

# INFORMATION SYSTEMS IN LEPROSY

Session on “Operational issues in leprosy, including management of patients”

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- The most current concepts of information systems include equally telecommunications systems, and/or their related equipment; interconnected systems or subsystems which use technology in the gathering, storage, treatment, management, control, presentation, exchange, transmission, reception of voice and/or data, including the software or hardware employed for these purposes.
- In regard to this definition, it is common in academic circles to use the term ICT - Information and Communication Technologies. An information system contains various interconnected elements which gather (input), treat and store (process), disseminate (output) data and information and provide a feedback mechanism.
- Before the popularization of computers, information systems were based fundamentally on techniques for storing and recovering information in large archives.
- Generally there existed the figure of the archivist, the person responsible for the organization of data, including recording, cataloguing and recovery, when needed.
- An information system does not necessarily require the use of computers; it only requires that the various parts of the system work among themselves to generate information.
- One of the principles of any system is ***that its parts work together towards a common objective***. Information systems are no different.

- The aim, however, is a more trustworthy and less bureaucratic flow of information. The main advantages of a well-constructed information system are:
  1. fast access to information;
  2. guaranteed integrity and veracity of information;
  3. guaranteed security and access to information;
  4. quality of information, which is essential for good decision making.
- The system can just as equally be manual as based on information technology, or on a mixture of both.
- We can classify information systems based on information technology according to the type of information processed:
  1. **Operational Information Systems:** these are generally found in companies using automated processes for their routine transactions.
  2. **Management Information Systems:** these group and synthesize data related to the operation of the organization with the aim of facilitating management decisions.
  3. **Strategic Information Systems:** these use complex analysis, comparison, simulation and other features to assist in strategic decision making. They integrate and synthesize data from sources both internal and external to the organization.
- The main benefit offered by information systems technology lies in its capacity to simultaneously process large amounts of data, making the desired information available practically on-line.

- This potential, however, is of little worth if systems and their routines, processes and methods are not well-coordinated and analyzed. Computerizing inefficient systems produces new problems and few solutions, as well as obscuring the possible causes of these failings.
- More than just a fad, information technology needs to be understood as a tool, one way with which to guarantee quality, competitiveness and cost reductions.
- The process of transforming data into information is highly necessary for the decision-making process. There is a strong connection between management information systems and the making of decisions. This implies that such an information system be efficient, in order to produce good decisions. The way in which information is presented can affect the way in which it is used.
- The World Health Organization defines a health information system as a mechanism for gathering, processing, organizing, operationalizing and evaluating health services. It should be taken into consideration that the transformation of data into information requires, as well as analysis, the dissemination of the information, followed by recommendations for initiatives.
- As in any other sector, information in the area of health should be understood as a tool for reducing uncertainties and an instrument for focusing priorities, leading to responsible planning and the execution of actions which shape and transform reality.
- Information processing requires both technological and human resources, as well as new forms of coordination and control which allow for the definition of the basic information needed.
- In most countries, the model of information system used in the area of leprosy is based on the gathering of data on mortality rates, generating epidemiological and operational information.

- In recent years, there has occurred a significant advance in information about leprosy, both in terms of access and also in terms of the possibility of analysis. Despite this, however, there still exist information systems with the following characteristics:
  1. centralization of data,
  2. limitations on the use of data and information,
  3. delays in analysis and its return to the source of the original data,
  4. little dissemination of information about the disease,
  5. restricted access
- There is a need to overhaul the current situation, aiming for information systems in which data is analyzed in the very locale where it is gathered, providing efficient support for planning and initiatives aimed at improvements in care.
- As such, they must include sentinel systems for avoidable situations, such as in advanced multibacillary (MB) and GII cases which require immediate treatment and investigation.
- Alerts for critical and grave situations need to be integrated, advising managers, care providers and health authorities immediately about incidences of the disease amongst children and their contacts, in order for immediate and effective measures to be taken.
- To avoid Leprosy need to take advantage of developments in information and communication technology in order to improve education and the dissemination of available knowledge about the disease.
- Maintaining and updating of case records in information systems is a fundamental activity for evaluating progress towards the goal of eliminating leprosy as a public health problem in many countries.

- Computerized mapping systems such as GIS provide an excellent means of analyzing epidemiological data, revealing trends, clustering of cases, dependencies and inter-relationships that would otherwise remain hidden in data shown only in a tabular format. GIS can therefore be seen as a valuable management tool in the elimination program, strengthening national, regional and sub-regional capacities for surveillance and monitoring.
- There are two basic elements in developing a GIS for leprosy. The first, geographic, element involves accurately recording the location of each health facility in the country. The second element is recording the relevant baseline data for each health facility including:
  1. location of the health facilities,
  2. number of registered cases,
  3. number of new cases detected annually, and
  4. type of leprosy treatment available.
- In the Western Pacific Region, a GIS was implemented as a pilot project in 2001 to identify pockets of leprosy cases at the provincial, operational, district and health centre levels to improve case detection. A WHO-supported training program was conducted in Cambodia and similar activities are on-going in Vietnam.
- Amongst those information technology systems which can be usefully employed to further the elimination of leprosy are digital versions of imaging, sound and physiological signals, etc.
- Various institutions are making available this type of information via Internet, using the World Wide Web, an interface which is easy to learn and use. Good examples in this area are initiatives by the DATASUS Brasil, that the national Leprosy Information Database in disseminating on the Internet since 2003. Other example, is the Instituto Lauro de Souza Lima, in Bauru-Brazil, with Tropical Dermatology On-Line, a collection of relevant images of clinical cases of dermatological diseases

with emphasis on leprosy, and the Health Virtual Library - Leprosy (BVS - hanseníase), a free-access virtual library that contains documents, information and links, and which hosts the on-line version of \*Hansenologia Internationalis\*, the single indexed periodical devoted to leprosy in the Americas.

- Another technological initiative which promotes quality care for those suffering from leprosy is the adoption of the Electronic Patient Record (EPR) is under development in the State of Paraná, in the south of Brazil.
- By means of the Internet, an outline of human / machine interaction – medical cyberspace - is being traced. A “virtual medical community” is not impossible, as is evidenced by diverse projects like the Virtual Hospital, discussion lists, increased use of e-mail, the World Wide Web, etc.
- The current global state of connectivity permits that medical information resources can be shared.
- There exists, for example, a world bank of bone marrow donors for transplant purposes, which can be consulted on the World Wide Web. It contains around 2.3 million donors from a number of countries, and is an example of how electronic information sharing can save the life many patients.
- Using the “Ciberambulatório”, a local doctor can fill in a patient’s details and receive a second opinion regarding the diagnosis. The "Tutor Eletrônico" offers educational content about various diseases, such as malaria, leprosy and tuberculosis.
- Telemedicine can be applied in three ways, using the available technology. At the high technology level, there is the use of videoconferencing systems and radiofrequency networks. These permit the performing of surgical procedures at a distance, using robotics, for example.

- The second category of telemedicine uses wideband Internet access, permitting chat for debates and distance courses, as well as making available high-resolution images. When only a lower level of technology is available, it is possible to use dial-up access in conjunction with CD-ROMs.
- The use of telemedicine in the area of leprosy, which has been developing with greater intensity since 2004, promotes care and education in geographically distant locations in the municipality of São Paulo, using telecommunication and computer technology.
- Currently, the main telemedicine complex in Latin America is in São Paulo. The successful experience of the use of telemedicine in leprosy treatment at the Hospital das Clínicas and at Bauru (Instituto Lauro de Souza Lima) shows that a second consultation is a powerful tool in increasing access and the opportunity for a quality diagnosis. In addition, this institution offers one of the most up-to-date videoconferencing facilities, including portable equipment, a classroom where all students have access to the internet and a centre for virtual medical attention.
- Globally, one of the most visible medical information systems is MEDLINE, the large bibliographic database developed and maintained by the US National Library of Medicine, which offers 9 million references, with abstracts, freely on the Internet by means of the PubMed system. The value of this resource for progress in medical knowledge and for access to scientific information for educational purposes is simply amazing, especially at the beginning of the century, when the volume of medical information is growing exponentially.
- Making the situation even more complex, many Internet sites have begun to publish medical information, such as MedScape, HealthGate and HighWire Press. In Brazil, for example, the e\*pub group at the University of Campinas is of note in this respect.
- We should not forget to mention the numerous lists, such as those of the World Health Organization, the French-language Association of Leprologists and Dr. Noto.

- Finally, it should be mentioned that this presentation on information systems in leprosy has followed all the steps in the formulation of an information system: content research on the World Wide Web, data gathering, and sharing of current and future applications in the treatment of leprosy with all of you present here today, ladies and gentlemen. I hope you have found it of interest.
- Thanks for you attention!