

# Psychiatric Case Register Conference, 1965

**T**HE THIRD psychiatric case register conference in the United States was held under auspices of the National Institute of Mental Health, Public Health Service, on July 1-2, 1965. Psychiatrists, statisticians, and other representatives of two State and two community research registers attended. The purposes of this meeting were to review progress since the last conference which was held in 1962; to discuss objectives and uses of registers, common problems, and needs; and to plan for the establishment of a cooperative register program.

These registers, fundamentally similar in purpose and method, are based on continual collection of patients' reports from psychiatric inpatient and outpatient facilities serving residents of a defined geographic area. The data are assembled to provide a cumulative record of each patient's psychiatric experiences. Such a data bank serves a variety of administrative and epidemiologic research objectives.

A psychiatric case register is a relatively new tool for psychiatric research and for planning community mental health services. Since the first register was established in January 1960, there have been constant gains in register technology and an increasing number of register-based studies. Some of these results, including the first comparative study of prevalence and admission rates among the four registers, were presented at the 1965 meeting of the American Public Health Association at a session devoted to psychiatric register research. Several unresolved problems remain, and a discussion of these is summarized in this report.

## Register Maintenance

*Basic operation.* Essential criteria for a case register are complete and accurate reporting and followup procedures. A psychiatric case register should include reports from all inpa-

tient and outpatient facilities in which one or more psychiatrists assume responsibility for all patients with a primary diagnosis of mental disorder and which serves residents of the defined geographic area. (Specifications of types of psychiatric and related facilities are given in "Guidelines for State Plans To Be Submitted Under the Community Mental Health Centers Act of 1963.")

Another requirement for maintaining a register is routine review of death certificates to remove from the active register names of patients who died, to provide data such as date and causes of death, and to help determine the correct number of persons who are "at risk" of readmission.

Similarly, it is necessary to remove from "risk" to readmission to a facility within the surveillance area former patients who have migrated from the area. Study is needed to determine the most efficient ways to detect migration. Migrants may be more or less ill than nonmigrants; therefore, their current status should be determined by studying samples of each group in order to develop inferences on recurrence and survival patterns.

Continued reporting participation and community support of the register require routine feedback of register data in addition to special research. Studies of samples of persons who do not reappear on psychiatric rosters may be desirable in order to determine the former patient's current level of functioning and whereabouts, such as jail or nursing home, so that better estimates can be made of the true prevalence of psychiatric disability and of outcome. Patient or family interviewing for followup

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studies must be undertaken only with the consent of the facility which reported the case.

Additional study is needed to ascertain which items of register information should be collected routinely (see table) and which on a sample basis. Items such as household composition, occupation, and duration of residence in the area may be questioned as to their reliability for routine reporting and because of the increase to the reporting burden. Yet they can add immeasurably to the value and interpretation of other register data by providing a more complete description of the patient's social circumstance or by aiding in identifying patients who may have received prior services outside the area. Evaluation of the kinds of items reported is a continuing need for psychiatric register maintenance.

Also necessary is additional work on defining terms such as a "case" and "episode of illness." Although data are reported as episodes of service by various facilities, through the cumulative records it is possible to study also the broader concept of episodes of illness. An episode of illness, for example, can be operationally defined to include several episodes of care with time-limited discontinuities between them.

*Safeguards.* One notable achievement in register maintenance has been development of safeguards to protect the confidentiality of register records. Special State legislation has been enacted to assure the use of these registers for research purposes only, their immunity to court subpoena, and protection of the reporting physician against lawsuit.

Locked files and record rooms, dissociation of names from other information after record matching, and storage of names on punchcards or in electronic form only are among the procedures established to insure the integrity of each register. As a result there has been no instance of abridgment of a patient's rights.

*Technology.* The large complex body of cumulative data on patients, the repetitive operations in register maintenance, and the demand for both routine and special statistical output make computerization of psychiatric registers essential in areas with large populations.

Automatic updating of case records, including record matching and data retrieval, has been developed for and accepted as essential to main-

taining psychiatric registers. The importance of these advances cannot be overemphasized. Additional and more sophisticated technological improvements can be anticipated as the registers continue to expand and more extensive experience is gained.

### **Expansion**

Psychiatric registers grow rapidly because of the following factors:

- The relatively high prevalence of psychiatric care.
- The chronicity of mental illness.
- Additions of new casefinding facilities.
- Rapid movement of patients between facilities.
- Identification of many cases in children.
- The need to follow patients over their lifetime in order to study diagnostic changes, patterns of illness, and other aspects of life history.
- The lifespan of people who are mentally ill, except for those with brain disorders, alcoholism, or certain depressive diseases, is not markedly shorter than that of the general population.

The concept of psychiatric case registers will influence reporting and recordkeeping techniques which will be developed for comprehensive community mental health centers. For example, when there is formal transfer of patients among various kinds of services—such as emergency, day-night, inpatient, and outpatient—in the center, reports on the sequence of patient flow are of administrative interest. However, consideration must be given to the volume of movement data which might result.

It was pointed out also that the unit record system of the community mental health center can aid in the study not only of the center's services but also of the interrelation of the center with other facilities. However, unless the center provides virtually all the mental health services received by the community, its records alone could not constitute a community case register.

### **Personnel**

Staffing was also of great concern to conference participants. Two types of personnel are required: Staff for register maintenance and data retrieval and staff for register analyses.

Computer programmers and clerks are needed

**Information collected routinely by four psychiatric case registers, July 1, 1965**

Data collected	Register			
	Hawaii	Maryland	Monroe County, N. Y.	North Carolina (3 counties)
<b>Identification and characteristics:</b>				
Name.....	A	X	X	X
Maiden name.....	A	X	X	X
Social security number.....	A	X		X
Mother's maiden name.....		E		
Address.....	X	X	X	X
Rural or urban residence.....				X
Duration of residence:				
In State.....		X		
In city or county.....		X	HE	
At present address.....		X	E	
Birthdate.....	X	X	X	X
Age.....	X	X	X	X
Birthplace.....	X	E	E	X
Sex.....	X	X	X	X
Color or race.....	X	X	X	X
Citizen (yes or no).....	X			
Veteran's status (service-connected illness or disability?).....	X			
Marital status.....	X	X	X	X
Multiple marriages (yes, no).....	X			
Education.....	X	X	E	X
Religion.....	X	X	E	X
Is patient employed?.....		X	E	X
Usual occupation.....	X	X	E	X
<b>Household composition:</b>				
Total number in household.....	X	X		
Living alone.....	X	X	E	
Living with spouse.....	A	X	E	
Patient's children.....	A	X	E	
Patient's parents.....	A	X	E	
Patient's siblings.....		X		
Other relatives.....	A	X	E	
Nonrelatives.....	A	X	E	
Institutional living.....		X		
<b>Family information (not necessarily current household):</b>				
Is patient a twin or triplet?.....				X
Number of older siblings.....	A		E	

<sup>1</sup> If patient is not employed.

NOTE: X, routinely collected; H, data collected by hospital only; C, data collected by clinic or day-care facility only; E, contemplated extension of present collection; A, available but not punched or coded; Y, for selected facilities.

to maintain high quality of cumulative records by assisting facilities with their reports, by investigating inconsistencies and correcting errors revealed by editing programs, and by collecting and processing data.

Professional persons are needed to convert program objectives into questions which can be researched and conversely to interpret register data as they relate to program goals. Psychiatrists, psychologists, epidemiologists, sociologists, and statisticians are required for research

including detailed field studies of samples drawn from the register. Such a team of technical and professional personnel adds a new dimension to administrative and epidemiologic research investigations not heretofore available.

**Uses of Register Data**

Because registers are difficult and costly to maintain and have certain limitations, their value is often questioned. A central topic, therefore, was the emerging uses of psychiatric

**Information collected routinely by four psychiatric case registers, July 1, 1965—Continued**

Data collected	Register			
	Hawaii	Maryland	Monroe County, N. Y.	North Carolina (3 counties)
Family information (not necessarily current household)—Continued				
Number of younger siblings.....	A		E	
Occupation of head of household.....	A	X <sup>1</sup>	E	X
Education of head of household.....			E	
Household and other family members (birthdates, race, psychiatric history).....	A			
Diagnostic classification:				
American Psychiatric Association diagnosis.....	X	X	X	X
American Association on Mental Deficiency diagnosis (for mental retardation facilities).....	X	X		X
Multiple psychiatric diagnoses.....	A		X	X
Mentally retarded only:				
Supplementary terms, such as type of impairment, measured intelligence level.....				X
Problem appraisal at intake.....		Y		
Problems noted at termination:				
Problem drinking.....		X		X
Suicide threat.....		X		X
Suicide attempt.....		X	X	X
Drug abuse or dependence.....		E		
Services:				
Date admitted.....	X	X	X	X
Previous admission to this facility.....	X	X	X	X
Previous psychiatric care (yes, no, unknown).....	X	X	X	X
Type of hospital commitment.....	H	H		H
Referral source.....	X	X	E	X
Number of interviews.....	C	C		C
Frequency of interviews.....		A	X	
Days in day-care facility.....	C	C		
Service received.....	X	X	X	C
Types of treatment.....	X	X	X	X
Condition after treatment.....	X	X	X	X
Disposition (including recommendations for further care).....	X	X	X	X
Recommendation for voluntary or involuntary hospitalization.....		X		
Date of final interview.....	C	C	C	C
Movement (hospital).....	X	X		X
Cause (and date) of death in hospital.....	X	X	X	
Date of significant hospital release or discharge.....	X	X	X	X

case registers at national, State, community, and clinic levels.

Register output has included model annual tables for reference purposes to answer specific questions by clinicians, program directors, and county health officers; monthly newsletters highlighting specific findings; articles on trends; and analytic and research reports.

Discussing register research with reporting agencies and establishing register advisory committees and mental health research councils have been valuable methods of interacting with the community. Since psychiatric registers are relatively new, more effective ways of using this

information resource must be learned. In addition to accumulated experience with the interpretation of the data, the more mature register provides a greater potential for answering questions relating to trends in service and to the natural history of disorders.

Uses of registers at the national level illustrate the wealth of information readily available in these data banks to supplement the routine reporting system. For queries pertaining to Medicare, psychiatric readmission rates were obtained for the elderly; so were correction factors to "unduplicate" national rates of admission pertaining to the aged.

Register data on the frequency with which various depressive disorders are diagnosed and the stability of these diagnoses have suggested areas of nomenclature modification. Epidemiologic studies have been initiated on racial differences in the development of alcoholism and on aspects of schizophrenia. Studies are planned on differential mortality and fertility rates for the psychiatric population, "crisis periods" in life, and cost of psychiatric care for the patient over long periods of time rather than per episode of service.

Data on facility use have aided in planning community mental health center construction. The registers have provided information on special problem areas such as psychiatric services to children, to nonwhites, and to urban and rural populations.

From the State administrator's point of view, the register has been of immense educational value for the public, the legislature, and the planner. It has provided documentation on the number and characteristics of persons served, the services rendered, and some dimensions on the extent of mental disability in the State. The register, by fulfilling an urgent need for baseline data of this type, will help administrators determine which programs are successful or should be changed for certain types of patients and what programs should be abandoned. It is being used as an aid in establishing better fiscal and insurance programs for mental health services, identifying the psychiatrically indigent, and deploying scarce manpower among the various programs.

A State register on electronic tape is readily divisible into registers for each county and for the inner city. When a statewide register cannot be established, there are enhanced values to two or more community register areas within a State if the areas have contrasting characteristics, such as those of an urban and a rural community.

At the community level, the register has been used to study the contribution of different types of facilities, such as the general hospital or the day hospital, and for observing gaps in the total service network, such as lack of care to nonwhite children. It is being used for ecological studies of the geographic concentration of multiproblem families, including not only

those in which there is mental illness but also families with other health and sociocultural deficits. Consequently, the register is an aid in selecting locations for community mental health centers. It will also implement evaluation of the impact of the mental health center on the community because it facilitates "before" and "after" comparisons.

Registers can help also in designing and evaluating preventive programs by indicating groups of persons most likely to require care in a mental hospital. It can aid in evaluating programs such as Project Head Start by providing ready information on subsequent psychiatric service to the children.

For clinical purposes the register is providing systematic followup information on the outcome of classic child guidance and other services and on experimental compared with control groups in the study of treatment modalities. It serves as a sampling frame for conducting field investigations of community adjustment of former mental patients. The register has been used to select and study a cohort of cases in terms of changes in diagnosis and treatment as related to psychiatric characteristics. Its data have suggested new treatment services, such as the mental health team for hard-to-reach groups, and these data are documenting the results of this experimentation in services.

### Limitations

A principal limitation of case registers, as well as of other service-based records, is that they include only those ill persons who receive services. Thus a psychiatric case register actually describes the epidemiology of psychiatric services; persons who need care but do not receive it are excluded.

However, "need" is a difficult concept to define; one must specify need for what services and patient readiness for such services. Thus far no practical way has been found to obtain on a large scale valid data on the incidence or prevalence of mental illness among people who do not seek help. It is likely that data from school and household surveys in conjunction with psychiatric case registers can yield better estimates of the total mentally ill population than surveys or registers alone. Complemen-

tary casefinding surveys should be conducted in register areas in order to facilitate cross-validation and interpretation of data from each source.

Reports from psychiatrists in private practice can provide highly desirable data to case registers because their practices may be selective and probably are large. These psychiatrists are an important element of the continuum of services to individuals who receive help. Psychiatrists' reports are valuable therefore for a more complete longitudinal history of the development of mental disorders whether or not their patients are eventually reported by psychiatric agencies. Only one register, however, routinely collects reports from a significant portion of psychiatrists engaged in private outpatient practice and consultation.

Estimates of the relative importance of omissions from reporting, such as characteristics and magnitude of the caseload in private practice or of other psychiatric resources, are needed. Such estimates can be made by special surveys or by studies of more complete registers.

Pilot studies are needed also to evaluate the contribution of and to develop reporting methodology for services to the mentally ill by non-psychiatric mental health agencies, such as schools, nursing and old age homes, and health and social welfare agencies. These may become particularly important because the psychiatrist's role as a consultant to caretaker or social service agencies is increasing and because lower socioeconomic groups may tend to use such agencies as alternatives to psychiatric services. Studies of the mental health service agencies underway in several register areas include both sample and routine collection of data from family service agencies, school and college mental health services, general practitioners, and medical clinics.

A study of the people who are arrested or imprisoned in relation to the persons receiving psychiatric treatment is also needed. Eventually it may be possible to develop a psychosocial register which would provide a more complete count of people who are mentally ill or have psychosocial disturbances, better data on their life pattern of deviant behavior and social problems, and on the total network of services on their behalf.

## Goals

To determine the number and characteristics of people who come to the attention of psychiatric personnel, surveillance-type research is needed. As stated by Dr. Stanley F. Yolles, Director of the National Institute of Mental Health, "In the attack on mental illness as a serious national problem of public health, we have for years desired to have data which can trace the services provided to a citizen when he becomes mentally ill. . . . This is the kind of information we need in planning the new community mental health services that will be part of every community's health protection within the next few years."

*Cooperative program.* A cooperative psychiatric register program would extend the usefulness of individual registers by providing a framework for comparative studies, for example, longitudinal studies of diagnostic consistency. Whereas data for individual registers may be limited to number of cases of a particular type, a greater pool of data is available from several registers. Whether observations from one register area are similar to those in other areas or uniquely different is of interest to both the individual register and the National Institute of Mental Health.

As background to further development of a cooperative program for psychiatric registers, other cooperative register programs sponsored by the National Institutes of Health were described. Hospital-based cancer registers provide baseline data on survival rates needed to evaluate improvements in cancer chemotherapy. Blindness registers based on population yield information on incidence, prevalence, and causes of blindness. Both register groups conduct large-scale cooperative studies based on duplicate punched cards or special abstracts of patients' histories submitted to the Institutes.

*Standardization.* Prerequisite to cooperative register studies is standardization of data. Electronic methods make possible some flexibility and variation in data items and reporting sources while furthering standardization, thereby facilitating complementary as well as comparative studies. The goals of standardization for psychiatric registers include increasing efficiency and economy of operations, such

as reducing programing costs and maximizing the potential usefulness of each register.

Flowcharts for complex computer programs, such as name matching, can be profitably exchanged. However, detailed programs, even in a common computer language, such as COBOL, are not readily transferable unless computer configuration and data systems are similar. Facets of standardization discussed included types and definitions of psychiatric facilities; a core of common items, definitions, categories, and codes; the format of the patient's cumulative electronic record; and computer programs for editing records, updating the register, and retrieving and analyzing data.

*Suggested procedures.* Three possible methods for achieving cooperation among psychiatric registers were reviewed.

1. Submission to the National Institute of Mental Health of statistical punched cards for each episode of mental illness of a patient. Each card would contain the patient's register number, and the Institute would prepare an updated standard tape and summary punched cards or tabulations or both for the use of each register.

This system would provide each register with substantial computer assistance—thereby eliminating duplicate programing and facilitating establishment of new registers. Tapes available from the central register at the National Institute of Mental Health could be used as a bank of uniform data for cooperative studies. However, such a scheme would require a high degree of standardization among registers and a much larger supporting staff than the Institute now has available.

2. Submission to the National Institute of Mental Health of standard summary punched

card records for each individual patient. These records then could be used in the same analytic computer program for special studies. This procedure would require that each register be able to carry out specific data reduction and code conversion procedures.

3. Submission to the National Institute of Mental Health of completed tables by each register. The tables then could be combined. This method might also require data processing beyond the computer capability of the individual register, depending upon the type of analyses to be carried out. Furthermore, it would provide no computer aid to the individual register unless the data records and computers were similar, enabling one computer program to be used by all registers.

The feasibility of these and other possible procedures will be considered, taking into account the size of the registers and computer capability and compatibility. Revised computer programs for the largest and most automated of the four registers are being written in common machine language to facilitate use by other registers.

### **Conclusion**

Standardization of certain operational definitions, items, and categories was considered preliminary to all further levels of cooperative effort. A working group was formed, therefore, to develop a joint operational manual. Another task force of program representatives will prepare a statement clarifying the uses of registers and suggesting priorities for register studies at the community, State, and national levels. The work of these two groups will be presented at the next register conference.