

Lesson Learned Health Information System of Taiwan Leprosy Control Program for Indonesia Leprosy Control Program

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Abstract

Background of study: Indonesia is the three biggest endemic areas after India and Brazil. In 2010, had been reported 19.785 registered prevalence, 17.012 new cases and 1.822 the new case found with grade-2 disabilities [2]. Utilization of technology in Leprosy Control Program was not maximize in developing countries include Indonesia although there were many cases. It posed a lot of problem in that program such as Drop out MDT (Multi Drug Treatment) treatment because difficulties in monitoring, difficult to conduct active case finding, and difficult to make timely report. Taiwan is one of the areas which already had eradication in leprosy; all new cases came from foreigner from epidemic countries [3]. Taiwan also one of the best implementor of health information system in the world so it necessary to learn how leprosy control program and implementation of health information system in Taiwan to develop Indonesia leprosy control program and maximize computerize of Leprosy Control Program in Indonesia.

Method: Data collections in this research through deep interview to 3 staff district leprosy supervisor in Disease Control Officer of Health Office of Pekalongan District and also 3 staff Control Disease Center (CDC) in Taipei. This research also made observation in information system of leprosy Control Program in Indonesia and Taipei

Result: In Taiwan, there are a drug observer and a public health nurse to observe patient treatment. This system made simple to monitor complete of patient treatment, and beside that regulation in Taiwan can drive patient to finish their treatment. Indonesia also using drug observer system but just in TB Program called DOTS (Directly Observer Treatment, Short Course). Taiwan did not have difficulties in continuity and availability of leprosy data because they have been using information system to store data and reporting system. Indonesia still had that problem because of a rotation system in civil servants work environment. Taiwan Leprosy information system through National ID connected patient with their contact so it very easy to contact trace to block

develop new case in Taiwan, Indonesia Leprosy electronic application have been implemented it was just registry patient to make report; it must be augment to optimize the effectiveness leprosy control program in Indonesia.

From Taiwan experience in leprosy control systems, Indonesia can learned that drug observer and information system play important role to prevent develop new case through trace contact and monitoring MDT treatment. The recent of Indonesia Leprosy electronic application should be build up with database management system for easier retrieve information and keep the data safely and store in a long time.

Keyword: Leprosy, DOTS, information system, national ID

INTRODUCTION

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae*. It usually affects the skin and peripheral nerves, but has a wide range of clinical manifestations. Among communicable diseases, leprosy is the leading cause of permanent physical disability. The mode of transmission of the leprosy bacillus remains uncertain, but most investigators believe that *M. leprae* spread from person to person primarily as a nasal droplet infection. The incubation period is unusually long for a bacterial disease: generally five to seven years.¹

The World Health Assembly had set the goal for elimination of leprosy as a public health problem since 1991. In fact until 2010, there was 130 countries still reported Leprosy case and globally there are 228 474 new cases were detected.²

Indonesia is the three biggest endemic areas after India and Brazil. In 2010, had been reported 19.785 registered prevalence, 17.012 new cases and 1.822 the new case found with grade-2 disabilities.² It means more than 10 % grade-2 disabilities found in Indonesia. That fact should draw attention for intervention because prevention of disability is therefore a main aim in a leprosy control programs. The data also showed that Indonesia still had problems on early detection of leprosy and adequate treatment because they were the most effective action to prevent disability.

There are 12 elements the Enhanced Global Strategy and some of them can be enriched with technology through Health Information Systems (HIS). Implementation of HIS in routine services, early case finding and surveillance will make performance more efficient and effective. The goal of leprosy elimination is not just optimistic if started using technology through development of computerized databases on leprosy, including data collection, reports and analysis, estimates and predictions of leprosy problem trends.

Utilization of technology in Leprosy Control Program was not maximize in developing countries include Indonesia although there were many cases. It posed a lot of problem in that program such as Drop out MDT (Multi Drug Treatment) treatment because difficulties in monitoring, difficult to conduct active case finding, and difficult to make timely report.

Taiwan is one of the areas which already had eradication in leprosy; all new cases came from foreigner from epidemic countries.³ Taiwan also one of the best

implementer of health information system in the world so it necessary to learn how leprosy control program and implementation of health information system in Taiwan to develop Indonesia leprosy control program and maximize computerize of Leprosy Control Program in Indonesia.

METHODS

Location

The elimination of Leprosy disease as a public health problem, defined as reaching a prevalence of less than one leprosy case per 10,000 populations. This research setting was taken on one of epidemic area in Central Java with a high prevalence rate.

This research has done in Division Control Disease at Pekalongan District Health and Taipei Control Disease Centre, Taiwan

Collecting data

Data collections through deep interview to 3 staff district leprosy supervisor in Disease Control Officer of Health Office of Pekalongan District and also 3 staff Control Disease Center (CDC) in Taipei. This research also made observation in HIS of leprosy Control Program in Indonesia and Taipei.

Data analysis

After all data had been collected, the author initially familiarized herself with the data by listening to tapes and re-reading field notes in order to list key ideas and recurrent themes until the researcher became familiar with them in their entirety. All of transcript and response summaries used for 'within-case' analyses and case reports for 'cross-case' analyses respectively.

RESULT

A. Indonesia's Leprosy Control Program

Leprosy Service

In Indonesia, Leprosy control performed by Primary Health Center (PHC) at sub-districts level or in villages. At the health center, leprosy services are provided by a Leprosy health worker. Usually LP had background education as nurse. It should be make LP easy to be trained and to manage Leprosy Control Program.

Leprosy health worker should treat patient with Multi Drug Treatment (MDT) drug and different in Leprosy type. Fixed duration treatment for MB patients are 12 monthly and for PB patients are 6 monthly doses of MDT. One on the month of their treatment, the patients should come to PHC get the MDT drug but there wasn't a supervisor for patient taking their drugs. After take all the dose those persons were cured and should be discharged from register.

Duration of treatment sometimes poses a problem because patients did not complete treatment due to many things. Sometimes was very hard to make patient came up to PHC get their drug otherwise Leprosy health worker at PHC was not just focus at Leprosy program, it made sometimes unwittingly patient get default and unmonitored. And sometimes unfortunately patients also reject to get and to take their medicine.

Leprosy Control program not also treating the leprosy patients but also detecting new case and increasing peoples knowledge and awareness of leprosy through health education, activities called "Leprosy Elimination Campaign" (LEC). In detecting new case, active and passive case finding methods have to done. It means need full support and focus from Leprosy health worker in their program. In the fact Leprosy health worker also has tasks in some other health center's programs too so very difficult for them to meet demand of the program. That condition occurred because of limited resources in Primary Health Centres.^{4,5}

The other problem was a job rotation in Primary Health Centre and District Health Office, sometimes it made no connection data or some file missed in the health program include Leprosy. It comes about because of the data just stored in some papers and some files in the computer like excel file so that when the staff changed there weren't completely transfer of documents or files.

Dataflow

All this time Leprosy control program in Indonesia has been carried out manually starting from medical records, monitoring and surveillance system in Primary Health Centre (PHC) by Leprosy Health worker (LW). LP staffs collect report to health office district level;

There was a leprosy book for medical record and cohort registry form for monitoring MDT Treatment. And a standard excel format for Leprosy Report which entry by district Leprosy Supervisor. (Figure 1)

Leprosy book had information about patient started from patient identification, case found, leprosy history contact, physical examination, registry contact and disability recorded. Once a month the book would collect to District office to process develop into excel format report

Information System

Collecting data from Leprosy patient have done manual through leprosy book and cohort registry by Leprosy health worker at PHC and Districts leprosy supervisor would aggregate from that form to excel format.

During make excel report; it found that there was a vacuum of record form at PHC because of all the form was taken to Health Office. But leprosy program service still routinely given in PHC but recorded in some papers and not included in PHC medical record.

Indonesia Leprosy electronic application was an excel format file (Figure 2) with consists many sheets. It was very simple, consist hyperlink between sheets to make some report sheets. The first sheet was the start menu, the second was the sum of leprosy patient by PHC, and the third and fifth sheets were individual cohort registry.

And because of excel format, it just single user and there was no authorization for user. Each districts had a different excel file which would be collected in province health office.

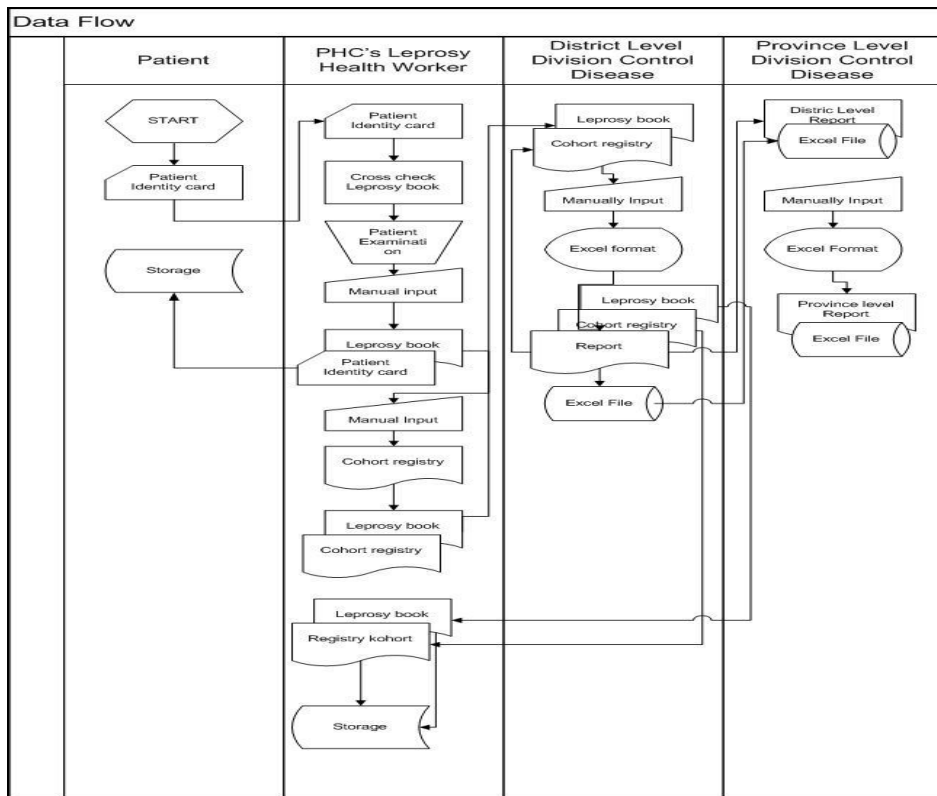


Figure 1. Data flow of Indonesia's Leprosy Control Program



Figure 2. Indonesia Leprosy Electronic Application

B. Taiwan Leprosy Control Program Leprosy Service

In recent ten years new case of leprosy in Taiwan was less than 10 cases/years and all of them were foreigner or imported cases. Taiwan had five destination hospitals for leprosy patients.

In Taiwan there was no Primary Health Center (PHC). People usually go to hospitals or private clinics when get sick, they can choose every hospital or clinics for destination because all of the health center covered by National Health Insurance.

Leprosy patients had drug an observer to monitoring patients swallowed the medicine everyday and a public health nurse that would visited them once a month. While visited patients public health nurses and drug observers brought some document and after that they would made entry to the Taiwan Leprosy Information systems. (Figure 3)

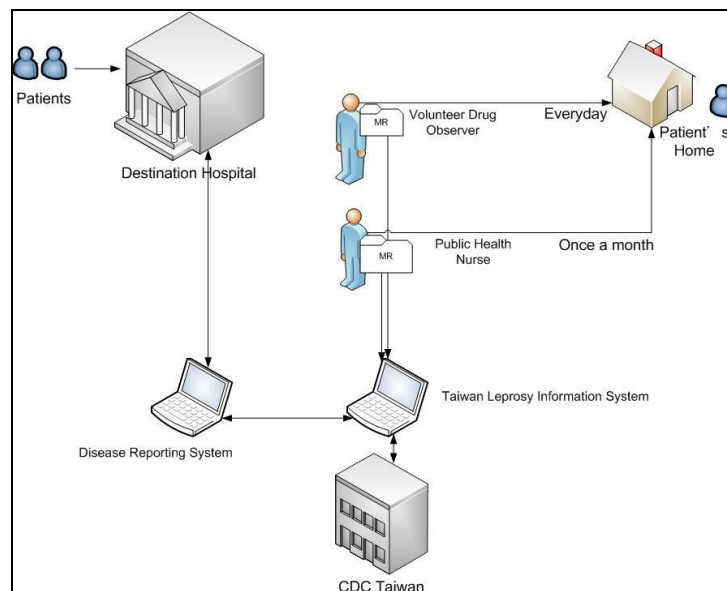


Figure 3. Taiwan Leprosy Service

Leprosy Patients should swallow their medicine through drug observer knowledge and according to the regulation, patients can not reject to take their medicine because they would be fined, because of leprosy patients usually were low income person they will comply that law.. Patients should take their medicine for six or twelve month depend on their leprosy type. After they finished their treatment (Release From Treatment-RTF) they would be followed by public health nurse once a month and still registered in Taiwan Leprosy Information System (Taiwan LIS).

Drug observer came everyday to patient house from Monday-Friday and in Friday they gave extra drug for patient took their medicine by them self in weekend.

Dataflow

There were some regulations for all health care providers in Taiwan to report notifiable infectious diseases. They were included physicians, clinics and hospitals. Other than that they would be fined. Control Disease Center (CDC) Taiwan already had prepared web based reporting systems to collect the information from health care providers.

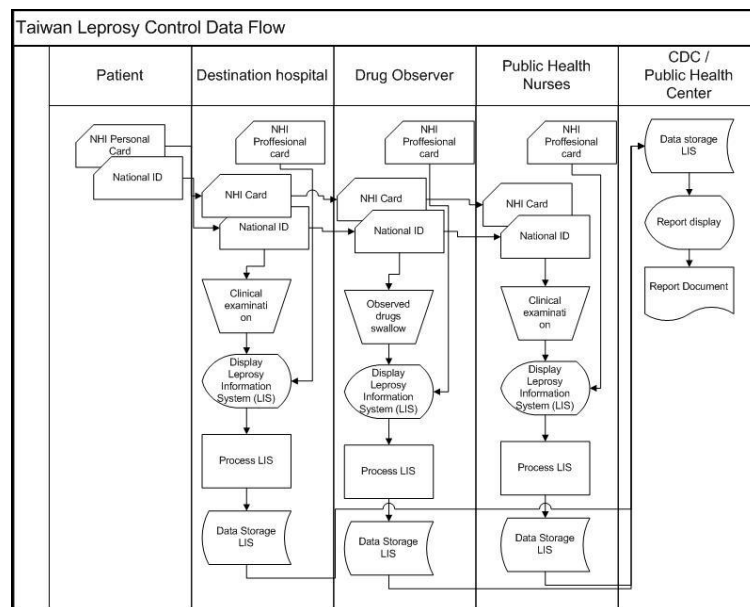


Figure 4. Taiwan Leprosy Control Data Flow

Taiwan LIS used National ID and National Health Insurance (NHI) in their system for Taiwan citizen and passport number or Alien Resident Card (ARC) number for foreigner.

Information System

Taiwan had CDC web-based communicable disease reporting system for hospitals, clinics and public health units reported notifiable disease. Reporting data were automatically transferred to Taiwan LIS which allow public health nurses to management cases.

Taiwan LIS had system login that required personal identification chip chards such as national health insurance cards, citizen digital cards or physician's identification card and log-in passwords (Figure 4,5)

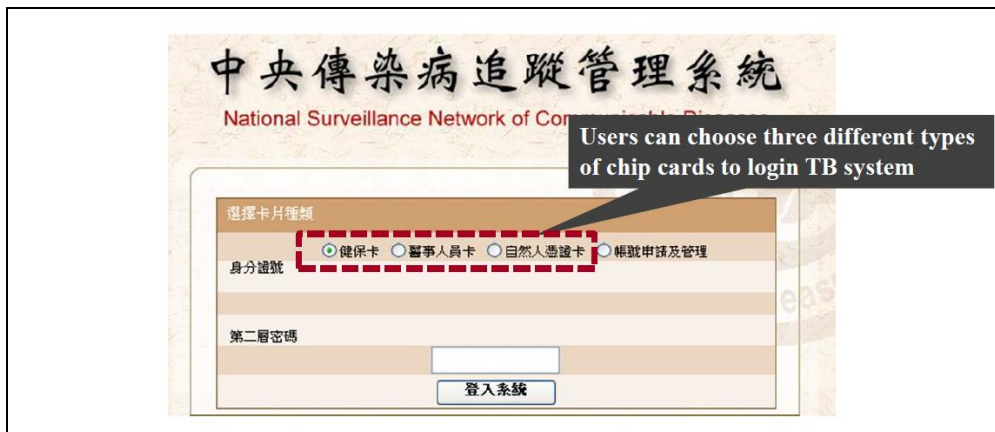


Figure5. Login System of Taiwan Leprosy Information System

Public health nurse and drug observer would enter to Taiwan LIS every time they visited patient leprosy patients. System would record every visited by drug observer daily and visited from public health nurse monthly. Because of drug observer didn't have medical background they had different interface with public health nurse, they didn't have task for physical examination.

Taiwan LIS made easy for monitoring regularly patient take their medicine (Figure 6) because it could detect daily which patient did not receive visited from drug observer.

結核病管理中個案地段負責人品管點稽催清冊

稽催事項: 2 - DOTS郵治日誌稽催清冊 | 管理縣市別: 基隆市 | 確定執行查詢作業 | 操作說明 | 摘要統計

管理轄區內截至昨日止符合篩選條件者: 8 人 · 查詢: 2012/1/25 下午 04:57:45 · 操作: 羅尹

管理單位	照護院所	姓名	身分證號	地段負責人	前次關懷日	前次郵治迄今	關懷天數	痰塗片	多重抗藥	最近就醫日	病障
基隆市中正區	0111070010				2012/7/13	12 ★	32	-		2012/6/29	
基隆市仁愛區	1301200010				2012/7/3	22 ★	82	-	MDR-TB	2012/7/18	
基隆市中山區	1111060015				2012/7/20	5	7			2012/7/20	
基隆市安樂區	1111060015				2012/7/10	15 ★	62	-		2012/7/11	
基隆市信義區	0111070010				2012/7/20	5	57	-		2012/7/17	
基隆市信義區	2211070014				2012/7/18	7 ★	85	+		2012/6/25	無障
基隆市信義區	2211070014				2012/7/18	7 ★	35	+		2012/7/9	2健
基隆市信義區	1111060015				2012/7/20	5	109	-		2012/7/20	

Patients did not receive DOTS observers visit for more than 3 days

Figure 6. User Interface for drug monitoring

The Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy will continue to be based on the principles of morbidity control, i.e. timely detection of new cases and their cure with effective chemotherapy. This control program consisted of passive case detection, treatment with MDT, and

active tracing of people in contact with patients [1]. The advantages of Taiwan LIS were easy to trace contacts with patient because it stored in system and connected with patient ID so the primary advantage was the active tracing of individuals that had been in contact with newly diagnosed leprosy patients [Figure 7].

◆ 接觸者發病警示：個案由管理單位先行受理，CDC分局必須於地方衛生機關受理後才可廣確執行。

指標個案	接觸者證號	姓名	管理單位	地段受理情形	CDC轄區受理者
A110*****	L103*****		台中市北屯區	地段未受理	CDC尚未受理
M122*****	M122*****		南投縣仁愛鄉	馬自琴	CDC尚未受理
A103*****	A121*****		台北市萬華區	吳瑋傑	CDC尚未受理
S100*****	R101*****		台南市官田區	地段未受理	CDC尚未受理
M121*****	M122*****		南投縣信義鄉	地段未受理	CDC尚未受理
4個指標	F124*****		桃園縣龍潭鄉	李佳芬	CDC尚未受理
V200*****	V200*****		台東縣成功鎮	地段未受理	CDC尚未受理
F127*****	T122*****		新北市中和區	地段未受理	CDC尚未受理
L121*****	L260*****		台中市南屯區	王詩萍	CDC尚未受理
T202*****	T102*****		屏東縣佳冬鄉	地段未受理	CDC尚未受理

Figure 7. Contact profile during Leprosy case report

DISCUSSION

A. Leprosy services

The mainstay of current leprosy control is early detection and treatment with multidrug therapy (MDT). In 2011, there was a decline number of Leprosy patient have finished their treatment in Central Java Province, Indonesia from 90% to 85% in PB Type and 95 to 76% in MB Type.⁷ In the fact some leprosy patient did not get MDT drug from Primary Health Center once a month and this condition was not aware by leprosy health worker until late. The most serious harm that can be done if patients do not take MDT regularly is that the cure will be delayed or incomplete. The disease activity will progress and the patient may develop serious disabilities and deformities. These patients will become a source of infection to the community, in addition to perpetuating stigma generated by unsightly deformities. More seriously, if the irregularity is selective to one or the other drug in MDT then there is a possibility of drug resistance to multiple drugs.⁸

In Taiwan, drug observer took medicine to the patient home and observe patient swallow their drug. This system made simple to monitor complete of patient treatment, beside that regulation in Taiwan can drive patient to finish their treatment. All of those factors can prevent the spread of infection, disabilities and resistance of leprosy. In fact in recent ten years only 10 new cases in Taiwan and

all of them are imported. It means the development of leprosy disease had been eradicated in Taiwan.

Drug observer system already used in TB Program called DOTS (Directly Observer Treatment, Short Course) in Indonesia but not implemented yet in leprosy program. Since every years Indonesia develops so many new cases and come to be the third biggest new case if leprosy, Indonesia Ministry of Health should be pay more attention to the leprosy program such as using DOTS systems. Although leprosy did not cause of death otherwise leprosy patient will through so many pain create by relapses and reaction and also social impacts that not easy to endure by patients and their family.

Relapses and reaction were different but both of them would make patient suffer. Relapse indicates a failure to treat the infection thoroughly and reaction was immune-inflammatory phenomena that occur during the evolution of the disease. Both of them often observed after the patient has been released from treatment (RFT) from multi-drug therapy (MDT).^{6,9} In the fact leprosy patient was very suffering because besides battling their illness also had to fight against stigma. No disease has been more closely associated with stigma than leprosy. Stigma attached to leprosy leads to loss of employment even before manual labor becomes more difficult due to disability that often results from late or no treatment. It also leads to exclusion from society, causing physical and emotional distress. Fear of stigma, can prevent patient and their families sought the help they need. Health care stakeholder should support patients and their families not in despair.

Leprosy health workers in Indonesia not also treating the leprosy patients but also detecting new case through active and passive methods and also increasing people's knowledge and awareness of leprosy through health education activities called "Leprosy Elimination Campaign" (LEC). And contrary they also have tasks in another health programs so it was very difficult for them to meet demand of the program. That condition occurred because of limited resources in Indonesia's Primary Health Center.^{8,10} The limitation of resources made they had burdensome time and effort to take care of data if there were rotations in PHC or districts health office. Referring to that fact, Indonesia should examine using information systems with database management system for Leprosy Control Program so that continuity information in leprosy patient will not be buried.

B. Data Flow

Taiwan did not have difficulties in continuity and availability of leprosy data because they have been using information system to store data and reporting system. There was not lack of information because of the change of staff in health care or health office because everyone who has authorization can retrieve information from the system and made query information whatever they need it (Figure 4)/

Indonesia has a rotation system for civil servants in their work environment. Sometimes it posed problems in sustainability of data in their program especially which using paper base.

During this time leprosy record still in paper base, patient who through RFT should remove from cohort registry and leprosy health worker should make surveillance for patient during 5 years after RFT .It made very difficult for them to find information for surveillance.

Duration of leprosy control program needed a good recording and reporting while paper base record had lacked such as easily lost and damage. The use excel format on the district level also do not help much because of separately in each year. In the fact finding information RTF patient after 5 years on paper base was not simple and easy to do by district leprosy supervisor and leprosy health worker.

C. Information System

The Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy will continue to be based on the principles of morbidity control, i.e. timely detection of new cases and their cure with effective chemotherapy. This control program consisted of passive case detection, treatment with MDT, and active tracing of people in contact with patients.¹ In Indonesia, control program focus on passive case detection because very difficult to trace household contact with paper base report. These conditions might be late because patient already have disability and for long time patient have become a source infection in their neighborhood. Passive case detection could make more than 10 % the new case in Indonesia found with disabilities. It means that contact tracing become very important.

Implementation of information systems will have so many advantages in new case finding. The primary advantage is the active tracing of individuals that had

been in contact with newly diagnosed leprosy patients. Information system can query or give reminder and reporting of household contact from 5 years patients have done Release from Treatment (RTF).

Taiwan LIS through National ID connected patient with their contact (figure 7) so it very easy to contact trace to block develop new case in Taiwan the opposite Indonesia leprosy electronic application still cannot do that because of there is not a registry contact in that system (figure 2).

Indonesia always develops many cases in every year and more than 10% found in disabilities it means that Indonesia Leprosy control program not hastily found new case. Contact tracing is not common in leprosy control programs in Indonesia but there was a study which tried to make modeling in ranking of the intervention in Leprosy control. Their modeling showed that contact tracing and subsequent treatment of newly found patients could contribute to a reduction in the transmission of *M.leprae* in the population.¹¹ It is time to expand focus of leprosy control program to the active surveillance through develop registry contact with assistance of information systems. In that case easier to trace new case as soon as possible so Indonesia leprosy control program. Leprosy electronic application have been implemented it was just registry patient to make report; it must be augment to optimize the effectiveness leprosy control program in Indonesia.

CONCLUSION

Health information system will be used concurrently for multiple and diverse purposes, including healthcare delivery and treatment, outcomes measurement, finance, and support of health services and policy research, clinical trials, and disease prevention and surveillance at the individual, community, national, and international levels.¹²

Indonesia is one of epidemic country with more than 10 % of leprosy patient not cured and there are some problems in Leprosy Control Program such as monitoring MDT Treatment, patient surveillance after RFT which could be solve with health information system.

Indonesia had problems on health care limited resouces and in the fact very difficult to fulfil demand of leprosy control programs. It means needed innovation approach in Leprosy Control Program through started develop a computerized

database on leprosy, including data collection, reports and analysis, estimates and predictions of leprosy problem trends.

From Taiwan experience in leprosy control systems, Indonesia can learned that drug observer and information system play important role to prevent develop new case through trace contact and monitoring MDT treatment. The recent of Indonesia Leprosy electronic application should be build up with database management system for easier retrieve information and keep the data safely and store in a long time while Indonesia just still developing e-KTP (National ID) for citizen registry.

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