Computerization of leprosy records: national leprosy recording and reporting system in China

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Summary This paper describes the national system of leprosy recording and reporting in China and the computerization of records. The system was designed for data collection at local level and data entry by optically scanned or manual mode as well as for sophisticated data analysis. The major functions include data entry, data check, sum-up, maintenance, communication, inquiry, statistics, graph and print. A total of 17 options for epidemiological and clinical data analysis are available. Through the implementation for about 10 years, the system has gained widespread acceptance. This acceptance would facilitate introduction of computer analysis to other leprosy projects and other disease control programs in China. Up to 1998, a database of more than 740,000 records covering all the leprosy patients detected since 1949 had been established by this system.

Introduction

One of the major roles of leprosy surveillance is the collection, analysis and dissemination of information relating to demographic, epidemiological and clinical aspects of the disease. To fulfil this role, a national leprosy recording and reporting system is needed to provide for efficient recording of a database, rapid retrieval of information about epidemiological status and rapid, economical analysis of collected information. The computerization of medical records with or without the automated data entry system has been pursued for various diseases. ¹⁻⁴ Along with the wider availability of micro-computers, computerized options for

data management should be applied in leprosy. This paper describes the computerization of records in the national system of leprosy recording and reporting in China.

The system

The national leprosy recording and reporting system in China was initiated by the Ministry of Public Health in 1990 and is managed and implemented by the National Centre for STD and Leprosy Control, which is located in Nanjing. The demographic and clinical data on all patients detected from 1949 through 1996 were collected each with the individual forms (four types of one-sided forms, Figure 1a–d). The different forms are distinguished by colours. Patients are tracked between the different forms through their area code and registry number.

The forms were completed manually by leprosy workers or clerical staff at county level according to the guideline and instructions for the system (5–10 min being needed for one patient). All items had to be completed by filling numbers in blank boxes and marking (shading) the printing digit that corresponded to the number.

Data on the forms were entered automatically into an IBM computer by the Optical Mark Reader A30 (OMR) with the computer program designed for the system. Two digits (computer generated) were added to each two-digit number of calendar year to differ the year 1999 from the unknown year coded "99", and to solve the problem of year 2000. During data entry, the computer could automatically check logical mistakes in the relationship between the items. If the computer found any mistake, it stopped to wait for a correction; alternatively, corrections could be ignored if the operator did not wish to correct it at once or if the apparent error was intentional. Data entry was readily performed by staff without previous keyboard skills or experience with computers, so that manual dexterity did not significantly influence the entry speed achievable; however, operators had to be familiar with the relationship between the items.

A total of more than 740,000 forms have been entered into the computer in this way to establish databases according to different forms, provinces and calendar years. Copies of the databases will be sent back to the original institutions. In order to undertake the management and analysis of the database, software for the system was developed through the cooperation of leprosy experts and computer programmers using C language. The system (Figure 2) is simple to use and has a series of multi-level menus for data entry, data check, sum-up, maintenance, communication, inquiry, statistics, graph and print. The data entry menu allows for addition, modification, or deletion of data. The data check menu can check for logical mistakes or duplications of registry numbers in the same area. The sum-up menu is used to collect data for the national level. The maintenance menu allows for duplication, deletion or restoration of databases, and for transformation of file formats. The statistics menu gives the descriptive epidemiological results at provincial, prefecture, or county levels. The graph menu produces the common graphs based upon epidemiological results.

Quality control is facilitated by the institutions at different levels and quality evaluation is undertaken by the National Centre for STD and Leprosy Control in Nanjing. Following implementation for almost 10 years, it has been found that data entry errors or logical mistakes are rare, occurring on less than 1% of forms, but coding or numbering errors occasionally occur in the follow-up patients, which leads to mis-connection of forms (<5%) if the errors cannot be found and corrected.

Outputs

The outputs of the system include selective inquiry, statistics, graph and data print (Figure 2). The selective inquiry can search original forms, or it provides a tabulation of areas and item, according to the calendar year and item selected. The statistics provide the calculation of numbers of patients and rates if the relevant population data have been entered, which includes incidence, detection, prevalence and periodic numbers and rates with or without stratification by sex and age group. In addition, the system can calculate the statistics for demographic, epidemiological and clinical characteristics of newly detected and active cases, MDT regularity and coverage, disability rates and so on using 17 options for statistical analysis. The graph menu produces a series of statistical graphs such as bar, line or distribution map with an assistance of other software, for example, Epi-Map. The print menu prints a series of results generated by the system as well as the original data of individual forms.

Application and dissemination

Data in the system can be used at national, sub-national or even county levels to describe the epidemiological and clinical profiles of leprosy. The annual national and provincial reports and statistics of leprosy can be automatically produced through the system. The national data can be used by the MOH or National Centre for STD and Leprosy Control, and the provincial and county data can be used by relevant leprosy institutions. Some scientific papers based upon data from the system have been or will be published in domestic or international journals. ⁵⁻⁸ In addition, the annual data summarized from the system not only provide feedback to sub-national or county levels, but provide useful information for policymakers, programme managers, leaders of the Leprosy Expert Committee and mass media. This is helpful in requesting expanded action or increased resources, to help increase the impact of control measures, to assist in designing effective control programmes and to influence beliefs about and attitudes to leprosy.

Discussion

The target of basic eradication of leprosy, defined as a reduction of the prevalence rate to less than 0·1 per 10,000 and an average detection rate for the past 5 years of less than 0·5 per 100,000 by the end of this century, was set up in 1981. At that time, the Ministry of Health (MOH) and its Expert Committee decided that when China came to declare its achievement of that target, it would not be enough simply to present the two indicators, but there should be a national system for collecting the data necessary to calculate them. National leprosy control in China was initiated in the mid-1950s and is well organized. All the leprosy institutions,

Figure 1. Registration forms for computerized system of leprosy reporting and recording in China. (a) Form 1. (b) Form 2. (c) Form 3. (d) Form 4. PDDS = previous DDS monotherapy; PB/MB = PB-MDT/MB-MDT; CC = clinical cure, **SI = significant improvement; ***FUC = follow-up complete; FAC = follow-up after cure; ACT = active disease; LBC = lost before cure; DBC = died before cure; MBC = move out before cure; LAC = lost after cure; DAC = died after cure; MAC = move out after cure.

FORM 1. REGISTRATION FORM OF NEWLY DETECTED PATIENT

PATIENT'S NAME:			R	EF. NO:	FILLEI		CHEC	CKED BY:	ATA: Y	M D			
A SEX	B BIRTH Y.	M.	C NATION	D JOB	E INFECT SOURCE		F ONSET YR. MONTH		G Detect y. M.		H :-IN Y. M.	I AREA CODE	II REG. NO.
	000	00	00	00		00	00	00	00	00	00	0000	0000
① M	0000	① ①	① ①	① ①	① With family	\bigcirc	① ①	111	① ①	111	① ①	0000	0000
② F	2222	2	22	2	② Out of family	22	2	22	2	22	2	0000	2222
	333	3	33	3		33	3	33	3	33	3	3333	3333
	444	4	44	4		44	4	44	4	44	4	4444	4444
	333	(5)	(3) (5)	(5)		(3)(3)	(5)	(3)(3)	(5)	(3) (3)	(\$)	3333	\$\$\$ \$
	666	6	66	6		66	6	66	6	66	6	6666	6666
	777	7	7	7		77	7	77	7	77	7	777	7777
	888	8	8	8		88	8	88	8	88	8	8888	8888
9 Unk	9999	99	99	99	9 Unk	99	99	99	99	99	99	9999	9999
DETEC	I CT MODE	_	J K DNFIRM UNIT NO. LES		ION NO. N DAM	AGE R	M EACTION	N DISABILITY		O P BI TYPE		III CATEGORY	IV FORM
			l					[
© Volu	untary	© Lepros	eprosy Unit		None	None		None		00	() I		
1	•	1 -		① Single	① 1-2	① Type I		① Grade I		\bigcirc	① TT	① Original	Form 1
② Noti	ification	② Dept I	Dept Dermatol ② 2-4		② ≥ 3	② Type II		② Grade II		22	② BT	② Correct	
3 Con	itact exam	3 Other	Dept.	③ ≥ 5	3 Countle	ess ③	Mixture	ture 3 Grad		33	3 BB	3 Suppl.	
Spot survey		4 Other	·	Count	tless	4	Type-less	4 Gra	ade-less	44	4 BL	Deletion	
© Group survey								S Oth	ner	(3)(3)	(S) LL	© Code chang	ge
© Clue survey										66	© T	Original	-
1	ss survey									77	⑦ B	Area Code	Reg. No.
	-									88	® L		
8 Other9 Unk		9 Unk		9 Unk	9 Unk	0	Unk	9 Un	1.	99	9 Unk		

FORM 2. ANNUAL FOLLOW-UP FORM OF ACTIVE PATIENT

PATIEN	T'S NAN	Æ:	REF. N	0:	F)	LLED	BY:		CHEC	KED BY	(:	D	ATA: Y	M D
A B FOL-UP Y. M. RELAPSE			C REGIMEN*		D DDS START Y. M		E MDT	MDT S	F MDT START Y. M.		G PLACE	H REGULAR	I AREA CODE	II REG. NO.
										[
00	00	© No	© Un-treatment		00	00	None	00	00			O Untreat	0000	0000
00	① ①	① 1st	① Mono-DDS		$\bigcirc\bigcirc$	\bigcirc	① 1st	$\bigcirc\bigcirc$	\bigcirc \bigcirc	① Ho	ospital	① Yes	0000	$\mathbb{O} \mathbb{O} \mathbb{O} \mathbb{O}$
22	2	② 2nd	@ PDDS+1/2 yr	. PB	22	2	② 2nd	22	2	② H	ome	② No	2222	2222
33	3	③ 3rd	3 PDDS+2 yr. N	ИΒ	33	3	③ 3rd	33	3				3333	3333
44	4	4th	@ PDDS+ MB-	>CC	44	4	4th	44	4				4444	4444
\$3	(5)		© 1/2 yr. PB		(3)(3)	(5)		(3)(3)	(5)				3333	3333
66	6		© 2 yr. MB		66	6		66	6				6666	6666
99	7		MB→CC		77	7		77	7				777	777
88	8		® Other MDT		88	8		88	8				8888	8888
99	99	9 Unk	Others		99	99		99	99	9 Ur	ık	9 Unk	9999	9999
		J	K	L	M		N	0	F			Q	III	IV
MDT CO	MPLETE	REACTION	DISABILITY	ВІ	TYPE	EFF	ECT**	STATUS***	CURE	Y. M.	FOL-U	P COMPLETE	CATEGORY	FORM
00	00	None	None	00	(I)	© Cu	ıre	© FUC	00	00	00	0 0		
00	00	① Type I	① Grade I	(1) (1)	① TT	① SI		① FAC	\bigcirc	① ①	00	0 0	① Original	
22	2	② Type II	② Grade II	22	② BT	② Im	prove	② ACT	22	2	22	2	② Correct	Form 2
33	3	③ Mixture	③ Grade III	33	3 BB	3 No	change	3 LBC	33	3	33	3	③ Suppl.	
44	4	Type-less	4 G-less	44	④ BL	4 W	orsen	DBC	44	4	44	(4)	Deletion	
33	(5)		⑤ Other	(3)(3)	③ LL	© Se	If-cure	③ MBC	\$\$	(5)	(S)(S)	(5)	© Code chan	ge
66	6			66	© T			© LAC	66	6	66	6	Original	
00	7			77	⑦ B			② DAC	77	7	7	7	Area Code	Reg. No.
88	8			88	8 L			® MAC	88	8	88	8		
99	99	9 Unk	9 Unk	99	9 Unk	9 Ur	nk	9 Unk	99	99	99			

Figure 1. (b) continued.

FORM 3. REGISTRATION FORM OF RELAPSED PATIENT

PATIENT	'S NAME:	RE	F. NO:	FILLED BY:				CHEC	CKED BY:		D	ATA: Y	M _a D
A RELAPSE			C ORIGINAL CURE		D RELAPSE Y. M.		E Detect y. M.		F E-IN Y. M.	G Detect mode		I AREA CODE	II REG. NO.
@ No	O Un-treatment	00	00	00	00	$\bigcirc\bigcirc$	0 0	00	00	Volu	ntary	0000	0000
① 1st	① Mono-DDS	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	① ①	\bigcirc	00	① Skin	Clinic	0000	0000
② 2nd	② PDDS+1/2 yr. PB	22	2	22	2	22	2	22	2	② Noti	fication	2222	2222
③ 3rd	③ PDDS+2 yr. MB	33	3	33	3	33	3	33	3	3 Regi	ılar exam	3333	3333
4th	④ PDDS+ MB→CC	44	4	44	4	44	4	44	4	4 Follo	ow-up	4444	4444
	© 1/2 yr. PB	(3)(3)	(5)	(3(3)	(\$)	33	(\$)	(3)(3)	(5)	Mass	s survey	SSSS	SSSS
	© 2 yr. MB	66	6	66	6	66	6	66	6	© Othe	ers	6666	6666
	MB→CC	77	7	77	7	77	7	77	7			0000	0000
	® Other MDT	88	8	88	8	88	8	88	8			8888	8888
9 Unk	Others	99	99	99	99	99	99	99	99	9 Unk		9999	9999
H REACTION	I ON DISABILITY	J Bl	K TYPE	L REGIMEN*		M Status**		N RELAPSE CURE			O IS Y. M.	III CATEGORY	IV FORM
						[
None	None	00	(D)	© Un-tr	eatment	@ F	UC	00	0 0	00	00		
① Type I	① Grade I	00	① TT	① Mono		① F		00	00	00	00	① Original	
② Type II	② Grade II	22 2 BT		② PDDS+1/2 yr. PB		② ACT		22	2	22	2	② Correct	
3 Mixture	3 Grade III	3 Grade III 33 3 BB		③ PDDS+2 yr. MB		③ LBC		33	3	33	3	③ Suppl.	■ Form 3
Type-les	ss	44	4 BL	4 PDDS	S+ MB→CC	4 D	DBC	44	4	44	4	Deletion	
	S Other	\$\$	③ LL	\$ 1/2 yr	. PB	(5) N	ИBC	S S	(\$)	\$\$	(\$)	© Code chan	ge
		66	6 T	© 2 yr. !	MB	6 L	AC	66	6	66	6	Original	_
		77	⑦ B	Ø MB→	CC	Ø D	DAC	77	7	77	7	Area Code	Reg. No.
		88	8 L	® Other	MDT	8 N	ЛАC	88	8	88	8		
9 Unk	(9) Unk	99	9 Unk	9 Other	S	9 [Jnk	99	99	99	99		

Figure 1. (c) continued.

FORM 4. REGISTRATION FORM OF PATIENT CURED, DIED OR MOVED OUT BEFORE 1990

PATIE	PATIENT'S NAME:			REF. NO:				FILLED BY:				KED BY	ATA: Y	M D		
A SEX	B BIRTH Y. M.				D Onset y. M.			E Detect y. M.		F -IN Y. M.	G DETECT MODE		H REGIMEN*		I AREA CODE	II REG. NO.
				[[0000	
	000	00			00	00		00	00	0 0	@ Voluntary	Y	© Un-tre	atment	0000	0000
① M	0000	① ①	① In fa	mily	11	① ①	\bigcirc	① ①	\bigcirc	① ①	① Skin Cli	nic	① Mono-	DDS	0000	0000
② F	2222	2	② Out t	fam.	22	2	22	2	22	2	② Notificat	tion	② PDDS-	+1/2 yr. PB	2222	2222
	333	3			33	3	33	3	33	3	3 Contact	exam	3 PDDS	+2 yr. MB	3333	3333
	444	4			44	4	44	4	44	4	Spot sur	vey	4 PDDS	+MB→CC	4444	4444
1	\$\$\$	(\$)			S S	(\$)	\$\$	(5)	(3)(3)	(\$)	⑤ Group st	urvey	⑤ 1/2 yr.	PB	3333	3333
	666	6			66	6	66	6	66	6	© Clue sur	vey	© 2 yr. N	1B	6666	6666
	777	7			77	7	77	7	77	7	Mass sur	rvey			7777	7777
	888	8			88	8	88	8	88	8	® Other		® Other	MDT	8888	8888
@Unk	9999	99	9 Unk		99	99	99	99	99	99	9 Unk		9 Others		9999	9999
		J	J	K		L		IV		N	0		Р	Q	111	IV
DDS ST	ART Y. M.	MDT STA	ART Y. M.	ВІ	BII	NEGATI	/E Y. M.	DISAB	ILITY	TYPE	RESULT**	RESU	ILT Y. M.	STATUS**	CATEGORY	FORM
00	00	00	00	00	0	0	00	None	e	O I	© Self	00	0 0	© FUC		
00	① ①	11	11 11	111	(1	0	① ①	① Grad	le I	① TT	① Clinic	111	① ①	① FAC	① Original	
22	2	22	2	22	(2	00	2	② Grad	le II	② BT	② LBC	22	2	② ACT	② Correct	
33	3	33	3	33	3	3	3	3 Grad	le III	3 BB	3 DBC	33	3	3 LBC	3 Suppl.	
44	4	44	4	44	4	(4)	4	Grad	le-less	4 BL		44	4	4 DBC	Deletion	Form 4
33	(\$)	(3)(3)	(5)	99	(5	3	(5)	S Other	r	3 LL		(3)(3)	(5)	③ MBC	S Code chang	ge
66	6	66	6	66	6	6	6			© T		66	6	© LAC	Original	
77	7	77	7	77	(7	7	7			② B		77	7	⑦ DAC	Area Code	Reg. No.
88	8	88	8	88	8	8	8			8 L		88	8	® MAC		
99	99	99	99	99	9	9	99	9 Unk		9 Unk	9 Unk	99	99	9 Unk		

Figure 1. (d) continued.

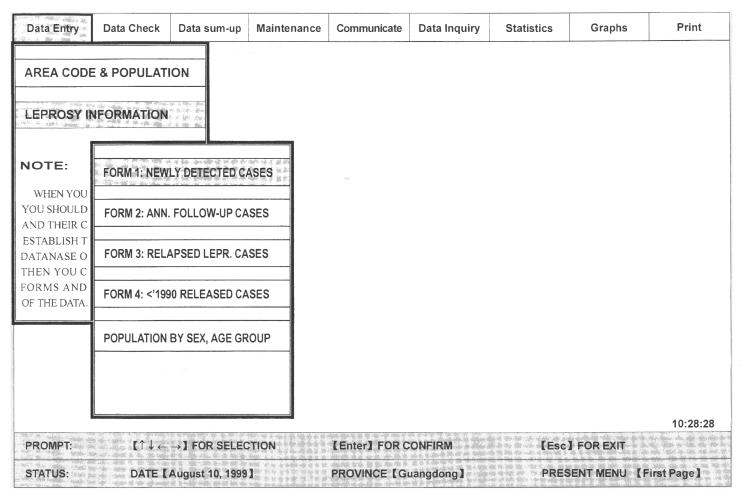


Figure 2. Screen display of computerized system of leprosy reporting and recording in China.

usually called institutes of skin disease control at provincial level or leprosy hospital or village at county level, have good storage of medical records for all leprosy patients. In order to tap this source of useful information further, it is important and necessary to establish a national system to collect these data using the structured forms. This will allow the data from different regions not only to be used to express the epidemiological trend and its relation to leprosy control strategies, but also to be compared with each other, thereby increasing their epidemiological value. It is obvious that the establishment of this system is a massive project covering the whole country. Financial support is vital to initiate the system. However, leprosy control in China is vertically implemented by a well organized programme, and therefore extra money for the system is only provided to cover the training courses at different levels, printing of recording forms and establishment of computer at national level and annual working meeting/training course as well as logistic expenses.

The OMSLEP system in the recording and reporting of leprosy patients was developed in cooperation between the Unit of Epidemiology, University of Louvain, Belgium, and WHO, and introduced into leprosy programmes in 1980.9 On the basis of technical developments as well as the feedback received from the field, a newer edition of OMSLEP was developed in 1987. With reference to the OMSLEP system and in the light of the leprosy programme in China, the individual patient forms for our system were designed and tested in the pilot areas. From the start, the system was also designed to facilitate the entry of data onto computers through an automated, optionally scanned machine. After some modifications, the system was approved by the Ministry of Public Health to be introduced nationwide in 1989. The system has been implemented in leprosy programs in China for 10 years, and the results have generally been very gratifying.

The uniform system for data recording and reporting offers considerable benefits for a leprosy programme. It facilitates standardization of data collection, whereas computerization of the data can motivate the full utilization of data that were previously stored or locked in wooden or metal drawers. The sophistication or subtleties of data analysis required can only be achieved by computerization. The present system can provide 17 analysis options on epidemiological and clinical aspects, covering most indicators used in a leprosy programme. More complex or detailed analysis of the data can be achieved by using a pre-programmed statistical package, such as SPSS 8.0. Although the system has worked well for years in China, some obstacles or problems have been encountered during its implementation. Firstly, the items in recording forms may be complex for leprosy workers at local levels, particularly in remote areas. Secondly, mis-recording of the area codes or registry numbers in some patients caused a mis-connection between different forms. Thirdly, incompleteness of or delay in reporting may influence the annual statistical report. Fourthly, a few logical mistakes in records or incomplete records have occurred in some patients; these can be found by OMR and immediately sent back to the original institutions for correction.

The automated, optionally scanned data entry mode is not only more efficient, rapid, accurate and cost-effective than the manual mode, but also able immediately to find logical mistakes in the records. This entry mode has played an important role in facilitating the transfer of data onto computers, particularly at the initiation of the system, because there were a huge number of backlog records (more than 500,000 forms) to be entered, which is time-consuming work by manual entry. However, in recent years there are fewer than 20,000 individual forms annually, half of which are entered by manual entry at provincial level using the program of the system in some areas (Figure 2). The database under the standardized structure is sent to the National Centre for STD and Leprosy Control by mail in form of 3·5-in

floppy disks or by e-mail in the form of attachments. In these areas, medical staff prefer to enter the data by themselves because: (1) manual entry avoids blurring of digits in data collection, which is a major task for local leprosy workers and one of the reasons causing optical entry errors; (2) logical mistakes in the forms can be found and corrected at once by themselves, so as not to waste time in mailing the wrong forms between local institutions and the Centre. Therefore, for data entry the system can be implemented flexibly.

The system has been widely accepted throughout China, mainly due to its feasibility and ease of operation, and the rapidly rising popularity of computers at local level as well as extensive training on the system. This acceptance would facilitate introduction of computer analysis to other leprosy projects and other disease control programmes, such as STD, for which a national computerization of STD epidemiological and clinical records has been established in our centre in recent years.

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