UNITED STATES ARMY
ARMY MEDICAL SERVICE SCHOOL

A STUDY TO DETERMINE THE BEST SYSTEM OF INFORMATION STORAGE AND RETRIEVAL FOR THE LEPROSY REGISTRY

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CHAPTER I

INTRODUCTION

Hospital Setting and History

On November 30, 1894 a state hospital for the treatment of patients afflicted with Hansen's disease or leprosy was established by Dr. L. A. Wailes at the Indian Camp Plantation along the Mississippi River twenty-three miles below Baton Rouge, Louisiana. This facility was known as the Louisiana Leper Home; but in 1921 the federal government purchased the site, and it became a U.S. Marine hospital operated by the U.S. Public Health Service. The hospital is now identified as the U.S. Public Health Service Hospital, Carville. The nursing care is rendered principally by the Daughters of Charity of St. Vincent de Paul--a function which the order has provided since 1896.[1] The Carville hospital is the only facility in the continental United States for the inpatient treatment of serious cases of leprosy. Less serious cases may receive treatment from their local hospital or physician, but the diagnoses of all cases of leprosy in the continental United States and most of the cases in the Caribbean area are made or confirmed at Carville. There have been 4513 cases of leprosy in this country since 1894. About 2100 of these patients are alive today. Each year approximately 140 new cases are reported.[2]

The Leprosy Registry Department of the Clinical Branch of the hospital serves as a repository for epidemiological data on all cases of this disease which are reported in the continental United States.

The information contained in this file is concerned with (1) patient identification and background history, (2) general medical background concerning leprosy, (3) family history, (4) periods of hospitalization, (5) therapy measures employed, and (6) miscellaneous remarks. Information has been collected and retained by the hospital since 1894, but nonstandardized forms of varying content were used prior to 1961 when the Louisiana and Texas report forms were developed and adopted for use. The Texas form was revised in 1964 and 1967, and a study is currently being conducted for another revision. The Louisiana form is also being studied for revision. Examples of these forms are shown in Appendices A and B. The Public Health Service has no form of its own. It uses Texas and Louisiana forms for most of its cases because these states have the most active reporting systems. When reports are received from other states, the form of the particular state is filed. If an informal report is received, the information is transcribed onto a Texas form.

Although data have been collected at Carville since 1894, a formal registry was not established until 1959. From 1947 until the mid-fifties, the National Communicable Disease Center (CDC) in Atlanta, Georgia assisted state agencies in collecting and recording data regarding leprosy patients. In the Mid-fifties the CDC records were moved to Carville. In 1959 Dr. Byron Olson was assigned to Carville as the chief of the Epidemiology Branch and began to develop a National Leprosy Registry. Although he retired in 1962, his work was not completed; and no qualified epidemiologist could be found to take the position. However, the records-keeping functions of the Epidemiological Branch did continue through the efforts of the registry clerk whose

duty was to initiate and continue a follow-up program to insure treatment for discharged patients. In the early nineteen-sixties, close cooperation was achieved with the Texas Health Department resulting in an increase in the amount of data received. Requests from physicians and researchers began to be received by Carville for statistical information regarding leprosy; and as these requests became more frequent, the registry was assigned the responsibility for providing answers whenever possible. Epidemiological efforts were renewed in early 1968 when Dr. Roger Feldman, Leprosy Surveillance Officer, CDC, agreed to act as consultant to the registry.[3] The Leprosy Surveillance Officer is in frequent correspondence and telephonic contact with the registry and makes occasional visits. He is the primary requester for, and user of, the registry services. Registry reporting activity during the period January, 1967 to April 30, 1969 reflects the increase of interest in registry data, as shown in Table 1.

TABLE 1

NUMBER OF MAJOR REPORTS REQUESTED FROM THE LEPROSY REGISTRY DURING THE PERIOD JANUARY 1962-APRIL 1969

Year	Number of Major Reports[a]
1962	2
1963	1
1964	3
1965	2
1966	2
1967	10
1968	19
1969 (January-April)	12

[a]A major report is defined as one which concerned two or more elements of information and which required a search of registry records for all cases.

Conditions Which Prompted Study

In September, 1966 the Medical Officer in Charge at Carville requested that his staff determine the operational areas which have missions that can be accomplished more efficiently by using automated data processing equipment. A committee was formed to study the question. Identification of application areas and exploration of practicable means to automate were continuing in late 1968 when the faculty of the Army-Baylor Program in Health Care Administration requested Carville's participation in problem solving projects which would be applicable to the Health Care Administration course. The reply from Carville referred to their automation study; and this was accepted by the faculty as the area for investigation.

Potential user elements were examined during a one week preliminary visit in February, 1969; and it was determined that the financial and property management systems are already included in automated systems centrally administered by the Public Health Service. The inclusion of personnel services into a similar system is anticipated in late 1969. Planning had proceeded significantly in the clinical laboratory area so that further study would duplicate previous effort. Implementation of an automated system for food service had been thoroughly explored by Carville personnel and rejected.

However, a great deal of information is present in the registry which could be helpful in achieving the epidemiological objectives of the hospital. Although the registry's information is valuable, it is relatively inaccessible because most of the information is written on multipart forms which are placed in file jackets and stored in cabinets. The existence of this information repository and the types of data

contained in it are known to few persons. Those who do know that the information is recorded appreciate its relative inaccessibility to detailed listing for analysis and correlation studies. Consequently, they are reluctant to make inquiries because they are aware of the lengthy, tedious process which is described below.

When a request for information is received, registry personnel interpret the applicability of registry data to the request elements; manually enter the requested characteristics across the top line of accounting paper as column titles; search each record to determine whether it is relevant to the request; extract the pertinent items of information; and list them in the appropriate column. When this handwritten list has been compiled, the reply is then typed and sent to the requestor. Because most statistics vary over time, and since each request differs in elements requested or in associated combinations, this laborious process is repeated in toto for every request.

Statement of the Problem

The problem is to determine the best procedures for storing, retrieving, and reporting the information which is collected, maintained, and stored by the Leprosy Registry Department of the U.S. Public Health Service Hospital at Carville, Louisiana.

Objectives

The objectives of an information processing system for the Leprosy Registry are to:

1. Develop an understanding of factors associated with the transmission mechanism of leprosy through exploration of hypotheses developed and made testable by the analysis of relationships of data which are in the registry.

2. Suggest and evaluate the effectiveness of control measures through the comparison of recorded incidence rates of leprosy under various conditions.

3. Register, record, and document in a uniform manner all cases of leprosy in the contiguous United States.

4. Serve as an authoritative source of information on which to base decisions regarding budgets and plans for the management of leprosy.

5. Determine the identity and location of source contacts of this disease.

6. Follow up patients under outpatient treatment or surveillance.

7. Assist in the eradication of leprosy through the determination and demonstration of effective control, and through preventive and treatment measures.

To achieve the objectives enumerated above it is necessary for the Leprosy Registry to be able to: (1) establish and maintain files on all reported cases of leprosy, (2) accomplish case recognition as a result of file searches, (3) provide requested reports which list characteristics of patients, (4) provide statistical analyses, and (5) produce correspondence necessary to insure continuous treatment of leprosy patients who are not at Carville. These activities are discussed in more detail below.

Establishment and maintenance of files

The files must contain as much of the information shown on the surveillance form as is possible to obtain. Additionally, provisions should be made to add other items as the need becomes known. For example, servicemen in Vietnam recently have begun to receive dapsone (DDS) therapy as an innovative prophylactic measure for malaria.

Dapsone is also the treatment of choice for leprosy--so statistical analysis of the relationship of dapsone prophylaxis to the incidence of leprosy among servicemen, or among servicemen of a particular ethnic origin, may well become a matter of epidemiological interest in the future. But no provision is made to include a history of previous drug therapy on the present forms.[4] Interviews with the Chief, Clinical Branch at Carville reveal that a description of the course of the disease is not presently recorded, but a listing of the chronological development of a case is definitely a matter of interest and value and should be recorded.[5] However, this study is concerned with the best basic method of processing data not with the development of forms or the specification of their content. These latter functions are important, nevertheless, for whatever information system is used; and their development should proceed regardless of the decision reached as to the acceptance or non-acceptance of the recommendations of this report.

Case recognition

The file searches must be capable of matching a reported case with records of previous reports or with admission records for that particular case even when incomplete or incorrect information has been provided. Such a search program is analogous to the procedures followed by a credit bureau in determining a credit rating for an applicant who may provide incorrect or erroneous data hoping to avoid revelation of previous unacceptable behavior. File searches to determine the number of cases with certain characteristics are of special interest to the epidemiologist who is concerned with groups of people having common characteristics which may be associated with the fact that they have

leprosy. This requires that each file be examined to determine its characteristics.

Listing characteristics

Listing is a function which is performed very efficiently by machines. If data were recorded in a machine-acceptable form, it would be possible to provide listings of previous residences; previous admissions and discharges; contacts; and therapies by dates. Provision of such listings is very desirable, but it is impractical using a manual system.

Statistical analyses

Allied to the production of lists of specified characteristics is the need for the capability to perform mathematical manipulations of relationships of patient characteristics such as incidence rates, population ratios, and multifactor or simple correlation analyses, so that quantitative expressions which allow meaningful comparisons of values can be effected.

Follow-up correspondence

As indicated in the flow charts presented in Appendices E, F, G, and H, patients who have been discharged from Carville, or those who have never been admitted to Carville but are managed or supported with medications from Carville, are contacted if no information concerning them has been received for one year. This correspondence is sent to the managing physician or to the patient to inquire about his status or to encourage continuation of treatment.

Criteria

The criteria to be applied to the alternative processing systems which will be considered are:

1. File search and query response for unusual, detailed requests should be accomplished within three to five working days, according to the Hospital Director.

2. Immediate response should be provided for routine requests to determine whether a reported case of leprosy is new or has been previously reported (case recognition).

3. Retrieval time should be minimized for the most significant or most frequently requested statistical elements of information.

4. The system should be flexible enough to fulfill demands for differing combinations of data.

5. The system should allow for updating existing data and adding new data. Updating entries should not destroy data of historical significance.

6. Follow-up correspondence must be accomplished at least as efficiently as it is by the present manual system.

Limitations

Current Civil Service Commission policies preclude the hiring of an epidemiologist. However, approval for plans to hire a programmer for a research project is expected within the next two years. Budget limitations do not permit the purchase of a computer.

Assumptions

It is assumed that leprosy investigation will continue to be required, and that it will be a matter of continued and increasing interest to researchers.

It is assumed that all systems under consideration will be operated in such a manner that confidentiality of recorded information will be assured.

Definitions

Bit. The smallest unit of information in the binary system. An abbreviation of binary digit. The applicability or nonapplicability of previously stipulated elements of information can be indicated by the use of two-state devices and appropriate coding. To be useable representations of information, bits must be referents for the most simple, elemental partitions of the information because of the intrinsic simplicity of the two-state device.

Case recognition. The ability to determine whether a reported case of leprosy is new or has previously been reported.

Character. A decimal digit, alphabetic letter, or a special symbol.

Code. A set of rules used to convert data from one representation to another.

Collator. A device to collate or merge sets of cards or other documents into sequence.

Data. A general term used to denote any facts, numbers, letters, or symbols that refer to or describe an object, idea, condition, situation, or other factors.

Data processing. Any operation or combination of operations on data to achieve a desired result.

Edge-notch card. A card in which holes have been punched around the edges. Notches made in the holes are used in coding information for a simple mechanical search technique.

Epidemiology. The field of science dealing with relationships of various factors which determine the frequencies and distributions of an infectious process, a disease, or a physiological state in a human community.

Opportunity cost. A loss sustained, a cost incurred, or a potential profit which is not realized because insufficient information is available on which to make a correct decision.

Program. A complete plan for the solution of a problem; more specifically, the complete sequence of machine instructions and routines necessary to solve a problem using ADP equipment.

Punch card. A heavy stiff paper of uniform size and shape suitable for being punched with a pattern of holes to represent data and for being handled mechanically.

Service bureau. A commercial enterprise which processes data for a fee.

Tabulating machine. A term sometimes used to describe a punched card data processing system.

Terminal. A device which is connected to a computer and through which information can be transmitted and/or received. Terminals may be located at the same place as the computer or at a remote location connected to the computer by telephone lines.

Unit record. A record in which all data concerning each item in a transaction is punched into one card.

Factors Bearing on the Problem

Facilitating retrieval of information regarding leprosy would assist researchers in determining the method of transmission of leprosy since identification of the mechanism through such inferential statistical methods as correlation analysis could allow epidemiologists to

interrupt the transmission cycle of the disease and identify relevant factors. Although skin to skin contact with an affected case seems to be the accepted method of transmission, strong evidence points to the digestive and respiratory tracts as portals of entry.[6]

A National Cash Register Company magnetic tape keyboard terminal is utilized at the Carville hospital for the purpose of placing financial management data on magnetic tapes which are transmitted by dataphone to a computer in Washington, D.C.

There is an International Business Machine Corporation key punch in use in the supply section. This machine may be available to produce registry cards.

The Medical College of Georgia has developed a computer program for a contagious disease registry. This program used an NCR 315 and is available without charge to any public health agency. The program can be operated with magnetic tape or punch card input.

Research Methodology

The technique of research methodology described in the International Business Machine Corporation's The Study Organization Plan provided the overall analytical framework for this project. The approach consists of three phases: understanding the present business, determining system requirements, and alternative new systems.[7]

An analysis of the existing system was made to define it, its components, and their relationships. The registry system and its relationships to subsuming systems were analyzed in general terms and detail. A frequency analysis was made of items of information which have been requested in the past. Unstructured interviews were conducted with the director of the hospital, staff physicians, and the

Leprosy Surveillance Officer of the National Communicable Disease Center in order to assess the relative value and essentiality of the elements of information presently recorded. The objectives to be attained through the use of this information were described or established. The stored data elements were examined to determine the relative merits and defects associated with alternative storage media such as punched cards, magnetic tape, or magnetic discs. Extensive interviews were conducted with the registry clerk; files were examined; and daily operations were observed.

When the system had been defined, and the objectives had been described, consultations were conducted with representatives of the International Business Machine Corporation and the National Cash Register Company in Baton Rouge and New Orleans in order to identify equipment which could serve as components of adequate systems. Associated financial and personnel resources were estimated for rented, on-site equipment and also for service bureau charges. A review of information retrieval and data processing literature was conducted to determine necessary system capabilities, and whether similar systems suitable for adaptation to meet the needs of Carville have been developed.

When the review of data processing literature revealed that a computerized program is in use for a tuberculosis registry, contact was made with the developer by telephone and mail. The representative of the participating computer firm was also contacted through the firm's representative in New Orleans with whom this writer had conferred. The purpose of this contact was to determine the problems and costs to be expected in the process of program adaptation and implementation.

Literature Review

The activities required to achieve the Leprosy Registry's goals involve the art of data processing and the science of information storage and retrieval. Only one article specifically related to this particular kind of computer application was identified in an extensive search of the data processing literature. The article, entitled "Medical Research Group Develops Program for Control of Tuberculosis, Other Chronic Diseases," describes the automation of a tuberculosis registry at the Medical College of Georgia at Augusta.[8] The kind of information stored and the reports rendered are almost identical to those desired by Carville. This article states that the computer programs are available to any public health agency with access to an NCR 315 system with four magnetic tape handling devices and a 10,000 word memory.[9]

Georgia's system is used to monitor and analyze the incidence of tuberculosis and other communicable diseases. It is the product of two man-years of programming effort. Every tuberculosis patient and contact is registered. The information produced during interviews and during the process of treatment is stored in the computer and reviewed regularly. Appointments are scheduled and notification letters for examinations are written by the computer. The system is designed to produce statistical reports abstracted from medical records in order to facilitate managing the registry's control function and to evaluate its effectiveness. The reports can be produced in any format and frequency desired.

A telephone conference with the National Cash Register representative in Augusta who is familiar with Georgia's system revealed that it could be adapted to the needs of the leprosy registry with minimal difficulty.

The science of information retrieval is in its infancy. However, F. Wilfrid Lancaster's book Information Retrieval Systems provides some comments and measures of effectiveness which should be kept in mind in designing a retrieval system. He observes:

> All subject indexes are matching devices. They allow matching of request descriptions against document descriptions. Mechanized systems may speed the matching operation, reduce the size of the file search, reduce human error, and improve the economy of document-request matching. However, they make no direct contribution to the central problem of information retrieval (i.e. the conceptual analysis of documents and requests and the translation of the conceptual analysis into the language of the system to allow the matching operation to take place).[10]

The translation function must be performed by the librarian or registrar. It can be assisted by the dissemination of information regarding the kinds of information available and the kinds of questions which can be answered. Lancaster also suggests that the user can best determine whether a response furnished by the system will meet his needs if the results of a partial search are given to him.

Lancaster's measures of system effectiveness include the recall ratio which is described as the number of relevant documents which are retrieved in a search divided by the total number of documents in the system that actually are relevant. Another measure is the precision ratio, defined as the number of relevant documents retrieved divided by the total number of documents retrieved. The user who requires maximum recall will normally be prepared to wait a longer period of time than the user who has no requirement for precision. The former is less concerned with rapid response than he is with a complete search and maximum retrieval.[11]

In the case of the Leprosy Registry, rapid response is required by the user who wants case recognition. But when reports and analyses

are needed, high recall and precision ratios are more important and the response time can be lengthened. The system designer must consider the acceptable limit of response time and the cost associated with the failure of the system to stay within this limit. In considering costs, the decision maker should examine the cost incurred because a system is unable to answer a question, as well as the cost to obtain answers. This inability to retrieve and process recorded information because of retrieval system deficiencies presents a cost similar to opportunity cost. It is possible that inability to retrieve data combinations about leprosy cases results in the continuation of the cost of patient care since knowledge gained by the discovery of cause and effect relationships through data analysis would permit interruption of the disease transmission cycle. The unacceptable lengthy response time inherent in the present manual system prevents the researcher from asking the questions which would require such things as a list of all patients with leprosy who have lived in a particular place at a certain time. The cost of the practical inability to accomplish similar searches which might produce significant information can only be speculated upon. Or as Robert Hayes states:

> The costs of acquiring data in the first place usually represent the major cost consideration. Since it is a capital 'investment' it must be amortized, in some sense, over the future, unknown uses to be made of it. As a result, the costs of an information retrieval system are difficult to justify. In fact, a primary problem lies in determining what data will be acquired by an information retrieval system.[12]

In regard to the function of case recognition, various matching programs for computers have been developed which employ phonetic equivalent spellings such as the soundex code, variation spellings, and secondary characteristics such as address to achieve identification.[13]

Footnotes

[1]"The History of Carville," The Star, November, 1954, p. 6.

[2]Dr. Roger Feldman, Leprosy Surveillance Officer, National Communicable Disease Center, Atlanta, Georgia, telephone interview, May 2, 1969.

[3]Mrs. Marilyn Sturdivant, Leprosy Registry Clerk, U.S. Public Health Service Hospital, Carville, Louisiana, personal interviews during the period April 28, 1969 to May 2, 1969.

[4]Dr. Carl D. Enna, Chief, Clinical Branch, U.S. Public Health Service Hospital, Carville, Louisiana, personal interview, May 2, 1969.

[5]Ibid.

[6]Texas State Department of Health, The Disease Kept Behind Closed Doors (Austin, Texas; n.d.), p. 3.

[7]International Business Machines Corporation, IBM Study Organization Plan (White Plains, New York: IBM Technical Publications Department, 1963), pp. 1-15.

[8]"Medical Research Group Develops Program for the Control of Tuberculosis, Other Chronic Diseases," Computer Applications Service, VII (Number 8, 1969), 108-110.

[9]Ibid., 109.

[10]F. Wilfrid Lancaster, Information Retrieval Systems (New York: John Wiley & Sons, Inc., 1968), p. 48.

[11]Ibid., pp. 54, 56.

[12]Robert M. Hayes, "Information Retrieval: An Introduction," Datamation, XII (October, 1966), 33, 34, 39; W. L. Hewes and K. H. Stow, "Information Retrieval by Proper Name," Data Processing Magazine, VII (June, 1965), 18-22.

[13]W. L. Hewes and K. H. Stow, "Information Processing by Proper Name," Data Processing Magazine, VII (June, 1965), 20.

CHAPTER II

DISCUSSION

Description of the Present System

Organizationally the Leprosy Registry Department is one of eight departments of the Clinical Branch of the U.S. Public Health Service Hospital, Carville. The Public Health Service is an agency of the Department of Health, Education, and Welfare. Officially the registry's mission is stated as: "Maintains custody of records. Compiles and prepares statistical reports and data including epidemiological. Makes available to local and state Health Officers. Develops secondary records and indexes."[1] The hospital organization chart is presented in Appendix I.

As shown in Appendix F, the basic inputs to the registry system are elements of information regarding the patient, his history, and condition. These elements may be some or all of those items which appear on the Texas Leprosy Surveillance Form Case Report. This information comes to the registry from private physicians, hospitals, clinics, state health departments, the National Communicable Disease Center, and from the patients and their relatives. The most complete records as far as non-medical information is concerned come from personal interviews conducted with the patient by members of state health departments, and by the personnel of the registry when an inpatient is seen during the admission routine.

Permanent outputs produced by the processing shown in detail in Appendices F, G, and H are: (1) The Surveillance Report File, (2) The Follow-up Card File, and (3) The Basic Registry File. Samples of the forms composing these files are shown in Appendices B, C, and D. The source documents most commonly used in the production of these files are the Louisiana and Texas report forms.

The basic purposes of the above mentioned files are as follows:

1. The Surveillance Report File provides epidemiological data for research reports and data for the other two files.

2. The Follow-up Card File is used to determine which cases that are away from Carville should be contacted to encourage continuation of treatment.

3. The Basic Registry File acts as a conveniently accessible master file of unit records for all reported cases of leprosy. Though it is an edge-notch card, this coding capability is utilized only for three conditions. One field is punched if the patient is deceased, another if he has used an alias, and a third if he has never been admitted to Carville. The latter two files are frequently used to accomplish case recognition. The Surveillance Report File contains historical data which is acted upon only when requests or updating information are received. The Current Outpatient portion of the Follow-up Card File is the action file for Carville-initiated follow-up actions on patients discharged from Carville or whose management is supported by the Public Health Service. The Inpatient portion of the Follow-up Card File is merely a pre-prepared card which is transferred to Current Outpatient or Deceased status at the appropriate time. The registry files contain approximately 2700 Surveillance Reports, 1600 Follow-up Cards, and 4513 Basic Registry Cards.

The nonpermanent outputs of this system are the follow-up correspondence and the statistical reports which are furnished on request. Examples of the kinds of information requested for reports are shown in Table 2.

TABLE 2

ITEMS OF LEPROSY REGISTRY INFORMATION REQUIRED FOR TWO OR MORE MAJOR REPORTS SINCE 1962 ARRANGED BY FREQUENCY OF REQUEST

Item	Frequency	Item	Frequency
1. Patient's name	18	18. Date therapy began	4
2. Location at admission	17	19. Veteran	4[a]
3. Date of admission	11	20. Disposition	4
4. Date of birth	11	21. Total cases reported but not admitted	3
5. Location at birth	10	22. Age at admission	2
6. Clinical form of disease	10	23. Age at time of study	2
7. Total cases reported	9	24. Total outpatients at time of study	2
8. Total number of admissions to Carville	9	25. Date of discharge	2
9. Date of onset	9	26. Clinical status of disease	2
10. Sex of patient	8	27. Cases reported in a given year	2
11. Carville number	8	28. Bacteriological Index at time of admission	2
12. Ethnic origin	7	29. Morphological Index at time of admission	2
13. Location to which discharged	7	30. Total admissions for aliens	2
14. Total deceased	5		
15. Total lost to follow-up	5		
16. Location at time disease was reported	4		
17. Present location	4		

[a]Veteran status has been the subject of frequent inquiries for minor reports in the last twelve months.

The controls operating upon this system are: (1) the mission statement, (2) patient interviews to verify the accuracy of reported information, (3) file cross-checks to determine whether supposed newly reported cases are already recorded, and (4) coordination with state agencies eliciting their cooperation in providing and checking

information. A significant input control is lacking because there is no law which requires a physician or a state health department to report cases of leprosy to Carville; and there is no law requiring a patient to submit himself to treatment or to provide information about himself, his family, or his contacts. In addition, there is no standard report form or widely known reporting channel.

Other problems associated with the information-gathering process are that patients may give false information in order to protect their families or friends from the stigma of this disease--a stigma which arises form society's ignorance about leprosy. Most people are unaware that although leprosy is contagious, it is only mildly so. Because leprosy is a chronic disease--that is, one which is marked by long duration and slow progression--the relevant facts may be hidden in the distant past and obscured by faulty memory of places worked, areas of military service, places of residence, and people known. The patient may have been in contact with another sufferer of the disease who never divulged the fact because of his fear and the secrecy surrounding leprosy.

Even if the patient did give accurate information, the problem still remains regarding what questions should be asked. The frequent revisions of the Texas report forms previously referred to reflect the fact that item selection is difficult since lack of medical knowledge limits the knowledge of relevant areas for questions. Inability to use factor analysis to determine which data factors are significant in the study of leprosy has resulted in the use of intuitive reasoning to select the factors that are included on the basic registry forms. At this point then it is not possible to make a judgement based on statistical methods whether or not the factors now listed on the forms possibly have causative effects and are valid candidates for analysis. Since

this basic question exists, and since these data are available, this study considers the entire case report for inclusion in the automated files. Automation would make these data more accessible for study; and as elements are judged non-significant, they would be removed from the form. Other items would be selected for inclusion on an intuitive basis or on the basis of the usual logical techniques used to develop hypotheses and independent variables by employment of the scientific method.

Resources used by the current system are shown in a list of the physical facilities, equipment, personnel and attendant costs presented in Table 3.

TABLE 3

LEPROSY REGISTRY FACILITIES AND PERSONNEL

Item		
Physical facilities		
Office space in square feet		198
Equipment		
Single pedestal typing desk		2
Typist chair		2
Interview chair		1
Electric typewriter		2
Electric adding machine		1
Intra station telephone		2
Standard telephone connected to Federal Telephone System		1
Four drawer letter size filing cabinet for Surveillance Reports		3
Twenty drawer 5x8 card filing cabinet for Basic Registry Cards		1
Two drawer 5x8 card filing cabinet for Follow-up Cards of deceased patients		1
Open file box for 5x8 (1000 card capacity) for Follow-up Cards		2
McBee Edge Punched Card Sorter		1
Storage cabinet for supplies		1
Cubic feet of files		38.2
Personnel		
GS 5 Registry Clerk	$8,750.00 per annum[a]	1
GS 3 Clerk-typist	$4,458.40 per annum[b]	1

[a]$7,000 at midrange, step 5, plus 25% differential for hazardous duty.

[b]$5,573 at midrange, step 5, adjusted to 80% for part time employee; no hazardous duty differential for part time employee. (Source: Proposed 1969 General Schedule Pay scales).

System Requirements

In order to achieve the proposed objectives in accordance with the stated criteria, the following activities and resources are required for any type of system:

1. Case information provided to Carville by state agencies, hospitals, and physicians.

2. Clerical personnel who initiate and maintain surveillance reports and process correspondence.

3. Processing and printing equipment which will perform searches, compile lists, and print them.

4. Personnel to program and operate the data processing equipment.

5. Personnel to formulate search routines or strategies, develop search requirements, and specify statistical analyses.

6. Operational site with necessary preparation.

The number of personnel, the amount of equipment, and the location and type of site preparation required to fulfill the aforementioned objectives will depend upon the system which offers the optimal cost-benefit ratio and which can be justified by the director of Carville hospital. The requirements and costs associated with the particular alternate systems will be discussed in the following section, Alternative New Systems.

Regular, complete, and uniform case reporting procedures for non-Carville agencies are currently being developed through the efforts of the Leprosy Surveillance Officer of the National Communicable Disease Center. He has made frequent contact with these agencies; informed them of the need, and the procedures for reporting information; and is providing advice relating to statistics, research, and follow-up methods to the various users. Representatives of state health agencies from

those states where leprosy is a problem met at the center early in May, 1969. They agreed to provide weekly telegraphic reports of new cases followed by uniform, detailed reports.

If research interest in leprosy continues as stated in the assumptions, the report workload requirement for the registry can be expected, at the very least, to continue at the current year's rate. On the basis of data from the first four months, this projects to an annual requirement of thirty-six reports. Demands for case recognition may rise sharply as a result of increased cooperation of case reporting by the various states.

Alternative New Systems

The following portion of this study discusses four alternative information processing systems in terms of their abilities to perform the registry functions and the associated costs. An edge-notch card system, on-site tabulating machines, service bureau tabulating machines, and the use of service bureau computers are presented.

An edge-notch card system

The current manual system with its limited utilization of the capability of the edge-notch cards is characterized by the poor response time previously described and by its inability to retrieve complicated combinations of data in a practical manner. To develop the full potential of the edge-notch cards requires at least the same amount of time and effort be spent in code development and card punching as for machine processable cards, but the edge-notch cards cannot be sorted as rapidly and listings cannot be machine produced. The edge-notch card system can extract relevant cases, but it cannot provide reports within the response time stipulated in the criteria because reports must be

typewritten rather than mechanically produced. Follow-up correspondence would have to be typed rather than machine produced. The costs which are avoided by the absence of equipment purchase are at least partially offset by typist salaries. Statistical analyses would have to be performed by the CDC personnel as is presently the case. Dr. Feldman estimated that the annual cost currently expended in preparing the results of the reports and in preforming the statistical analyses is approximately $4,000. This includes classification coding, forwarding, and source document preparation.[2]

Steps preliminary to the institution of any automated system, and necessary for the improvement of the manual system, are the development of an information coding system and the design of a form to capture patient data. This form should be easy to complete, machine-acceptable, and should categorize information according to the coding system. The code and form development should be accomplished in conjunction with an experienced epidemiologist.

A tabulating machine system

A punch card-tabulating machine system provides an inexpensive method for the accomplishment of the sorting-by-category and the listing functions. However, the fact that information is limited to eighty or ninety bits per card necessitates the creation of a voluminous file. Since each of the 2700 surveillance reports has more than 500 fields, each of which would average approximately five characters in length even with codes; cases with completed surveillance reports would require about 35 cards per case or 91,000 cards. The remaining 1913 cases, for which there is only registry card data, have approximately 30 five character fields which would result in two cards per case or 3800 cards.[3] Therefore, the magnitude is approximately 95,000 cards for a complete file.

Punch card files can be created with the IBM key punch which is already operating at Carville to produce cards for the supply system. Utilizing a cost estimate of $75. per 1000 cards and a file size of 95,000 cards, the file creation would cost $7,100.[4] The fact that tabulating machines can accomplish case recognition matches through the use of secondary characteristics is a point in its favor. But the file size of 95,000 cards severely inhibits its efficiency in performing this function because numerous passes through the collator would have to be accomplished. Various categorizations of files can minimize the number of cards to be sorted. For example, files of addresses or of diagnoses can be created. Such supplementary files can be cross-referenced with the master file if the Carville case number is included on every card pertaining to a case. The supplementary files would also be useful for statistical reporting. The additional costs of secondary file creation would be amortized by the fact that fewer cards would need to be sorted on each request. Using the cost estimates of $75. per 1000 cards creation cost as opposed to $5. per 1000 processing cost, the amortization would be realized after 15 requests.[5] Additionally, the requirement to minimize retrieval time of most frequently requested data necessitates the supplemental files.

Rapid case recognition possibly can be accomplished through the services of a bureau if a telephone connection with the registry is provided. The Federal Telecommunication System (FTS) enables participating federal agencies to place calls to distant cities at no charge. Calls can be placed from Carville to an FTS operator at New Orleans, for example, and the operator can dial any local number--such as the service bureau--at no extra charge. However, if other files are being

processed at the time of the call, immediate recognition cannot be provided. So while the arrangement is possible, it is not practical.

An outside tabulating system also would require a programmer to wire and rewire program boards as different report contents and formats are requested. This person would have sufficient time to act as machine operator. A basic understanding of common statistical measures are methods on the part of the programmer-operator would be highly desirable. This job would probably be rated at the General Schedule level of six or seven.[6] The annual salaries for these grades, including the hazardous duty 25% differential paid to Carville Civil Service employees, are $9,747.50 and $10,823.75 respectively.[7] The midpoint between the two salary estimates is $10,285. Annual equipment costs are estimated at $5,340 based on monthly rental charges of $445. for a collator, a sorter, and an accounting machine which would be necessary to print follow-up correspondence; perform case recognition searches; and produce listing reports.[8] This is a total annual cost of $15,625. Considering the projection of 36 reports annually, each report would cost $435. Site preparation costs are unknown but would increase this figure. The costs of site preparation, space utilization, equipment rental, and employee hire do not appear to be justified by the projected workload of the registry alone.

Service bureau tabulating system

A feasible variation of the on-site punch card equipment is to utilize the services of a data processing service bureau in either New Orleans or Baton Rouge. The $7,000. file creation cost mentioned above will also be incurred if a service bureau is used.

Personnel resources required for the service bureau system include the services of a programmer who would assist in code development and accomplish the wiring of program boards, and the services of a key punch operator to create and update the punch card file. Estimated bureau costs for processing reports as presented were estimated at approximately $5. per 1000 cards; so an average report might cost about $240. This estimate assumes a file size of 95,000 cards. On the average, it can be assumed that only half of these cards would be processed since preliminary sort procedures based on variously categorized files will eliminate many of the 4,500 for most reports.

Requests to the service bureau and the consequent transport of card files could be provided by the frequent trips made for the supply section, so no significant transportation costs would be incurred. Even with this requirement, reports can be accomplished within the five working days criterion. Either the on-site or the service bureau tabulating machine system can perform case recognition for the difficult cases and produce totals to serve as computer input for further, more complicated, statistical analyses. These analyses would have to be accomplished using a computer which is available at the Communicable Disease Center in Atlanta.

Tabulating machines can produce follow-up correspondence automatically at greater speed than typists. Punch card systems permit the addition of new data without destruction of historical files simply by the addition of new cards.

A computerized system

A computer which is accessible, properly designed, and has the appropriate program can accomplish all the missions of the registry more

rapidly than a manual or tabulating machine system. Since on-site computer equipment is prohibitively expensive, the immediacy required for response to telephonic requests for case recognition could be achieved through the use of the FTS network if the service bureau selected provides direct access to the computer. Computers available at the National Cash Register (NCR) or the IBM service bureaus in New Orleans, or other FTS-serviced cities, have this "on-line" characteristic and the capability to interrupt programs in process in order to respond to such a request. However, the manual system would respond more rapidly and at less expense for the routine cases.

Since almost all registry functions can be performed most efficiently by a computer, the cost factor is most important in deciding whether it is the system to be selected. Development of the computer program is the major cost involved in using the services of a computer bureau because the programming of a complex operation is a lengthy procedure which requires highly skilled personnel. Preparation of input media such as punched cards or magnetic tape is another cost element. However, the input preparation costs and activities would be essentially the same for computers as for tabulating machines or an edge-notch card system.

Magnetic tape computer files lend themselves to performing the report listing and special case recognition functions of the registry by virtue of the fact that searches for information stored on tape is accomplished by scanning each record-increment of the tape as it passes the reading station--one after the other. This differs from the random access capability of storage media such as magnetic discs and drums where the computer refers to a reference file, determines proper storage location, and moves an accessing mechanism directly to the location.

The use of random access storage devices is more expensive than tape storage because the equipment is more complicated and the devices themselves are more expensive. So the less expensive system meets the major need of the registry; but a random access system would be of value for routine case recognition.

The Service Bureau Corporation (formerly the data processing service bureau of IBM) has developed a computer program called "Praline" which accomplishes file searches and listings from magnetic tape files; up to forty report categories can be requested. This program is available only through the Washington, D.C. or Dallas, Texas offices. Aside from the cost of revising the program to meet the Leprosy Registry needs, a rough cost estimate of $350. per report was provided.[9] This estimate is tenuous because certain elements of the cost determination depend upon the input format and the coding system, both of which are yet to be developed. Nevertheless it is the best estimate available at this time.

Problems of developing codes, input forms and programs can be greatly simplified by accepting the offer of Dr. Rufus Payne of the Medical College of Georgia to provide its Contagious Disease Registry System to any public health agency without cost. The only qualifications to Dr. Payne's offer are that no proprietary use be made of the system, and that an NCR 315 with a 10,000 word memory is available for use. An NCR 315 will accept input of magnetic tapes produced by Carville's NCR terminal or the punched cards produced by the IBM key punch. The NCR 315 system possesses a sequential search and a random access capability. This computer also schedules appointments and automatically produces the letters of notification for appointment which

are necessary for the follow-up requirements of the registry. And the necessary statistical analyses can be performed.[10]

The above mentioned NCR system with the necessary characteristics is available at their service bureau in New Orleans. Representatives at New Orleans contacted those personnel in the NCR Augusta, Georgia office who worked with Dr. Payne in developing the system at the Medical College of Georgia. The manager of the NCR New Orleans service bureau provided a planning estimate cost of $175. per report based on information provided by the Augusta personnel and on knowledge of the forms, files, and requirements of the Leprosy Registry provided by this writer during a conference.[11]

The NCR 315 system possesses the capability to fulfill all the data processing requirements of the Leprosy Registry. Costs of developing a program, codes, and forms should be minimized because of the existence of related programs. The ease of interchangeability of NCR programs has been demonstrated by a cooperative endeavor of two hospitals which shared their financial reporting programs. They reported immediate applications and the savings of four months of programming effort.[12] One hospital is in Florida and the other is in Baltimore, Maryland. Reports which include statistical analyses can be provided at a very reasonable cost--with no increase in the number of registry personnel--once the input files have been prepared. Use can be made of on-site means of input preparation which are available at no extra cost. The present system, described by the flow charts presented in Appendices E, F, G, and H, appears complete and non-redundant. The proposal is to automate the present system rather than replace or redesign it. The versatility of the NCR system might enable it to assist

in accomplishing automation of the other functions of the hospital at Carville. And a single, integrated data processing system which meets the needs of both the clinical and the administrative elements of the hospital is preferable to a combination of fragmented, multiple, diverse systems which result from a series of short range, uncoordinated plans.

Summary

An information matrix which summarizes the discussion above is presented in Table 4. The alternate systems are arrayed across the top and the critical decision considerations are listed along the side.

In determining the best information processing system for the Leprosy Registry, the requirement for the system to accomplish five tasks was established. These tasks are to establish and maintain files, case recognition, listing of requested case characteristics, statistical analyses of the file search results, and production of correspondence related to case follow-up.

The present system was described and four alternative systems were presented. An edge-notch card system would provide a limited improvement in file search techniques, but does not print listings automatically. The tabulating machine systems permit more rapid searches, automatic printing, and case recognition, but each report would cost approximately $435. for on-site equipment; or $240. for a service bureau. The use of a computer service bureau would accomplish all required functions, but would cost $350. for each report, plus the costs of program adaptation unless the computerized contagious disease registry system developed by the Medical College of Georgia is adopted.

TABLE 4

ALTERNATE SYSTEMS

Decision Considerations	Manual	Edge-notch Cards	On-site Tabulating Machines	Svc.Bureau Tabulating Machines
Follow-up letters machine produced	No	No	Yes	Yes
Capability for case recognition	Yes	Yes	Yes	Yes
Performance time	Rapid--except for non-routine cases	Slow	Fast	Slow
Capability for correlation computations	No	No	No	No
Performance time	Too time-consuming to be practical in quantities desired	Too time-consuming	--	--
File organization--ability to reorganize	Reorganization is difficult; multiple files w/different arrangements rqd.	Same as manual	Yes	Yes
Program development	Not applicable	Same as manual	Wiring boards must be arranged as requirements are received by on-site personnel or sent to svc. bureau	
Capability to produce listing mechanically	No	No	No	No
Time required per page	25 minutes (average)	Same as manual	1 minute (50-100 lines per minute)	1 minute (50-100 lines per minute)
File accessibility	Immediate	Immediate	Slight delay	Slight delay
Data accessibility--single cases	Good	Good	Good	Good
multiple cases	Poor	Poor	Good	Good
Additional costs per report (file preparation excluded)	No addition	No addition	$435[a]	$240

[a]Computed on the basis of $5,340 annual machine rental and $10,285 programmer-operator salary.

TABLE 4--Continued

Decision Considerations	Non-NCR Service Bureau Computer		NCR Service Bureau Computer	
	Remote Terminal	Delivery	Remote Terminal	Delivery
Follow-up letters machine produced	Yes	Yes	Yes	Yes
Capability for case recognition Performance time	Yes Fast	No[b] --	Yes Fast	No[b] --
Capability for correlation computations Performance time	Yes Fast	Yes Slow	Yes Fast	Yes Slow
File organization--ability to reorganize	Yes	Yes	Sequential Processing using Magnetic Tape	
Program development	Required	Required	Adapt Program which is available from Medical College of Georgia	
Capability to produce listing mechanically Time required per page	Yes 6 seconds	Yes 6 seconds	Yes 6 seconds	Yes 6 seconds
File accessibility Data accessibility single cases multiple cases	Immediate Better Better	Delayed Better Better	Immediate Better Better	Delayed Better Better
Additional costs per report (file preparation excluded)	$360	$350	$175	$175

[b]Case recognition can be accomplished but response time is unacceptably long for routine cases.

As presented in the final alternative, utilization of the Medical College of Georgia's programs and the services of a bureau, all registry tasks would be accomplished and estimated report costs would be $175.

The implementation of any of the proposed systems requires the development of category codes; and the automated systems require the development of, and conversion to, a machine-acceptable input medium. These costs are not considered in the analysis because automation appears to be inevitable. So the cost is common to all feasible alternatives.

Footnotes

[1]U.S. Public Health Service Hospital, Carville, Louisiana, Functional Chart, October 1, 1967.

[2]Dr. Roger Feldman, Leprosy Surveillance Officer, National Communicable Disease Center, Atlanta, Georgia, telephone interview, May 2, 1969.

[3]Robert Smith, a representative of the Service Bureau Corporation, New Orleans, telephone interview, May 8, 1969. Because of uncertainties regarding coding system and program development, the representative would not provide a firm quotation of charges.

[4]Ibid.

[5]Ibid.

[6]U.S. Civil Service Commission, Position Standards (Washington, D.C.: Government Printing Office, GS 357, June, 1963), pp. 1-11; (GS 359, June, 1960), pp. 1-27; (GS 362, February, 1961), pp. 1-20.

[7]"Proposed Federal Pay Rates," San Antonio News, March 4, 1969, p. 9D.

[8]Donald E. Yeager, Marketing Manager, Data Processing Division, International Business Machines Corporation, personal interview, Baton Rouge, Louisiana, May 7, 1969.

[9]Robert Smith, Service Bureau Corporation representative, interview.

[10]Joseph Simokatz, Manager, National Cash Register Service Bureau, New Orleans, personal interview, May 9, 1969.

[11]Ibid.

[12]"Unusual Example of Cooperation Between Hospitals Over 1,000 Miles Apart," The Nation's Hospitals (Number 4, 1969), 6.

CHAPTER III

CONCLUSION

Conclusion

The NCR 315 system which is available through the NCR service bureau in New Orleans in conjunction with the contagious disease registry program developed by the Medical College of Georgia provides the best system for storing, processing, retrieving, and reporting the information collected, maintained, and stored by the Leprosy Registry Department of the U.S. Public Health Service Hospital at Carville, Louisiana.

Recommendations

It is recommended:

1. That the Director of the U.S. Public Health Service Hospital, Carville, effect liaison with Dr. Rufus R. Payne of the Medical College of Georgia in Augusta, Georgia to obtain the information necessary to adapt and implement the contagious disease registry program.

2. That the development of a code system and a machine-acceptable input form be developed through the cooperative efforts of the Leprosy Registry personnel; the Leprosy Surveillance Officer, Communicable Disease Center, Atlanta, Georgia; and representatives of the NCR Service Bureau in New Orleans.

3. That funds be obtained to support the conversion of information from the present file media to a machine-acceptable form developed from the actions recommended above.

4. That a study be conducted to determine whether the file conversion can be presented in such a way that additional operating funds will be provided, or that will justify research funds from a federal grant.

5. That the need for operating funds to procure computer services for registry reports be presented in the next five-year budget submission.

6. That a representative of the committee established by the Director of the Carville hospital to study the feasibility of automation for all hospital areas be instructed to follow the development of the new system for the Leprosy Registry Department.

APPENDIX A

LEPROSY SURVEILLANCE REPORT (LOUISIANA)

40

NATIONAL LEPROSY SURVEILLANCE REPORT
CASE REPORT

DO NOT WRITE IN THIS SPACE

Patient's name – Last | First | Middle

Sex ☐ Male ☐ Female

Aliases

Race ☐ White ☐ Negro ☐ Other, specify:

Maiden name (if married)

PERSONAL DATA

National Derivation	Present Address	Street or rural address	City or town	County / State
	Usual Residence (If different than above)	Street or rural address	City or town	County / State
	Birthplace	City or town	County / State	Country
	Date of birth	Entered Texas Date: From Where:	Entered US (if foreign born) Date: From Where:	Citizen of

	Occupation(s) – Area of Employment	Inclusive Dates
Occupation		

	Branch of Service	Overseas Areas Where Served	Inclusive Dates
Military Service ☐ Yes ☐ No If "Yes":			

	Locale	Inclusive Dates
Residence or Visit of Any Duration in Endemic Areas Not Given Above		

PRESENT ILLNESS

Date of Onset	Describe Onset		
Diagnosis	Type	Activity	Dates
	Confirmed clinically, by whom		
Bacteriologic findings ☐ Positive ☐ Negative	By whom		
Biopsy ☐ Positive ☐ Negative	By whom		
Other test (specify): ☐ Positive ☐ Negative	By Whom		

RESENT
LNESS
ont'd)

Admitted to Carville? ☐ Yes ☐ No	Date of Admission	Case Number – Carville

Name and address of physician making diagnosis:

Medical supervision, if not admitted to Carville:

Final disposition: Died ☐ Moved – To where: ☐ Lost ☐ Other, specify: ☐

AMILY
DATA

	Name (Maiden Name if Married)	Place of birth	Residence & Present Status *
Father			
Paternal Grandfather			
Paternal Grandmother			
Mother			
Maternal Grandfather			
Maternal Grandmother			

Name of Siblings **	Place of Birth	Sex	Date of Birth	Residence & Present Status *

Marital Status — Check: ☐ Single ☐ Married ☐ Widowed ☐ Divorced or Separated

Name of Spouse(s) ***	Date Married

Name of Children **	Sex	Date of Birth	Residence & Present Status *

* Dead, living and well. If case, give number.

** Married name if married.

*** Maiden name.

OTHER CONTACTS

LEGEND FOR PROBABLE SOURCES OF INFECTION:

Column 1 – For married females, give married name.
Column 2 – Signify the contact category as follows:
A. Known leprosy case, household, family or not.
B. Known leprosy case, not household, family.
C. Known leprosy case, not household, not family.
D. Suspected leprosy case, household, family or not.
E. Suspected leprosy case, not household, family.
F. Suspected leprosy case, not household, not family.
Column 3 – Enter national registry number
Column 4 – Relationship of contact to case.
Column 5 – Present address if living.

☐ No known contact with case of leprosy

ROBABLE OURCE OF FECTION

Name (1)	Contact Category (2)	Number (3)	Relation (4)	Address (5)

EMARKS

Date	Remarks	Initials

STI-OR

Case investigated by

Date

ccasional visitor in home; contacts at work or neighbors with approximate inclusive dates.

PLACES OF RESIDENCE
(Start with most recent residence)

STATE	COUNTY	TOWN	INCLUSIVE DATES

FURTHER REMARKS

ATE

APPENDIX B

TEXAS LEPROSY SURVEILLANCE FORM CASE REPORT

45

(1)

TEXAS
LEPROSY SURVEILLANCE FORM
CASE REPORT

DO NOT WRITE IN THIS SPACE

Patient's name – Last | First | Middle

Date reported:

Aliases

Sex ☐ Male ☐ Female

Maiden name (if married)

Ethnological group:

NATIONAL DERIVATION

Present Address	Street or rural address	City or town	County	State
Usual address (if different than above)	Street or rural address	City or town	County	State
Birthplace	City or town	County	State	Country
Date of Birth	Entered Texas Date: From Where:	Entered US (if foreign born) Date: From Where:		Citizen of

EDUCATION AND OCCUPATION

Education, Occupations – Area of employment	Inclusive Dates

MILITARY SERVICE

☐ Yes ☐ No	Branch of Service	Overseas areas where served	Inclusive Dates

Date of onset

Describe onset:

DIAGNOSIS

Type	Activity	Date
Bacteriological findings ☐ Positive ☐ Negative	By Whom	Date
Biopsy findings:		
Other tests (Specify)		
Admitted to Carville ☐ Yes ☐ No	Date of 1st admission	Case Number–Carville
Name and address of physician making diagnosis:		
Case investigated by:		Date

FORM NO. C-12

Morphological Index at Diagnosis:

Morphological Index upon admission to Carville:

Bacteriological Index at Diagnosis:

Bacteriological Index upon admission to Carville:

Subsequent Morphological Index and Bacteriological Index determinations:

Date	M. I.	B. I.	By Whom	Accession Number

LEGEND FOR PROBABLE SOURCES OF INFECTION:

Column 1 – For married females, give married name.
Column 2 – Signify the contact category as follows:

A. Known leprosy case, household, family or not.
B. Known leprosy case, not household, family.
C. Known leprosy case, not household, not family.
D. Suspected leprosy case, household, family or not.
E. Suspected leprosy case, not household, family.
F. Suspected leprosy case, not household, not family.
G. Knowledge of a case of leprosy, whether there was any contact or not.

Column 3 – Enter national registry number.
Column 4 – Relationship of contact to case.
Column 5 – Present address if living.

☐ No known contact with case of leprosy

Name (1)	Contact Category (2)	Number (3)	Relation (4)	Address (5)	Year of Contact

(3)

	Name (Maiden name if married)	Place of Birth	Residence & Present Status*
Father			
(P) Grandmother			
(P) Grandfather			
Mother			
(M) Grandmother			
(M) Grandfather			

Name of Siblings**	Place of Birth	Sex	Date of Birth	Residence & Present Status*

Name of Spouse (s) ***	Date Married	Divorced	Separated	Widowed

	Name of Spouse's Family	Place of Birth	Residence & Present Status*
Father			
(P) Grandmother			
(P) Grandfather			
Mother			
(M) Grandmother			
(M) Grandfather			

Spouse's Siblings	Place of Birth	Sex	Date of Birth	Residence & Present Status*

Name of Children (Case's) **	Sex	Date of Birth	Residence & Present Status

Other Contacts (*): Name	Sex	Date of Birth	Residence & Present Status

Dead, living and well. If case, give number.

*** Maiden name

How many people live in the home? _____
How many beds are there in the home? _____
What is the usual sleeping arrangement? _____
How many persons per bed? _____
Does the patient practice good personal hygiene habits? _____
How often are medical check-ups taken? _____
Is the home properly cleaned? _____
Are there evidences of breeding places for insects? _____
Has the family ever been plagued by: fleas_____, cockroaches_____, bedbugs_____, mosquitoes _____
Other insects? (specify) _____
Has there been any other type of illness in the family? (specify) _____
Has the patient himself ever suffered from any other disease or has he experienced periods of disability? _____
When? _____
Is there a history of allergy, diabetes, tuberculosis, or thyroid? _____
Has the patient ever worn "hand-me-down" clothes or secondhand clothes? _____
Did he know the source of the clothes? _____
Has the patient gone without shoes for a period of time? _____
What is the usual diet of the patient? _____

Does he eat meals at regular hours at home? _____
What are the patient's resting habits? _____
Does the patient have the habit of embracing friends and/or relatives? _____
Did he feel he was under an emotional strain of some kind before noticing the first symptoms of his disease? _____

Did an injury precede or precipitate the onset? _____
Did an injury make the patient aware of anesthesia? _____
Does the patient suffer any disability due to this disease? (Elaborate) (anesthesia, contractures, facial disfigurement, including alopecia, ulcers, anesthesia of feet, loss of digits, difficulty in breathing, difficulty in swallowing, photophobia) _____
Does the patient smoke? _____ How long has he been smoking? _____ About how many cigarettes does he smoke in one day? _____
Does the patient consume alcoholic beverages? _____ To what degree? _____
Where does the patient obtain his drinking water? _____
Where does the patient obtain his milk supply? _____
Explanation of foregoing questions?

PLACES OF RESIDENCE
(Start with most recent residence)

State	County	Town	Inclusive Dates

GRANT WORKERS

hat month does the migrant usually leave his home to join the migrant labor force? _____

of transportation? ☐ truck ☐ private automobile ☐ bus ☐ train etc. _____

at counties in Texas did the migrant work? _____

hat states has the migrant passed through? _____

ow long does the migrant usually stay at these places? _____

hat type of living accommodations does the migrant have when away from home? _____

oes he have friends in the localities where he works? _____

o they visit each other frequently? _____

hat month do they return home? _____

hat do they do when they return home? _____

XPLANATION OF FOREGOING QUESTIONS:

HART APPROXIMATE ROUTES OF MIGRANT WORKER AND INDICATE STAYS OF DURATION WITH AN (*)

ST ADMISSIONS AND DISMISSALS FROM U.S.P.H.S. HOSPITAL, CARVILLE, LA.

(6)

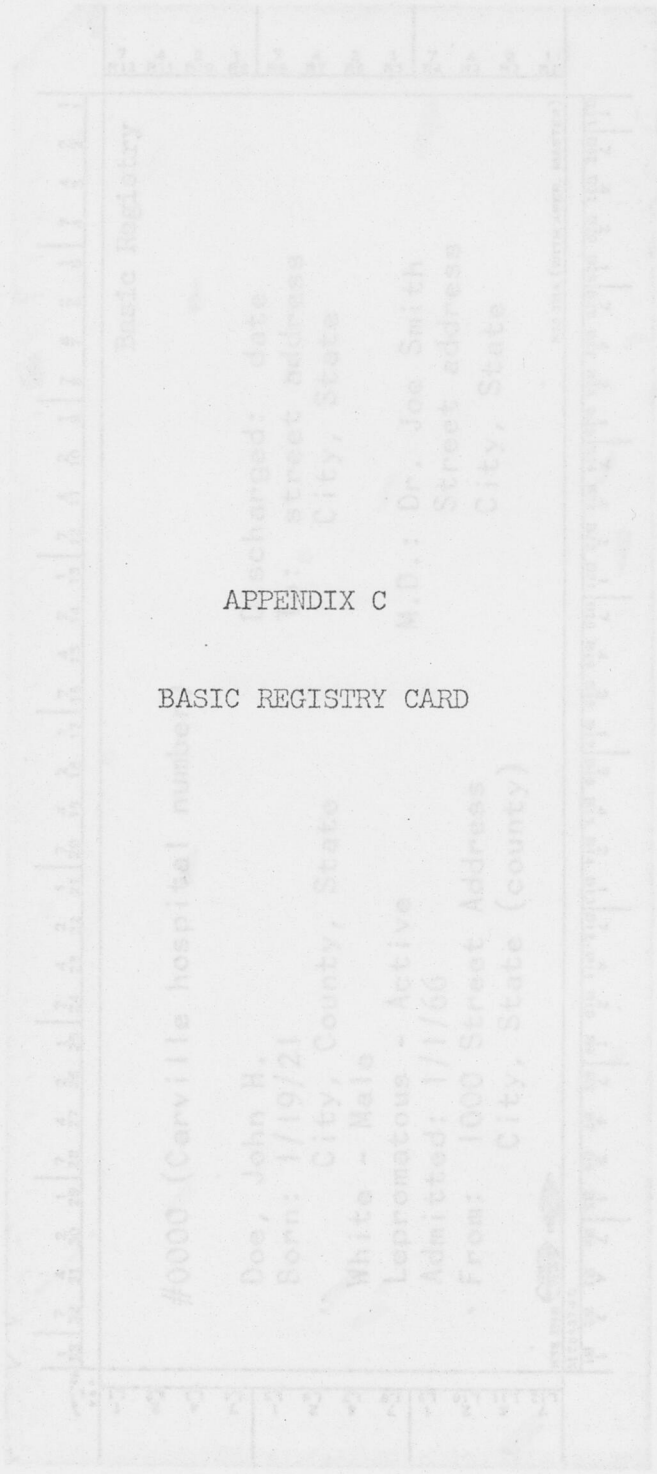
FURTHER REMARKS

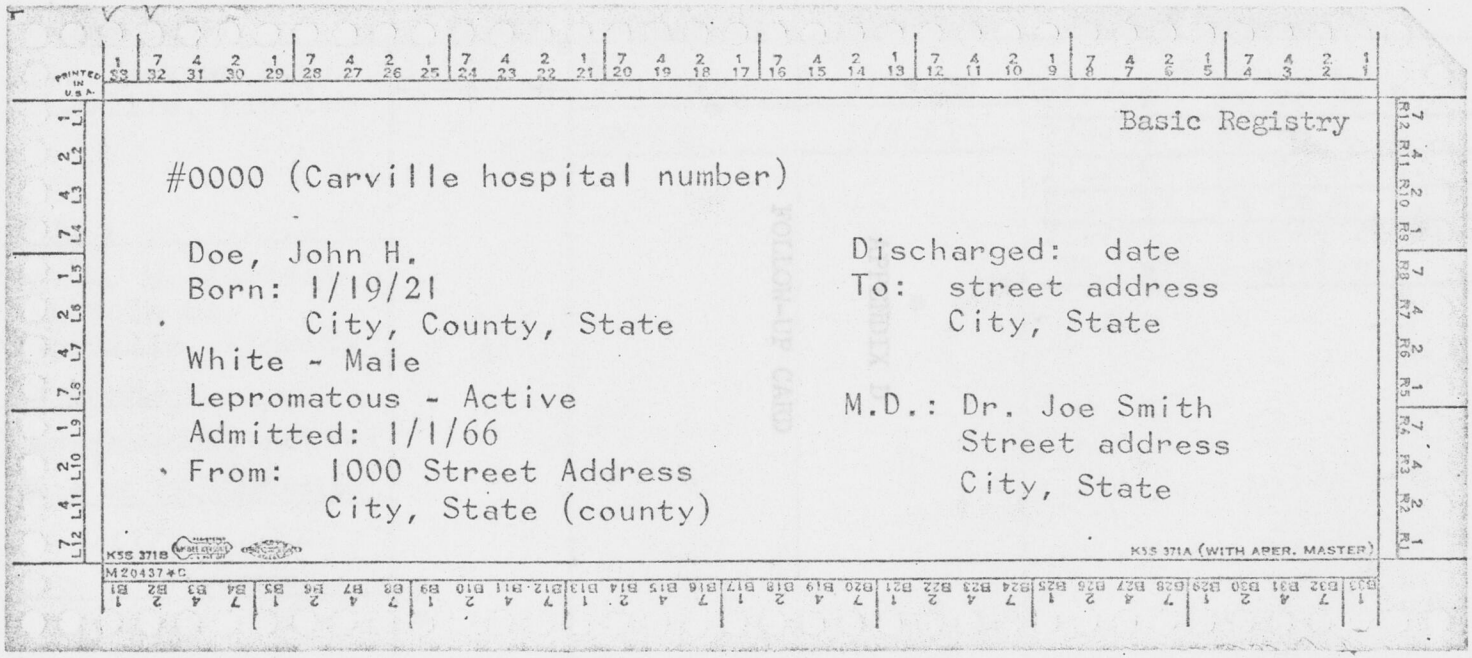
TE

DICAL SUPERVISION AND MEDICATION (INCLUDE THERAPY AND RESPONSE)

APPENDIX C

BASIC REGISTRY CARD





Basic Registry

#0000 (Carville hospital number)

Doe, John H.
Born: 1/19/21
City, County, State
White - Male
Lepromatous - Active
Admitted: 1/1/66
From: 1000 Street Address
City, State (county)

Discharged: date
To: street address
City, State

M.D.: Dr. Joe Smith
Street address
City, State

K5S 3718

K5S 371A (WITH APER. MASTER)

M20437*C

APPENDIX D

FOLLOW-UP CARD

Follow-up Card

#0000
SMITH, JOHN C.

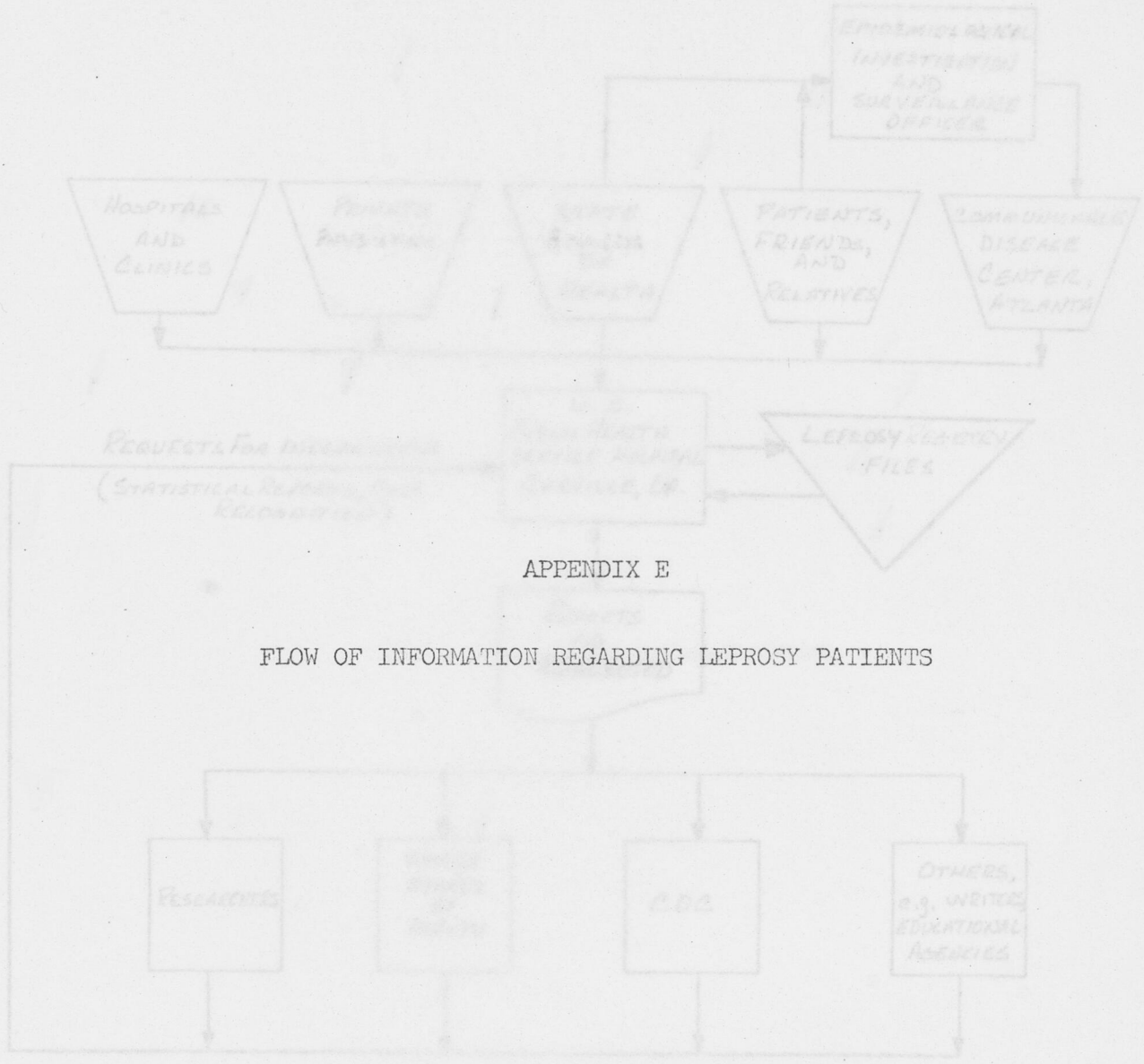
D.O.B. 1/21/36

RACE: Puerto Rican

SEX: Male

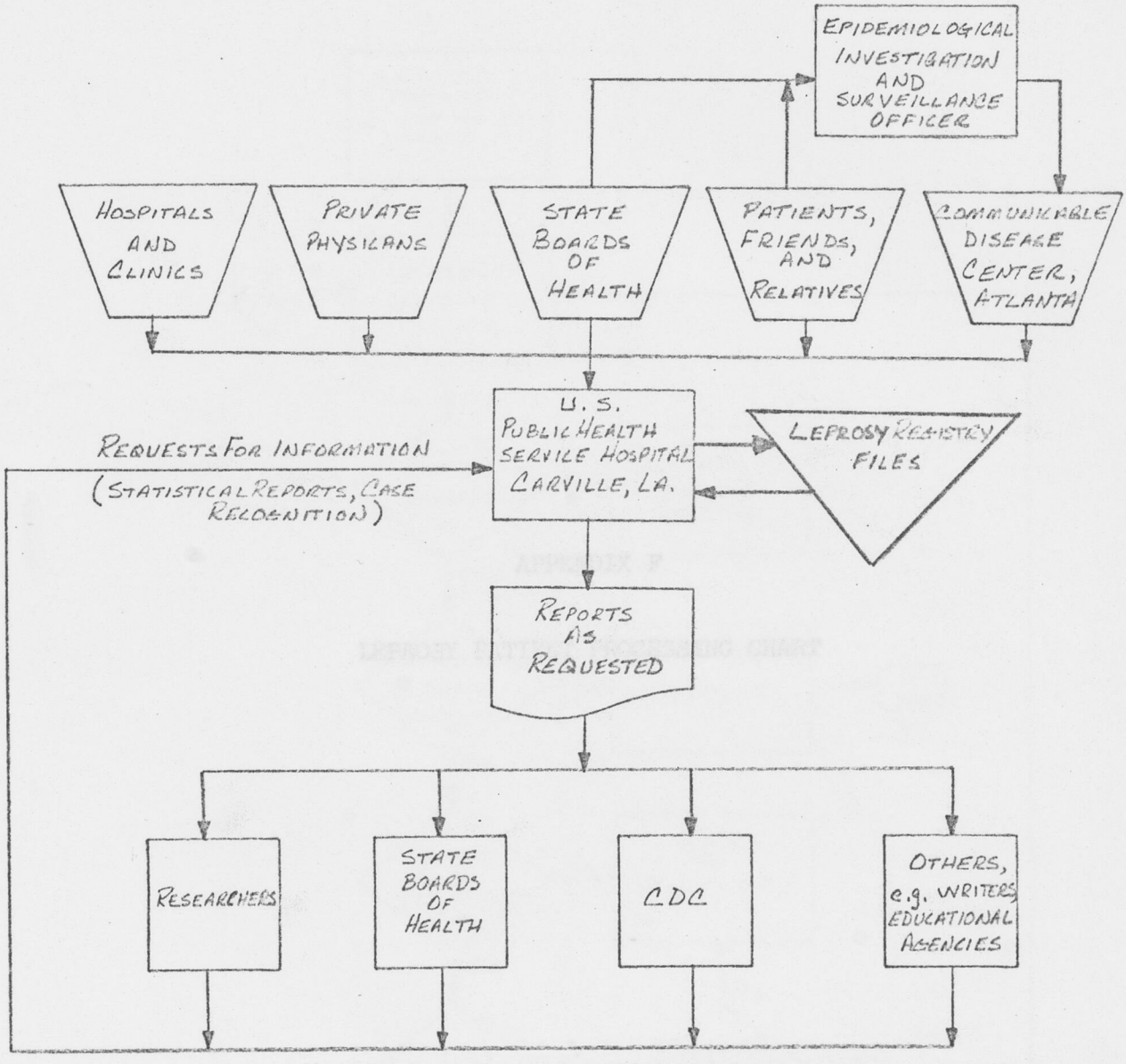
ADDRESS OF PT.	O.P. VISITS	ADMISSIONS	DISCHARGES	CURRENT INFORMATION
1116 Jackson Ave. Hopeville, Florida	3/5/66	1/21/58	3/24/58	2/5/62 Rx to M. D.
		2/4/60	2/5/61	2/4/63 Rx to M. D.
				2/12/64 Rx to M. D.
				2/11/65 Rx to M. D.
M.D.				2/5/67 - Biopsy received. Pt. still active.
Dr. M. M. Jackson 411 Main St. Hopeville, Florida				
Diagnosis				
Lepromatous, active				
Date of 1st Admission				
1/11/54				
Date of Discharge				
2/22/56				

DHS-32 (Cont.)



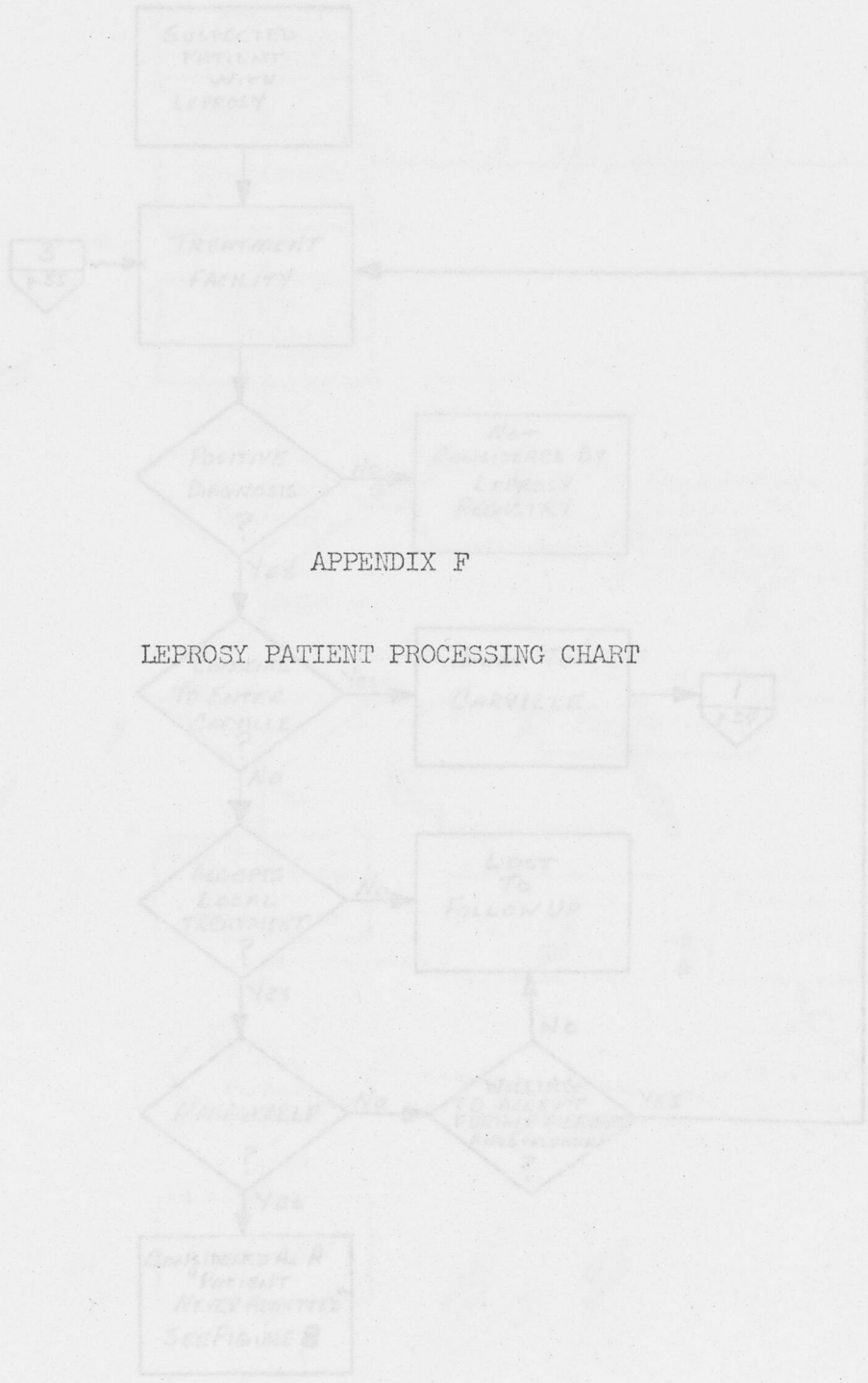
APPENDIX E

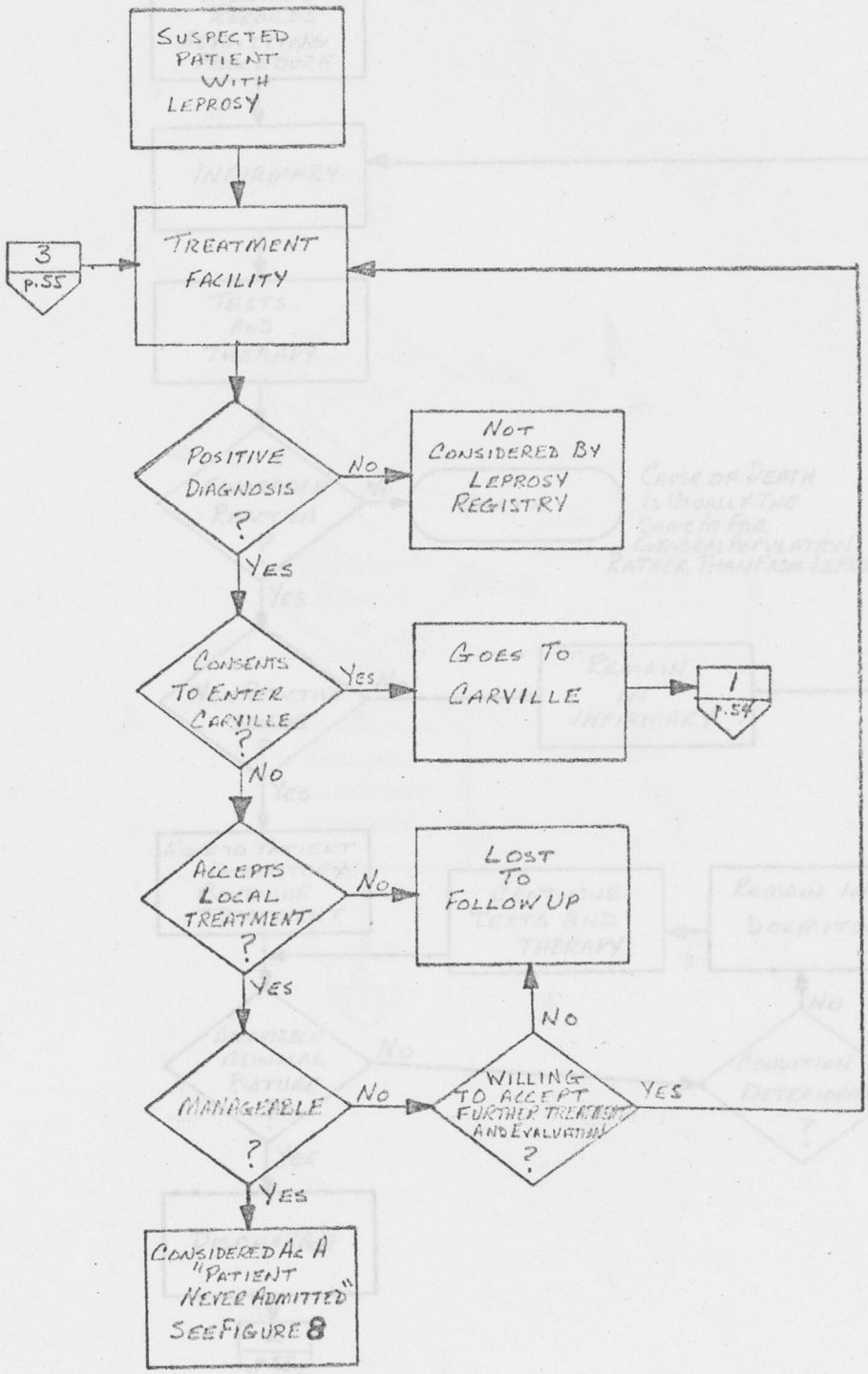
FLOW OF INFORMATION REGARDING LEPROSY PATIENTS

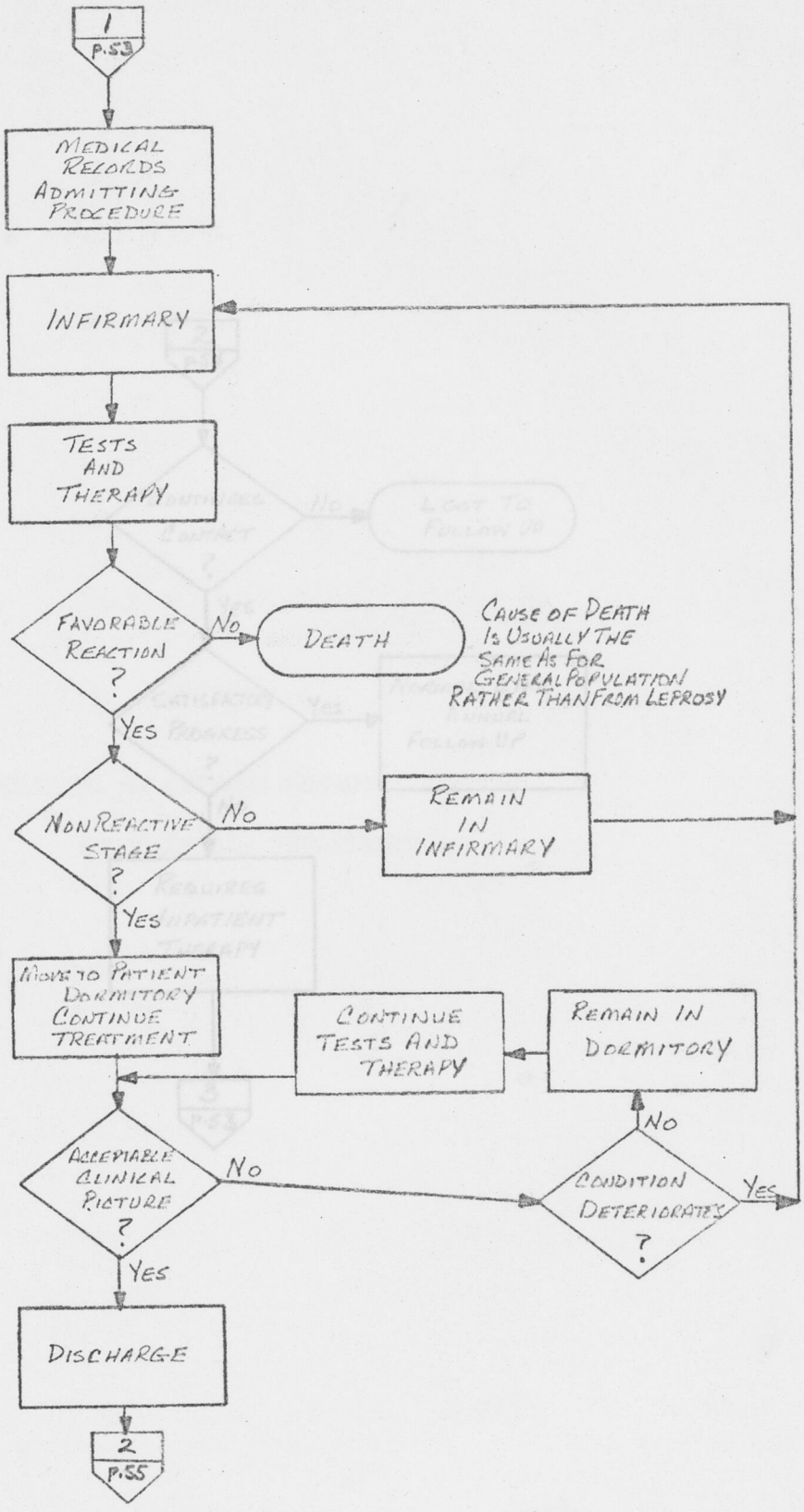

EPIDEMIOLOGICAL INVESTIGATION AND SURVEILLANCE OFFICER
HOSPITALS AND CLINICS
PRIVATE PHYSICANS
STATE BOARDS OF HEALTH
PATIENTS, FRIENDS, AND RELATIVES
COMMUNICABLE DISEASE CENTER, ATLANTA
U. S. PUBLIC HEALTH SERVICE HOSPITAL CARVILLE, LA.
LEPROSY REGISTRY FILES
REQUESTS FOR INFORMATION
(STATISTICAL REPORTS, CASE RECOGNITION)
REPORTS AS REQUESTED
RESEARCHERS
STATE BOARDS OF HEALTH
CDC
OTHERS, e.g. WRITERS, EDUCATIONAL AGENCIES

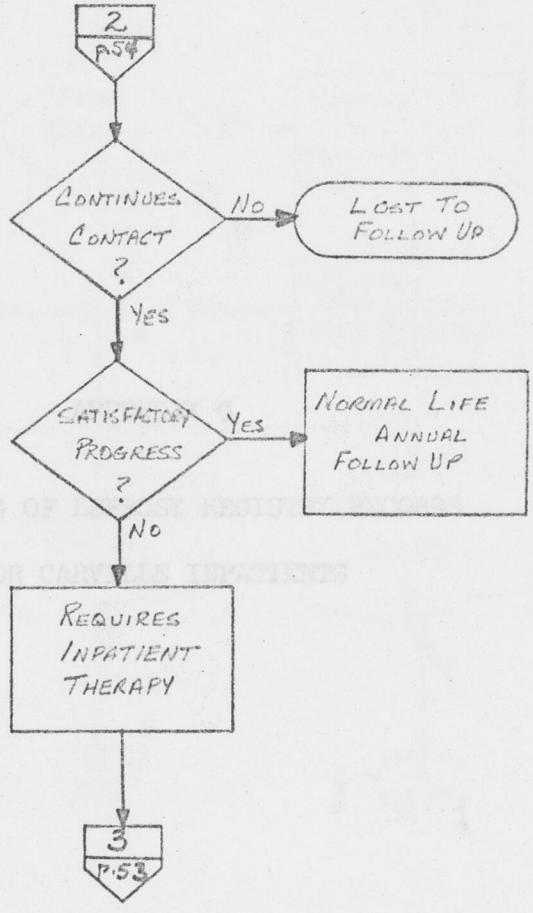
APPENDIX F

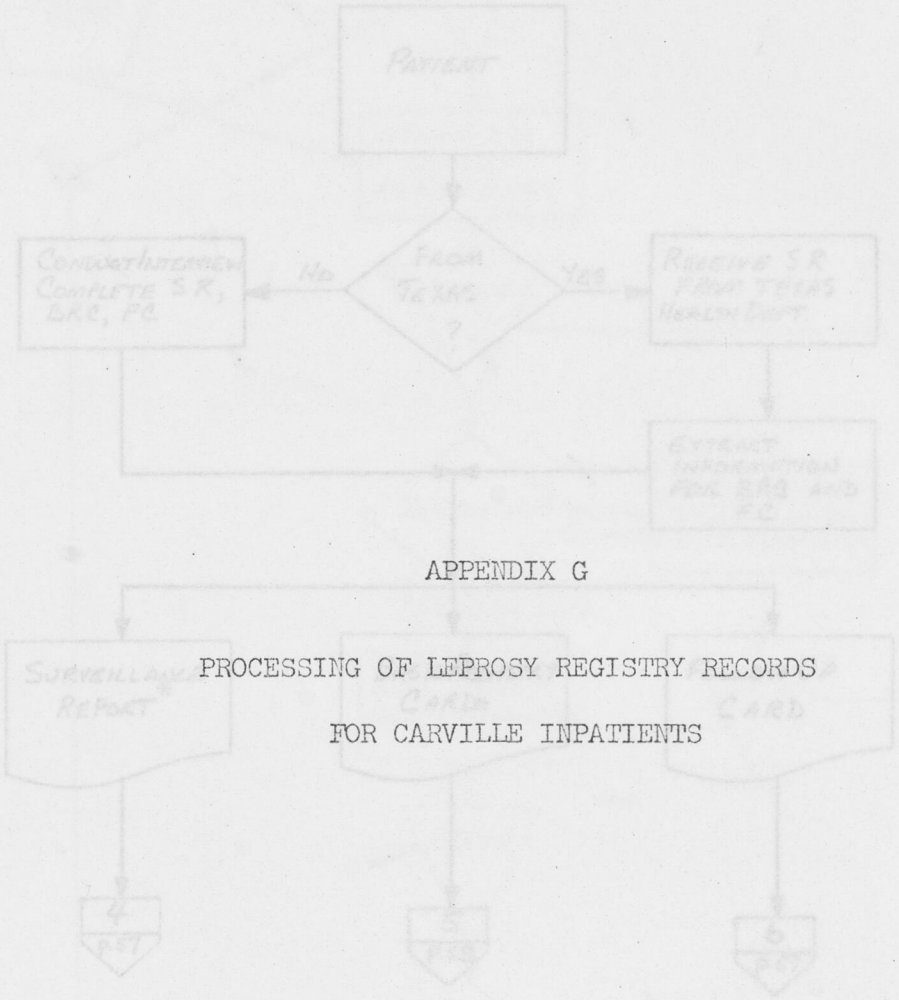
LEPROSY PATIENT PROCESSING CHART




SUSPECTED PATIENT WITH LEPROSY
TREATMENT FACILITY
3 P.55
POSITIVE DIAGNOSIS ?
NO
NOT CONSIDERED BY LEPROSY REGISTRY
YES
CONSENTS TO ENTER CARVILLE ?
YES
GOES TO CARVILLE
1 P.54
NO
ACCEPTS LOCAL TREATMENT ?
NO
LOST TO FOLLOW UP
YES
MANAGEABLE ?
NO
WILLING TO ACCEPT FURTHER TREATMENT AND EVALUATION ?
YES
NO
YES
CONSIDERED AS A "PATIENT NEVER ADMITTED" SEE FIGURE 8


1
P.53
MEDICAL RECORDS ADMITTING PROCEDURE
INFIRMARY
TESTS AND THERAPY
FAVORABLE REACTION ?
No
DEATH
CAUSE OF DEATH IS USUALLY THE SAME AS FOR GENERAL POPULATION RATHER THAN FROM LEPROSY
Yes
NON REACTIVE STAGE ?
No
REMAIN IN INFIRMARY
Yes
MOVE TO PATIENT DORMITORY CONTINUE TREATMENT
CONTINUE TESTS AND THERAPY
REMAIN IN DORMITORY
ACCEPTABLE CLINICAL PICTURE ?
No
CONDITION DETERIORATES ?
No
Yes
Yes
DISCHARGE
2
P.55

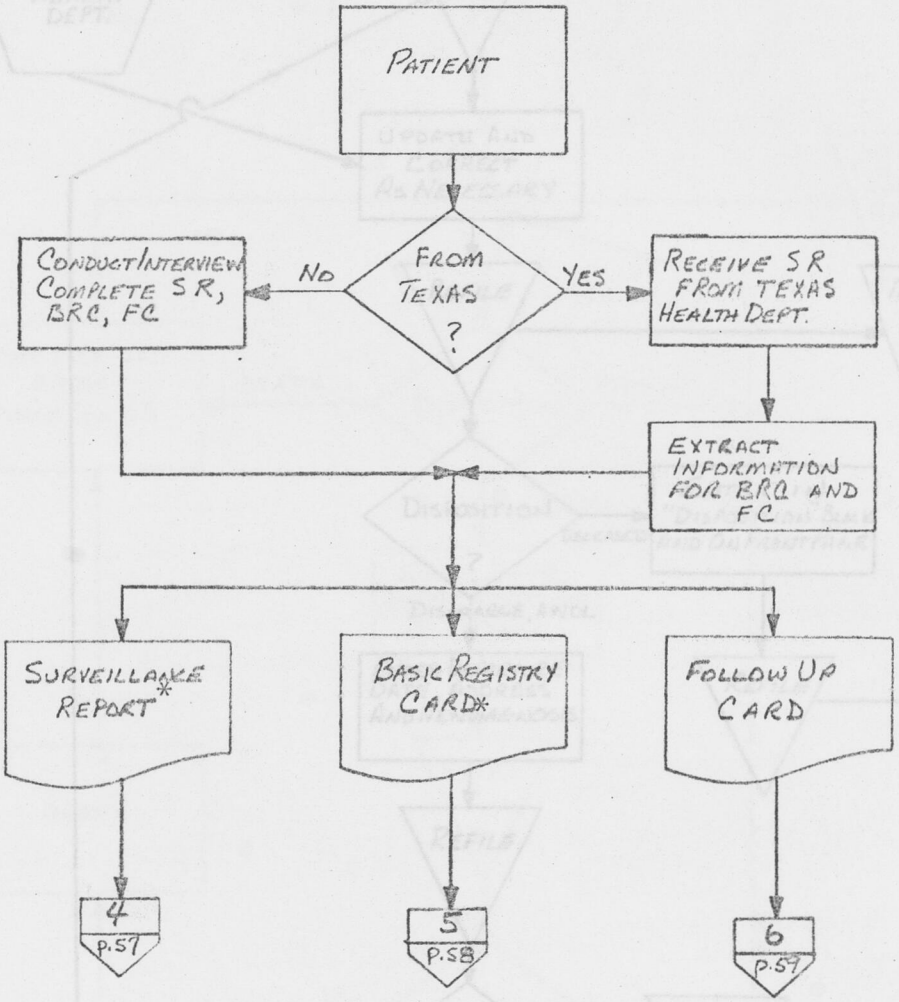

2
P.54
CONTINUES CONTACT ?
No
LOST TO FOLLOW UP
Yes
SATISFACTORY PROGRESS ?
Yes
NORMAL LIFE ANNUAL FOLLOW UP
No
REQUIRES INPATIENT THERAPY
3
P.53



APPENDIX G

PROCESSING OF LEPROSY REGISTRY RECORDS

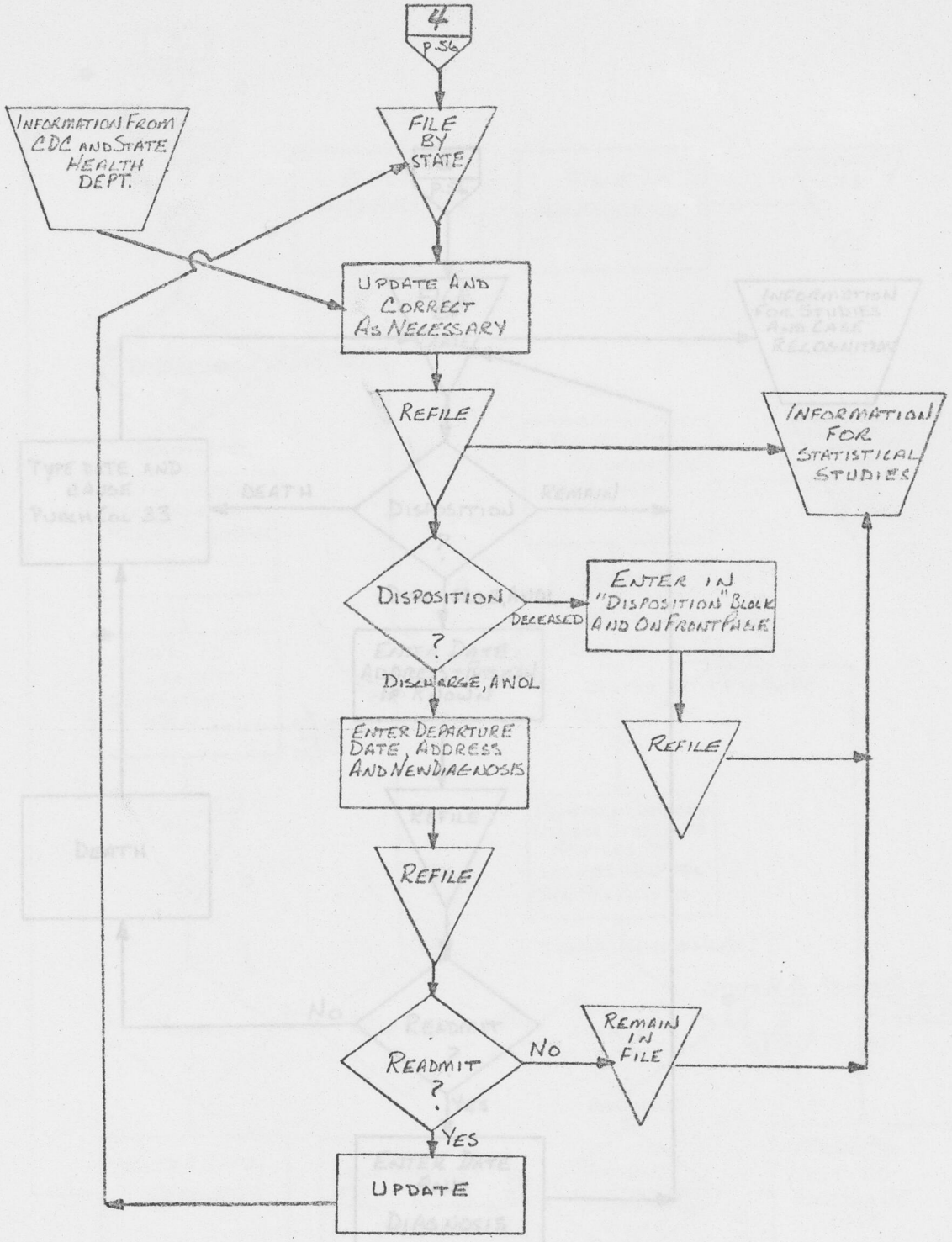
FOR CARVILLE INPATIENTS

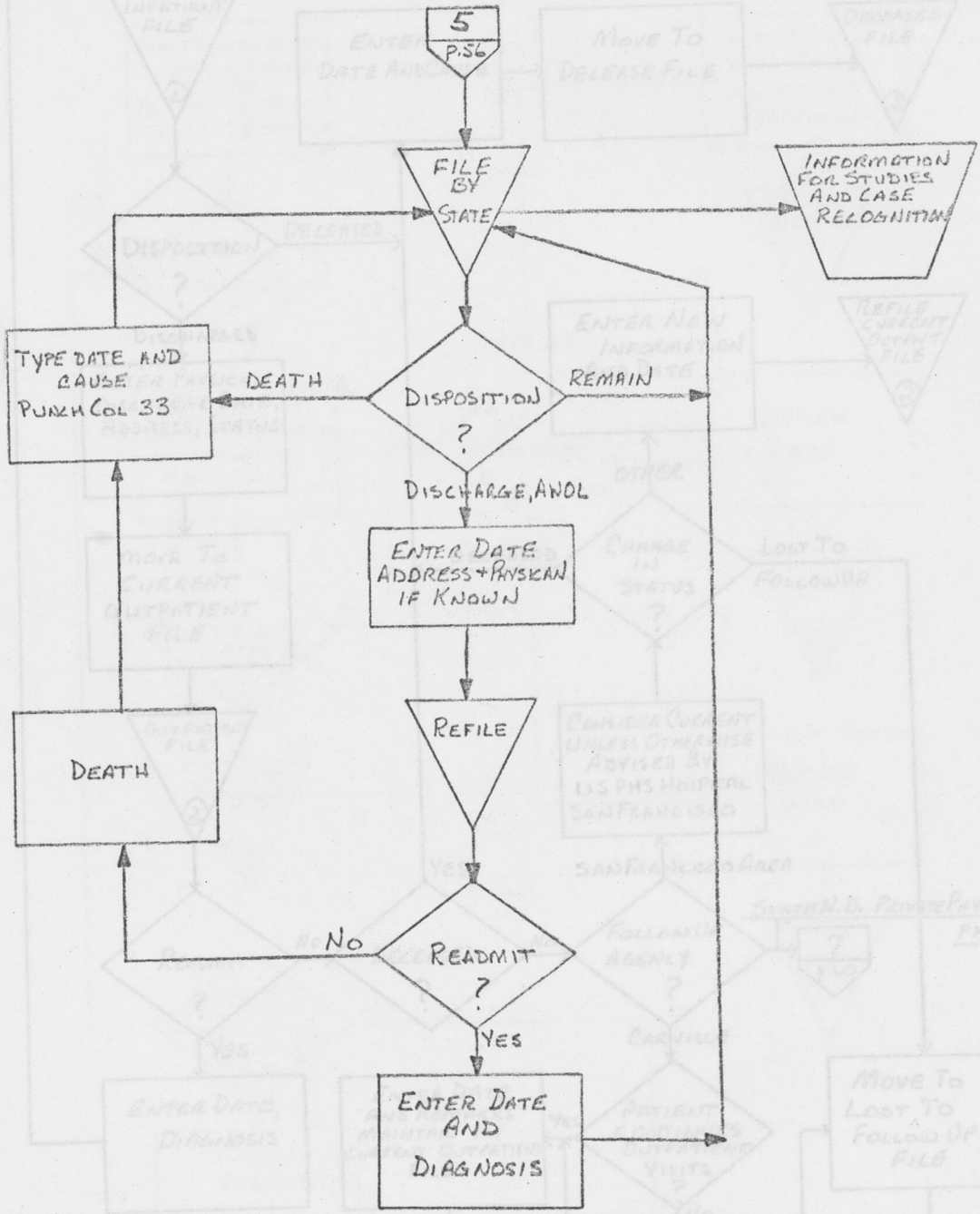


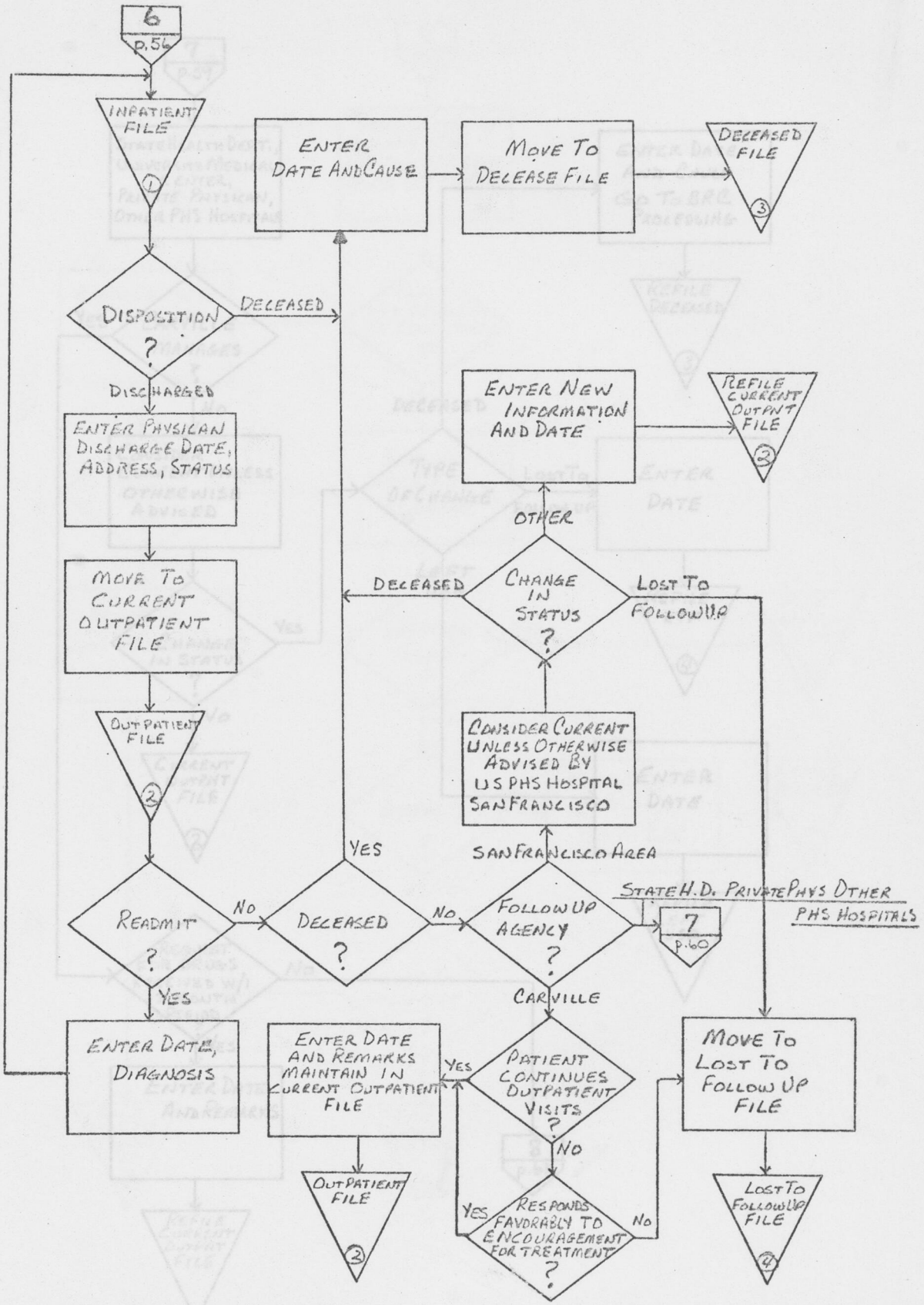
Abbreviations:

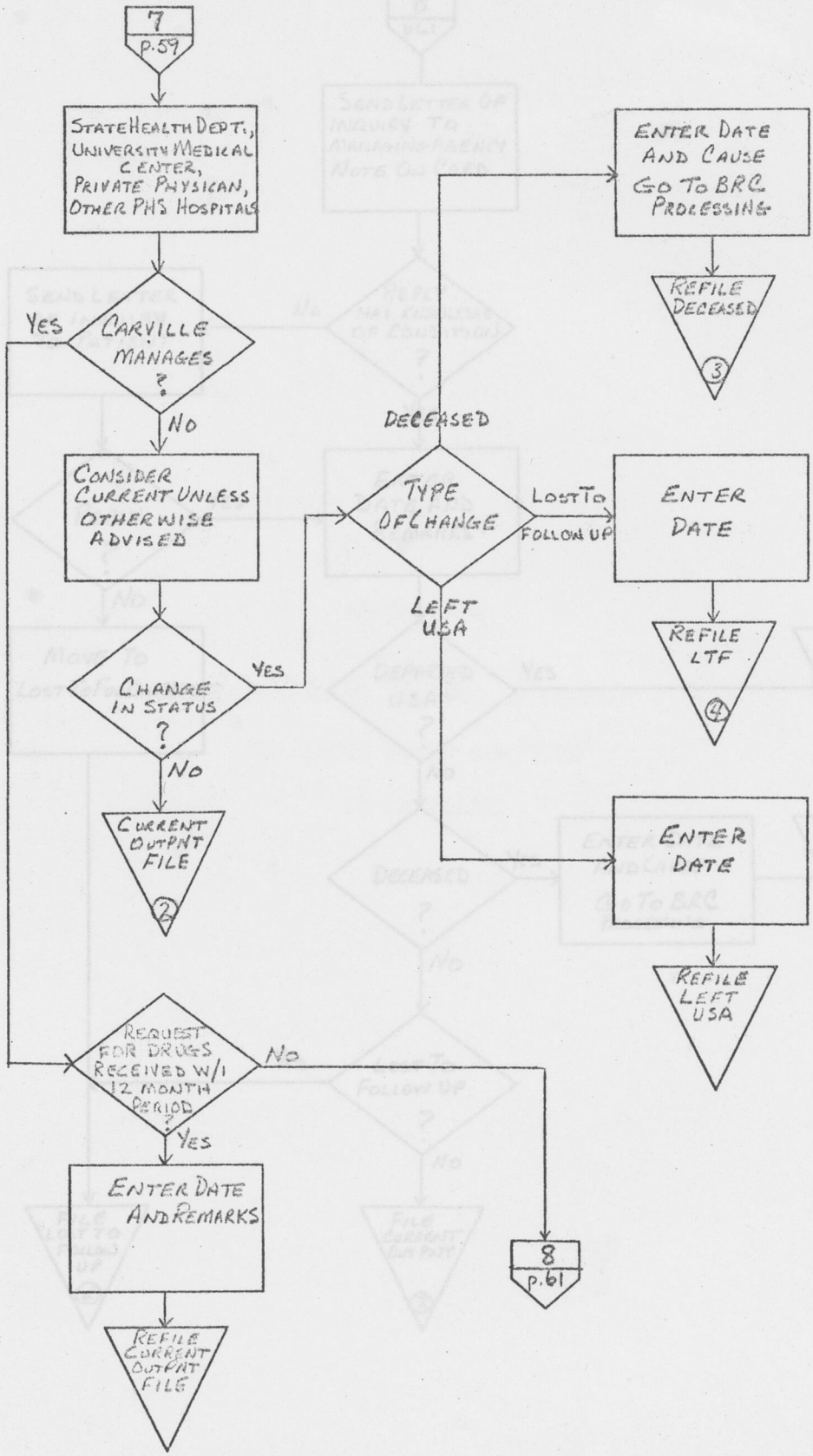
BRC: Basic Registry Card
FC: Follow-up Card
SR: Surveillance Report
CURRCUTPNT: Current Outpatient
LTF: Lost to Follow-up

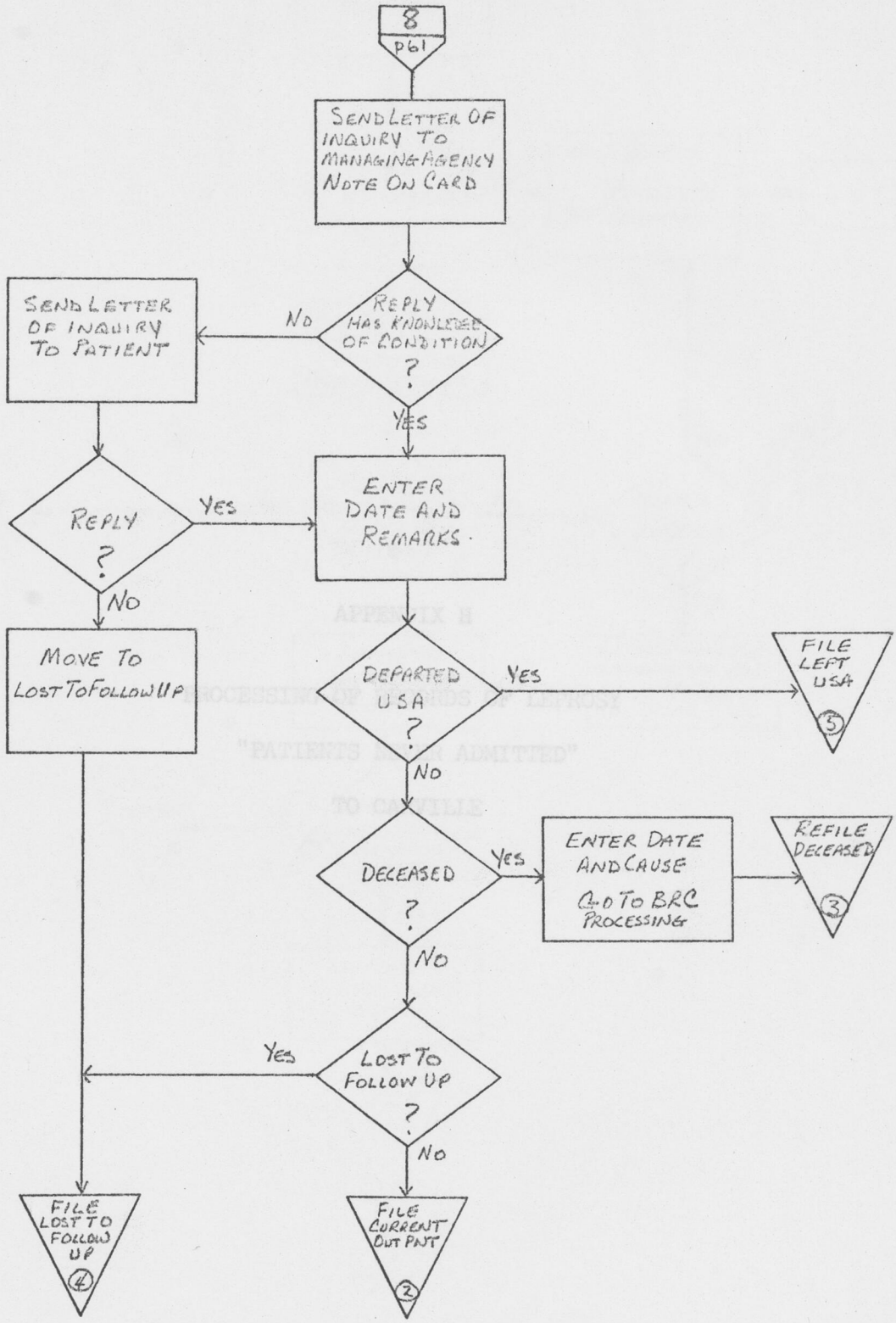
*If patient is a previous admission or a "Patient Never Admitted" (to Carville), additions are made to SR and BRC. Follow-up card is initiated.


4
P.56
INFORMATION FROM CDC AND STATE HEALTH DEPT.
FILE BY STATE
UPDATE AND CORRECT AS NECESSARY
REFILE
INFORMATION FOR STATISTICAL STUDIES
DISPOSITION ?
DECEASED
ENTER IN "DISPOSITION" BLOCK AND ON FRONT FILE
DISCHARGE, AWOL
ENTER DEPARTURE DATE, ADDRESS AND NEW DIAGNOSIS
REFILE
REFILE
READMIT ?
NO
REMAIN IN FILE
YES
UPDATE


5
P.56
FILE BY STATE
INFORMATION FOR STUDIES AND CASE RECOGNITION
TYPE DATE AND CAUSE PUNCH COL 33
DEATH
DISPOSITION ?
REMAIN
DISCHARGE, ANOL
ENTER DATE ADDRESS + PHYSICAN IF KNOWN
REFILE
DEATH
No
READMIT ?
Yes
ENTER DATE AND DIAGNOSIS


6
p.56
INPATIENT FILE
1
ENTER DATE AND CAUSE
MOVE TO DECEASE FILE
DECEASED FILE
3
DISPOSITION ?
DECEASED
DISCHARGED
ENTER PHYSICAN DISCHARGE DATE, ADDRESS, STATUS
ENTER NEW INFORMATION AND DATE
REFILE CURRENT OUTPT FILE
2
OTHER
MOVE TO CURRENT OUTPATIENT FILE
DECEASED
CHANGE IN STATUS ?
LOST TO FOLLOW UP
OUTPATIENT FILE
2
CONSIDER CURRENT UNLESS OTHERWISE ADVISED BY U S PHS HOSPITAL SAN FRANCISCO
YES
SAN FRANCISCO AREA
STATE H.D. PRIVATE PHYS OTHER PHS HOSPITALS
READMIT ?
NO
DECEASED ?
NO
FOLLOW UP AGENCY ?
7
p.60
YES
CARVILLE
ENTER DATE, DIAGNOSIS
ENTER DATE AND REMARKS MAINTAIN IN CURRENT OUTPATIENT FILE
YES
PATIENT CONTINUES OUTPATIENT VISITS ?
MOVE TO LOST TO FOLLOW UP FILE
NO
OUTPATIENT FILE
2
YES
RESPONDS FAVORABLY TO ENCOURAGEMENT FOR TREATMENT ?
NO
LOST TO FOLLOW UP FILE
4


7
p.59
STATE HEALTH DEPT., UNIVERSITY MEDICAL CENTER, PRIVATE PHYSICAN, OTHER PHS HOSPITALS
CARVILLE MANAGES ?
YES
NO
CONSIDER CURRENT UNLESS OTHERWISE ADVISED
CHANGE IN STATUS ?
YES
NO
CURRENT OUTPNT FILE
2
TYPE OF CHANGE
DECEASED
LOST TO FOLLOW UP
LEFT USA
ENTER DATE AND CAUSE GO TO BRC PROCESSING
REFILE DECEASED
3
ENTER DATE
REFILE LTF
4
ENTER DATE
REFILE LEFT USA
REQUEST FOR DRUGS RECEIVED W/I 12 MONTH PERIOD ?
NO
YES
ENTER DATE AND REMARKS
REFILE CURRENT OUTPNT FILE
8
p.61

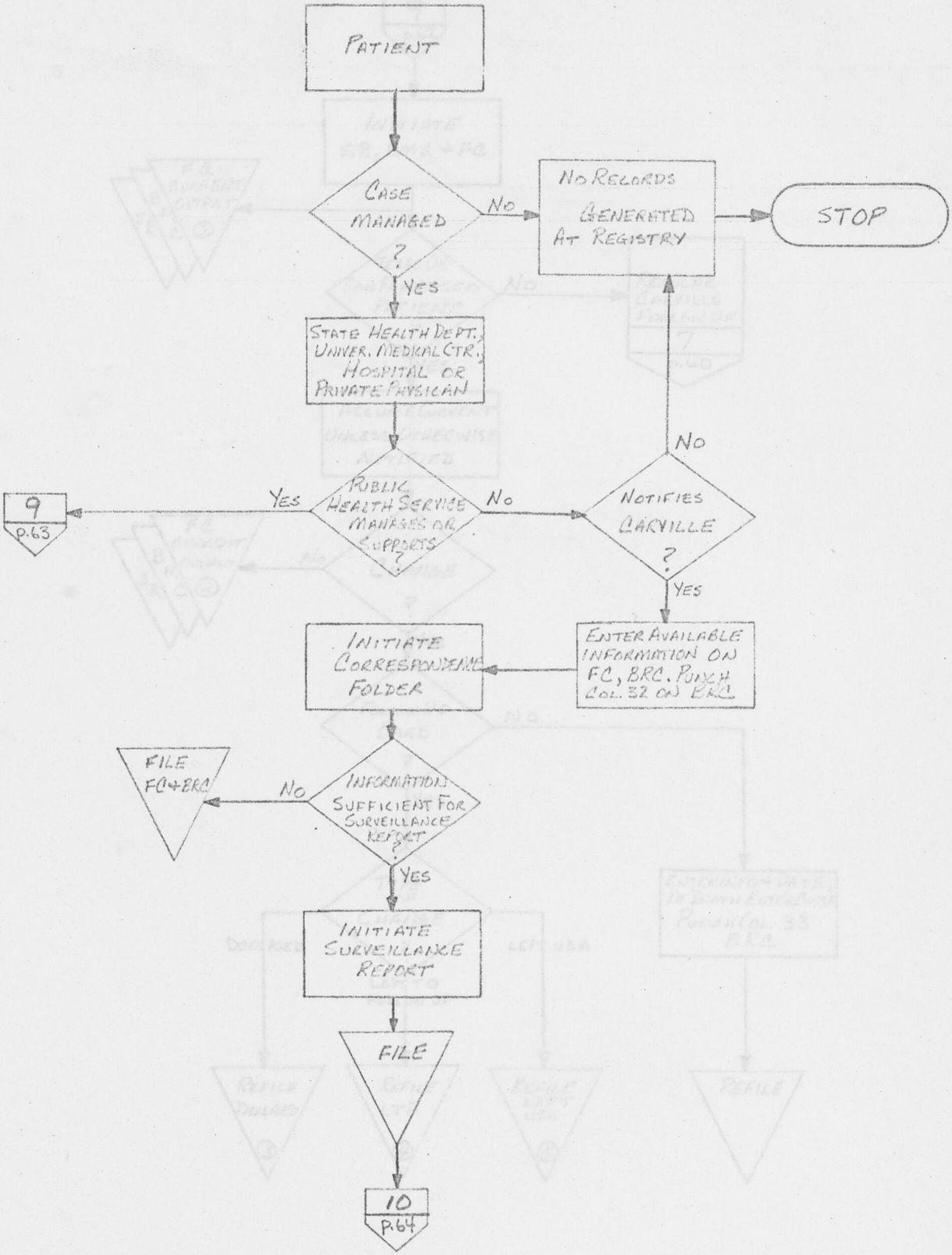

8
p61
SEND LETTER OF INQUIRY TO MANAGING AGENCY NOTE ON CARD
REPLY HAS KNOWLEDGE OF CONDITION ?
NO
SEND LETTER OF INQUIRY TO PATIENT
YES
REPLY ?
YES
ENTER DATE AND REMARKS.
NO
MOVE TO LOST TO FOLLOW UP
DEPARTED USA ?
YES
FILE LEFT USA
5
NO
DECEASED ?
YES
ENTER DATE AND CAUSE
GO TO BRC PROCESSING
REFILE DECEASED
3
NO
LOST TO FOLLOW UP ?
YES
NO
FILE LOST TO FOLLOW UP
4
FILE CURRENT OUT PAT
2

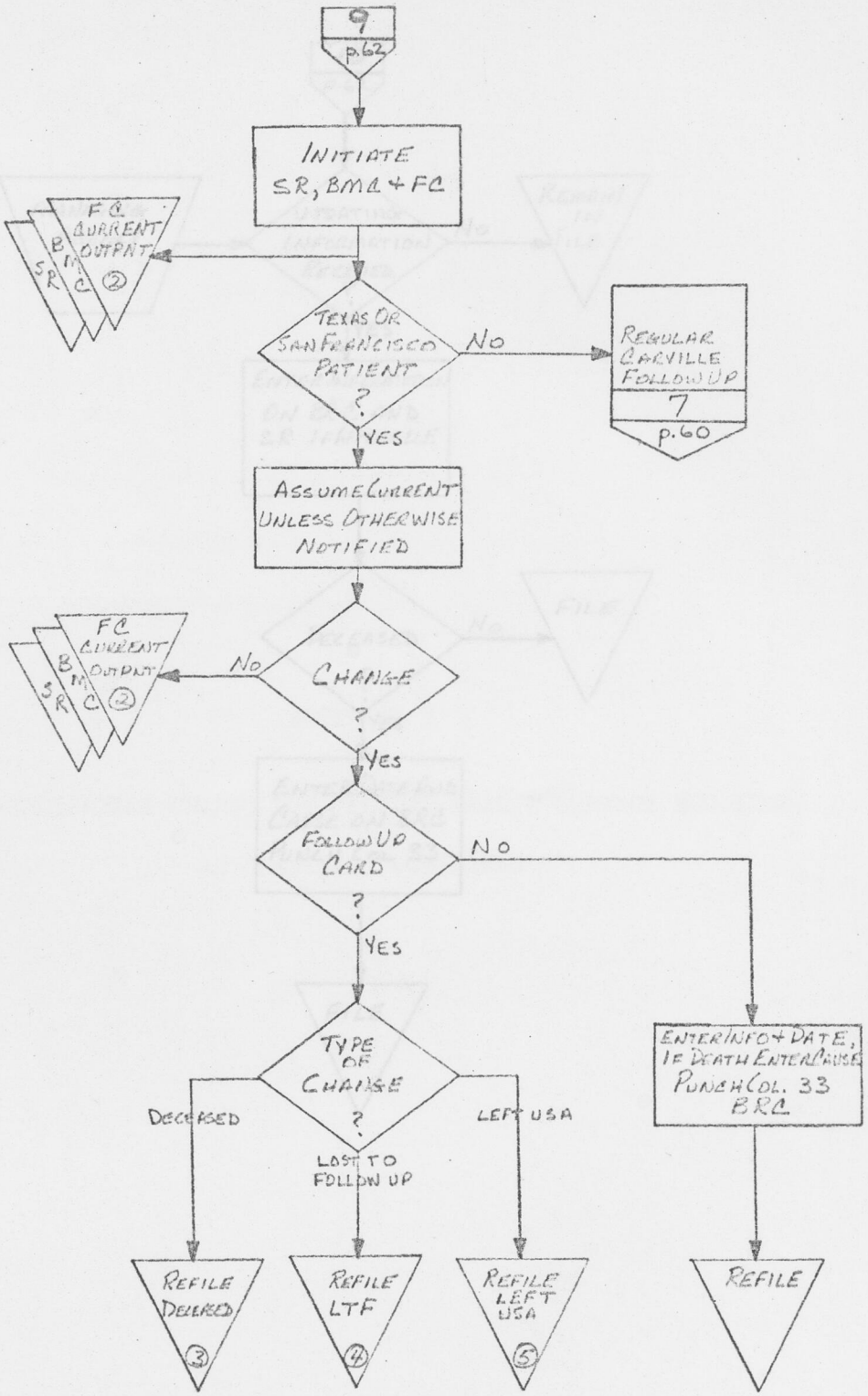
APPENDIX H

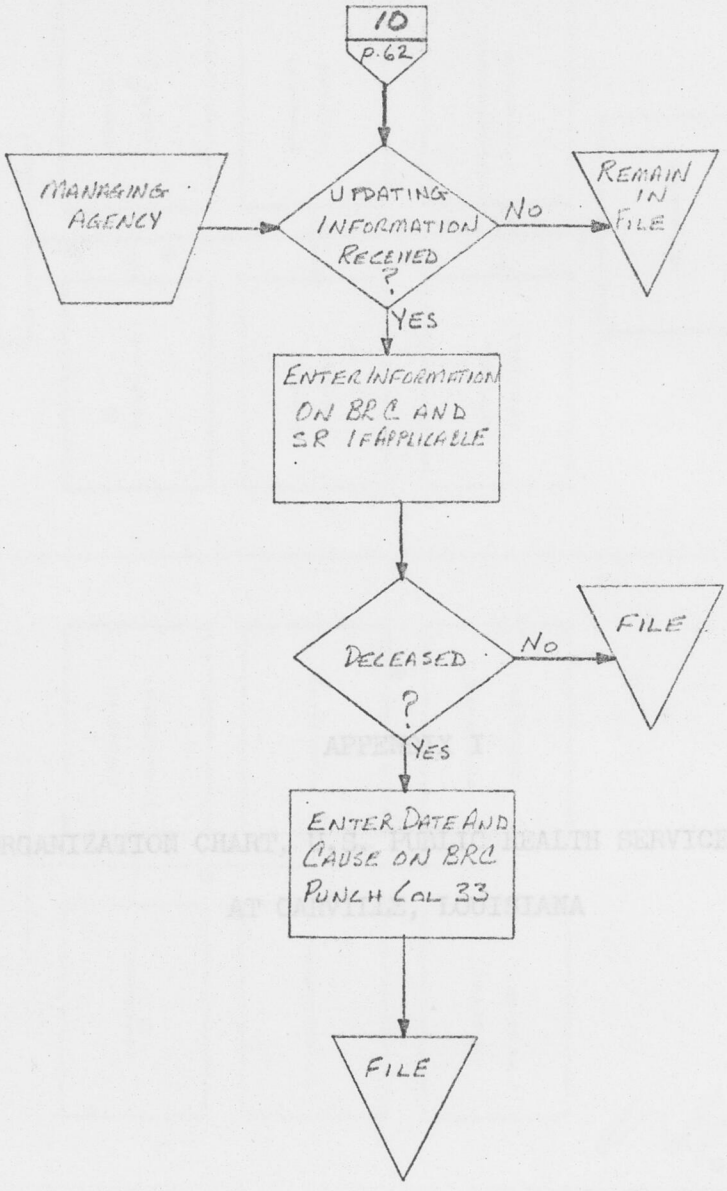
PROCESSING OF RECORDS OF LEPROSY

"PATIENTS NEVER ADMITTED"

TO CARVILLE


PATIENT
CASE MANAGED ?
No
NO RECORDS GENERATED AT REGISTRY
STOP
Yes
STATE HEALTH DEPT., UNIVER. MEDICAL CTR., HOSPITAL OR PRIVATE PHYSICIAN
PUBLIC HEALTH SERVICE MANAGES OR SUPPORTS ?
Yes
9 p.63
No
NOTIFIES CARYILLE ?
No
Yes
ENTER AVAILABLE INFORMATION ON F.C., BRC. PUNCH COL. 32 ON BRC
INITIATE CORRESPONDENCE FOLDER
INFORMATION SUFFICIENT FOR SURVEILLANCE REPORT ?
No
FILE F.C. + BRC
Yes
INITIATE SURVEILLANCE REPORT
FILE
10 p.64


9
p.62
INITIATE SR, BMC + FC
FC CURRENT OUTPUT
SR BMC ②
TEXAS OR SAN FRANCISCO PATIENT ?
No
REGULAR CARVILLE FOLLOW UP
7
p.60
YES
ASSUME CURRENT UNLESS OTHERWISE NOTIFIED
FC CURRENT OUTPUT
SR BMC ②
No
CHANGE ?
Yes
FOLLOW UP CARD ?
No
YES
TYPE OF CHANGE ?
DECEASED
LOST TO FOLLOW UP
LEFT USA
ENTER INFO + DATE, IE DEATH ENTER CAUSE
PUNCH COL. 33
BRC
REFILE DECEASED ③
REFILE LTF ④
REFILE LEFT USA ⑤
REFILE


10
P.62
MANAGING AGENCY
UPDATING INFORMATION RECEIVED ?
No
REMAIN IN FILE
YES
ENTER INFORMATION ON BRC AND SR IF APPLICABLE
DECEASED ?
No
FILE
YES
ENTER DATE AND CAUSE ON BRC PUNCH COL 33
FILE

APPENDIX I

ORGANIZATION CHART, U.S. PUBLIC HEALTH SERVICE HOSPITAL AT CARVILLE, LOUISIANA

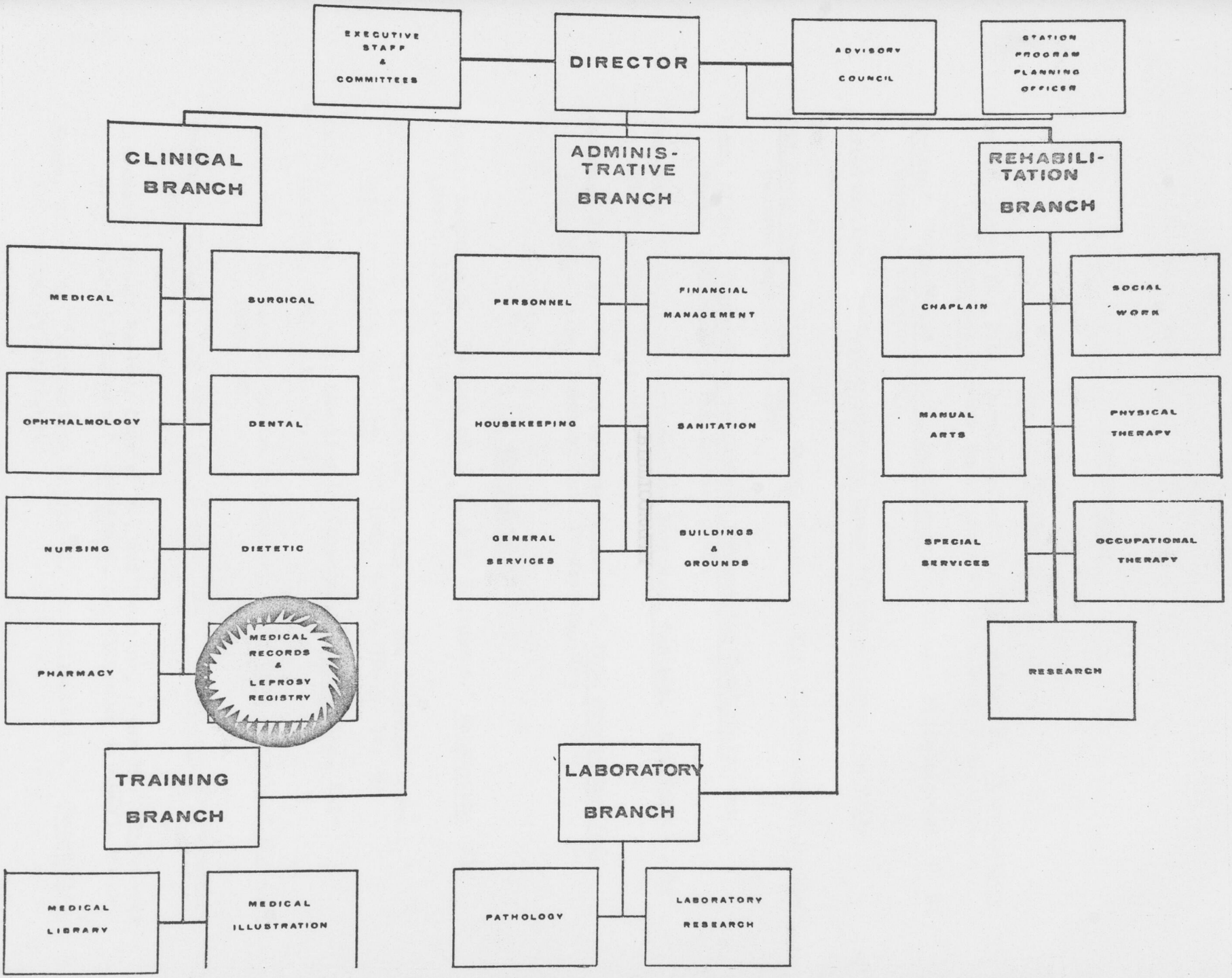


Figure 9.--Organization Chart, U.S. Public Health Service Hospital, Carville

BIBLIOGRAPHY

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Books

Arnold, Robert R.; Hill, Harold C.; and Nichols, Aylmer V. Introduction to Data Processing. New York: John Wiley & Sons, Inc., 1966.

Dorland's Illustrated Medical Dictionary. 24th ed. Philadelphia: W. B. Saunders Company, 1965.

Horowitz, Ira. An Introduction to Quantitative Business Analysis. New York: McGraw-Hill Book Company, 1965.

IBM Study Organization Plan. White Plains, N. Y.: IBM Technical Publications Department, 1963.

Kent, Allen. Textbook on Mechanized Information Retrieval. New York: Interscience Publishers, 1962.

Lancaster, F. Wilfrid. Information Retrieval Systems. New York: John Wiley & Sons, Inc., 1968.

Sweeney, James B. "Medical Records Research." Data Processing Yearbook 1965. n.p. American Data Processing, Inc., 1964.

Periodicals

Berul, Lawrence H. "Survey of I. S. & R. Equipment." Datamation, XIV (March, 1968), 27-32.

Blumberg, Donald F. "Information Systems and the Planning Process." Data Processing Magazine, VII (May, 1965), 72-75, 78, 79.

Cole, William. "Credit Checking by Computer." Datamation, XII (October, 1966), 33, 34, 39.

"Estimating the Cost of System Implementation." Data Processing Magazine, XI (March, 1969), 32.

Greanias, Evon C. "The Computer in Medicine." Datamation, XI (December, 1965), 25-28.

Greenwood, Frank; Barlow, Charles M.; and Danziger, Erwin M. "The Rigors of Choosing A Computer." Hospitals, XLI (December 1, 1967), 40-44.

Hayes, Robert M. "Information Retrieval: An Introduction." Datamation, XIV (March, 1968), 22-26.

Hewes, W. L. and Stow, K. H. "Information Retrieval by Proper Name." Data Processing Magazine, VII (June, 1965), 18-22.

Kaimann, Richard A. "Entry to the File, Randomize or Index." Part II. Data Processing Magazine, X (December, 1968), 24-28.

"Medical Research Group Develops Program for the Control of Tuberculosis, Other Chronic Diseases." Computer Applications Service, VII (Number 8, 1969), 108-110.

Postley, John A. and Buetell, T. Dwight. "Generalized Information Retrieval and Listing System." Datamation, VIII (December, 1962), 22-25.

Pryor, T. Allan and Warner, Homer R. "Time-Sharing in Biomedical Research." Datamation, XII (April, 1966), 54, 57, 59, 61-63.

Roach, Charles A.; Ellestad, Myrvin H.; and Lake, Raymond B. "Medical Data Processing & Computer Automated Hospitals." Datamation, VIII (June, 1962), 25-28.

Scharf, Tom Gilb. "How Not to Choose an EDP System." Datamation, XV (April, 1969), 73, 74.

"The History of Carville." The Star, November-December, 1954, pp. 3, 6, 9.

Trautman, John R. "Clinical Aspects of Leprosy." Southern Medical Journal, LVIII (April, 1965), 421-424.

"Unusual Example of Cooperation Between Hospitals Over 1,000 Miles Apart." The Nation's Hospitals, (Number 4, 1969), 6-8.

Newspaper

San Antonio News. "Proposed Federal Pay Rates," March 4, 1969.

Government Publications

Texas State Department of Health. The Disease Kept Behind Closed Doors. Austin, Texas: n.p., n.d.

_____. What You Should Know About Leprosy. Austin, Texas: n.p., n.d.

_____. The History of Leprosy. Austin, Texas: n.p., n.d.

U.S. Civil Service Commission. Position Standards, GS 357. Washington, D.C.: Government Printing Office, June, 1963.

_____. Position Standards, GS 359. Washington, D.C.: Government Printing Office, June, 1960.

_____. Position Standards, GS 362. Washington, D.C.: Government Printing Office, February, 1961.

U.S. Public Health Service Hospital, Carville, Louisiana. Functional Chart. Carville, Louisiana, October 1, 1967.

Unpublished Materials

U.S. Public Health Service Hospital, Carville, Louisiana. "Carville." (Brochure).

_____. "Facts About the U.S. Public Health Service Hospital, Carville, Louisiana." (Brochure).

Interviews

Enna, Carl D. Chief, Clinical Branch, U.S. Public Health Service Hospital, Carville, Louisiana. Personal interview on May 2, 1969.

Feldman, Roger. Leprosy Surveillance Officer, National Communicable Disease Center, Atlanta, Georgia. Telephone interview on May 2, 1969.

Payne, Rufus F. Director, Hospital Research and Development, Medical College of Georgia. Telephone interview on May 2, 1969.

Simokatz, Joseph. Manager, New Orleans, Louisiana Office; National Cash Register Company. Personal interview on May 9, 1969.

Smith, Robert. Service Bureau Corporation Representative, New Orleans, Louisiana. Personal interview on May 8, 1969.

Sturdivant, Marilyn. Leprosy Registry Clerk, U.S. Public Health Service Hospital, Carville, Louisiana. Personal interviews April 28, 1969 through May 9, 1969.

Trautman, John R. Director, U.S. Public Health Service Hospital, Carville, Louisiana. Personal interviews on May 2, 1969 and May 9, 1969.

Yeager, Donald E. Marketing Manager, Data Processing Division, Baton Rouge, Louisiana Office; International Business Machines Corporation. Personal interview on May 7, 1969.

ABSTRACT

A STUDY TO DETERMINE THE BEST SYSTEM OF INFORMATION STORAGE AND RETRIEVAL FOR THE LEPROSY REGISTRY U.S. PUBLIC HEALTH SERVICE HOSPITAL, CARVILLE, LOUISIANA

By Major Herbert E. Cygan, MSC

August, 1970 77 Pages

A copy of this document may be obtained on loan from the United States Army Medical Field Service School, Brooke Army Medical Center, Fort Sam Houston, Texas.

The problem explored by this study was to determine the best method for storing, retrieving, and reporting the information which is collected, maintained, and stored by the Leprosy Registry Department of the U.S. Public Health Service Hospital at Carville, Louisiana. Patient data stored in the records of the registry date from 1894 and are of potential epidemiologic value; but the information is not economically retrievable for reporting and statistical analyses using a manual processing system.

The current system was examined to define existing inputs, processes, controls, and outputs. Inter-relationships within the system and with other systems were studied. System goals and the requirements necessary for their achievement were established or described. Four alternative automated systems were presented. These systems involved the use of edge-notch cards, punch cards, or computers. The systems were compared according to their cost per report, performance times, and ability to accomplish the desired functions such as mechanical production of case follow-up correspondence, case recognition, file search and patient characteristic listing, and statistical analyses of data.

It was concluded that the computer system developed at the Medical College of Georgia was the best system since it afforded the optimal cost/benefit ratio and coincided with future plans of the hospital for automation. Recommendations were made to proceed with the development of machine-acceptable forms, to effect liaison with the college, and to develop necessary budgetary justifications to permit implementation of the system.