.

An indication of the savings in resources when child prevalence or registered cases are used to estimate total prevalence is provided in the illustrative example in Annex 3.

The test study design

A rural area with an expected prevalence rate of at least five per thousand will be selected. It is suggested that the area should be such that, as far as possible, all the three methods outlined above can be tested. This pre-supposes that some form of leprosy service exists in the area with registers of cases.

It is proposed to compare the three methods, either individually or in a suitable combination, with the standard sample survey method.

If the study is specifically designed to obtain estimates of prevalence with great precision, a very large sample will be required. Since the aim of this study is primarily to test the cheaper methods, a much smaller sample size is suggested. In the absence of prior knowledge of the precise extrapolating factors from each one of the methods and their variations, it is difficult to arrive at a suitable sample size for the study. However, limited experience from some population based sample surveys suggests that with an endemic level as indicated five sample blocks with a population of 3000 in each block should be enough in the first instance. Depending on the findings, the sample size could be suitably increased if the situation so warrants.

Thus, with a sample size of 15 000 individuals, clusters of approximately 600-1000 will be chosen at random according to standard sampling procedures. As far as possible, whole villages, or groups of villages should be considered as clusters.

To avoid possible bias that may be introduced by repeated visits to the same villages, it is preferable to test the "Rapid Village Survey Method" on a separate set of villages if possible. In any case, the suggested sequence of operations is as follows:

- (1) The rapid village survey;
- (2) An examination of the registers with the leprosy service, and
- (3) Population based random sample survey

In order to secure a larger base of children all the children of selected age groups (e.g., 5-14) in the schools serving the selected clusters will be examined. In practice, this would mean not only examining children from the selected villages but also from the neighbouring villages.

It is expected that there will be two independent examinations of: (1) many children, once during household visits and again at school; (2) many of the cases presenting themselves during rapid village surveys and again later during household visits; (3) the cases on the leprosy registers would have already been seen by the services. They will again be examined during the sample survey.

It is important that the teams engaged in the study are independent of the personnel of the leprosy services working in the area of study. Also, it is preferable to have two independent teams, one for the rapid village survey and another for the population-based survey where the teams visit the houses.

In all these instances where double or multiple independent examinations are involved, a good record linkage system should be established to provide information on:

- (1) the characteristics relevant to leprosy of children not attending school;
- (2) the characteristics of the population such as visible lesions or deformities that prompt voluntary reporting in rapid village surveys;

- (3) the characteristics, such as proportion of multibacillary patients and with presence of disabilities, of the patients on register as compared to the cases detected in the sample survey; and
- (4) estimates of observer variation in the diagnosis of different forms and stages of the disease.

It is expected that the information obtained above from record linkage would permit the development of more refined statistical procedures for the derivation of true population prevalence from the rapid assessment methods.

Leprosy: Comparison of Child Prevalence Rates with
Total Prevalence Rates per 1000
(As observed and estimated)

Country	Prev.rate/1000 Age: 5-14	Prev.rate/1000 All ages	<u>Child prev.</u> Total prev.
Burma (69-72)	19.8	25.1	0.79
Shwebo (63)	33.6	32.2	1.04
Myingan (63)	40.2	44.3	0.91
N. Nigeria (60)	32.6	28.7	1.14
India (62)	14.4	21.4	0.67
India (67)	17.1	29.4	0.58
India (69)	44	40.6	1.08
India (69)	22.8	32.7	0.70
India (62-67)	23.8	25.8	0.92

ANNEX 2

LEPROSY SURVEYS - POLAMBAKKAM (INDIA)

(As observed and estimated)

YEAR	Prev.rate/1000 Age: 5-14	Prev.rate/1000 All ages	Child prev. Total prev.
1955	10.21	13.47	0.76
1956	22.27	25.03	0.89
1957	28.68	29.18	0.98
1958	28.90	29.90	0.97
1959	22.69	26.42	0.86
1960	17.69	20.99	0.84
1961	15.12	19.95	0.76
1962	13.74	19.04	0.72
1963	12.44	17.91	0.69
1964	10.71	16.56	0.65
1965	9.42	15.15	0.62
1966	8.81	14.37	0.61
1967	8.91	13.99	0.64
1968	9.24	13.85	0.67
1969	8.86	13.17	0.67
1970	7.85	12.47	0.63
1971	7.94	12.37	0.64
1972	7.98	11.83	0.67
1973	7.47	11.19	0.67
1974	7.38	10.39	0.71
1975	7.11	9.55	0.74
1976	6.29	9.04	0.70
1977	6.33	8.34	0.76
1978	6.20	7.83	0.79
1979	6.16	7.62	0.81
1980	6.34	7.59	0.84
1981	6.05	7.30	0.83
1982	5.66	7.76	0.73

RESOURCES SAVED BY THE RAPID METHODS OF ASSESSMENT OF THE
LEPROSY SITUATION IN COMPARISON WITH SAMPLE SURVEYS

T.K. Sundaresan

Introduction

In order to give an idea of the possible economy in resources when surrogate variables such as child prevalence or registered cases are used to estimate overall prevalence rates, the following two examples are given:

1. Extrapolation from child prevalence rates

Suppose that in a region with a population of one million it is suspected that the prevalence rate of leprosy is over 5 per 1000 and it is desired to assess objectively and with a reasonable degree of precision, the order of magnitude of the problem as it actually exists.

Based on past experiences, within one community (such as a province of a country) and within a broad range of endemicity (e.g., between 5 per 1000 and 20 per 1000), where the epidemiological pattern of the disease has not changed appreciably (for example, prior to the introduction of MDT) the prevalence rates in children are seen to be closely correlated to the prevalence for all age groups and remains reasonably constant over a period of time.

In a situation where the nature of the relationship is not precisely known, let us suppose a sample of 15 000 population is selected in a rural area. Since it is usual to adopt cluster sampling with whole villages as clusters, wherever possible, the clusters can be grouped to form "blocks" of 3000 resulting in five such blocks. Further, all the children in schools serving the selected clusters will be examined resulting in the examination of say 30 000 in the 5-14 age group.

Let us further suppose that the survey has yielded the following results which are based on the surveys carried out over a period of five years from 1978-1982 in Polambakkam and given in Annex 2.

Prevalence rates per 1000			
Block	All ages	Ages 5-14	Total prev. rate/child prev.rate
1	7.83	6.20	1.26
2	7.62	6.16	1.24
3	7.59	6.34	1.20
4	7.30	6.05	1.21
5	7.76	5.66	1.37
ALL	7.62	6.08	1.26

Thus, on the average, the prevalence rate for all ages is seen to be 1.26 times that of the prevalence rate in children between the ages 5-14. The number, viz, 1.26, which we might call as an "extrapolating factor" has itself some statistical variability which is measured by its variance which in this instance has been computed to be 0.00093.

Suppose in another but similar part of the country or in a subsequent year in the same community some 30 000 children are examined and the prevalence rate is found to be 5 per 1000, we might be able to say that the expected overall prevalence rate is 6.3 per 1000 with 95% confidence intervals of 5.3 per 1000 and 7.3 per 1000.

A simple random sample of a population of 22 000 individuals will yield the same order of precision but allowing for the effects of cluster sampling, in practice, one may need to choose a sample size of 50 000.

Thus the resource requirements for examining 30 000 children, mostly from schools, can be compared for the resources needed to do a population based survey of 50 000 individuals.

In an effort to simulate a real-life situation the data in the above example were taken from total population surveys over a period of five years in an area in South India, on a population of over 600 000 with children in the age group 5-14 years constituting nearly 20%. With samples of 30 000 children, the variance could be higher. With the age distribution of the population being similar, the 30 000 children would be drawn from a population of 150 000.

The example is provided to illustrate the order of magnitude in the saving of resources. A moderate loss in precision of the estimates when extrapolating from child prevalence is more than offset by the saving in resources. This is especially true when it is recognized that non-sampling errors, such as non-coverage, incomplete physical examinations etc., are much higher when examining adult population.

Extrapolation from registered cases

In the sample survey in Khon Kaen in Thailand in 1962, it was possible to obtain the following comparison between registered cases and total cases by sampling blocks.

Sample block	Pop. examined	Cases registered	All cases	Registered cases All cases
1	3 019	25	34	73.5%
2	2 448	34	49	69.4%
3	2 457	36	56	64.3%
4 + 5	3 711	20	31	64.5%
6	3 291	4	5	80.0%
7+8+9	3 932	22	30	73.3%
All	18 858	141	205	68.8%

The prevalence rate as computed from the sample survey was 12.37 per thousand with 95% confidence limits of 14.4 and 10.16.

In population groups of around 3000 it is seen that the registered cases represent between 64% and 80%. If one makes an assumption that on the average the registered cases are 70% of all cases but could range from 64% to 80%, the estimate for prevalence rates as extrapolated from registered cases would be 11.9 per 1000 but could range from 13.1 per 1000 to 10.5 per 1000. Thus, extrapolation from registered cases can provide estimates just as precise as from expensive population based surveys.

In practice, estimates are often based on registered cases only. A test study on the lines suggested will give an objective basis for the extrapolation.

MEETING ON METHODS FOR THE RAPID
ASSESSMENT OF THE LEPROSY SITUATION

Geneva, 15-16 April 1988

LIST OF PARTICIPANTS

- Dr J.L. CARTEL, Institut Malarde, P.O. Box 30, Papeete, Tahiti, French Polynesia.
- Dr D. DAUMERIE, Institut Marchoux, B.P. 251, Bamako, Mali.
- Dr E. DECLERCQ, Ecole de Santé publique, Epidémiologie, UCL 30.34, Clos Chapelle-aux-Champs 30, 1200 Brussels, Belgium.
- Dr P. FEENSTRA, Royal Tropical Institute, Wibautstraat 135, Amsterdam, The Netherlands.
- Dr G. GROENEN, Coordinateur National des Amis Père Damien, Attaché au Bureau National de la Lèpre, B.P. 8075, Kinshasa, Zaire.
- Dr HAIDAR ABU AHMED, University of Khartoum, Khartoum, Sudan
- Dr C. STEENBERGEN, Office of the Permanent Secretary, Ministry of Health, P.O. Box 30205, Lusaka, Zambia.
- Dr M. ZUNIGA, Epidemiologist, Instituto de Biomedicina, Apartado postal 4043 (Carmelitas) Caracas 1010-A, Venezuela.

Secretariat

- Dr N. Chitimba, STC, AFRO
Dr J.W. Lee, WPRO
Dr L. Lopez Bravo, LEP/HQ
Dr S.K. Noordeen, LEP/HQ
Dr H. Sansarriq, STC, LEP
Dr P. Smith, Consultant, TDR
Mr T. Sundaresan, Consultant, LEP
Dr K. Uemura, HST/HQ
-