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ABSTRACT

This report presents recommendations for compiling inventories of state health data sources in an attempt to stimulate preparation and publication of a "Compendium of State Data Sources for Health Planners" for each state. Areas considered are: (1) planning the project; (2) technical assistance available; (3) kinds of data needed; (4) the forms of data sources; (5) data access considerations; (6) standards for including data sources--quality and utility; (7) agencies and organizations to be surveyed; (8) information to be obtained on each data source; and (9) publication and distribution of the compendium. (MM)

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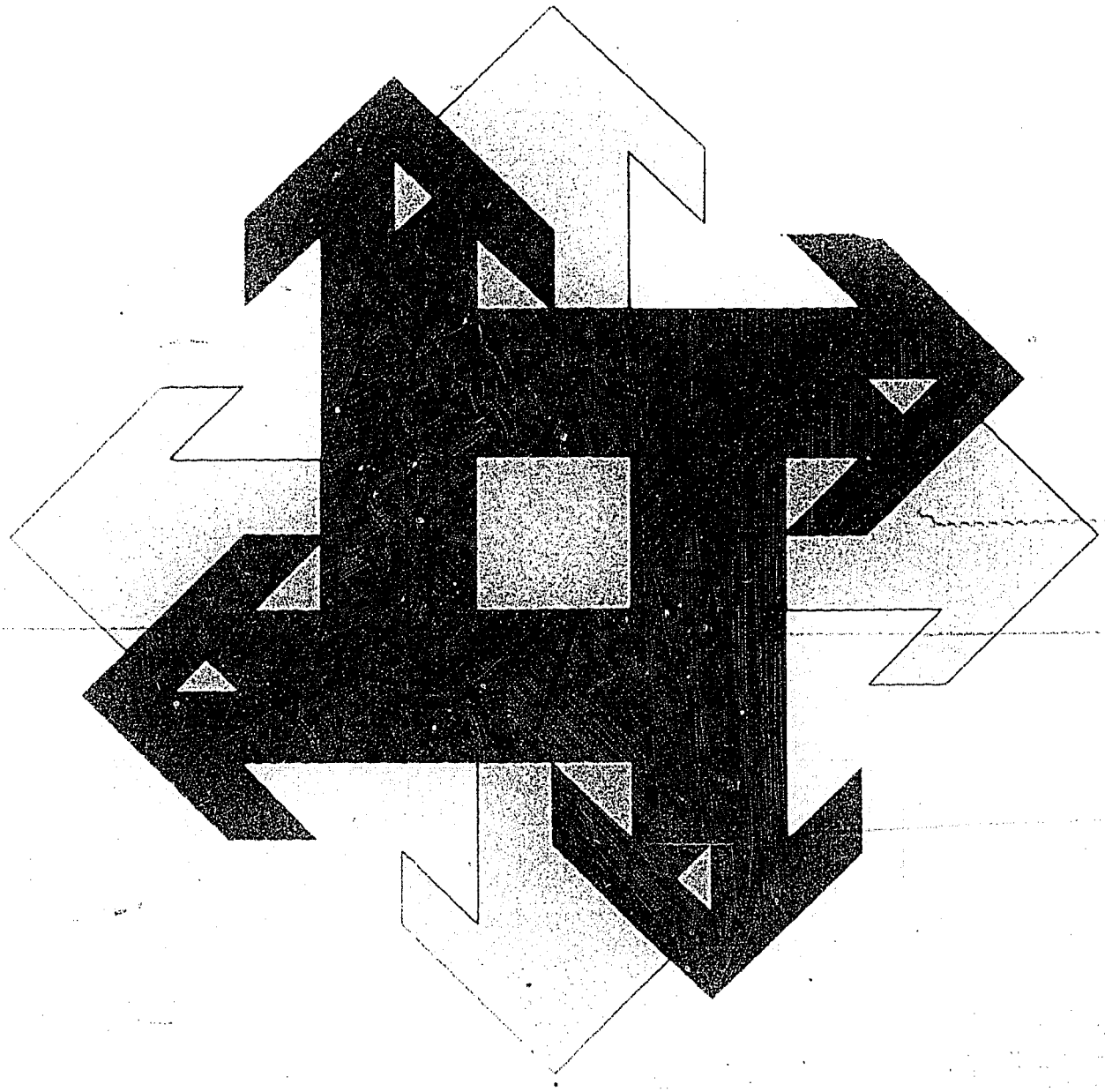
Health Planning Methods and Technology Series

Guidelines for Conducting an Inventory of State Data Sources for Health Planners



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[illegible] publications in three series:

[illegible] Planning Methods and Technology

[illegible] series will focus on the technical and
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[illegible], including such areas as methods and
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[illegible] Guidelines for Conducting an Inventory of State Data
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Guidelines for Conducting an Inventory of State Data Sources for Health Planners

Prepared
by the
National Center for Health Statistics

October 1976

US DEPARTMENT OF HEALTH, EDUCATION AND WELFARE
Public Health Service
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Bureau of Health Planning and Resources Development
Division of Planning Methods and Technology
National Health Planning Information Center

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FOREWORD

Dr. Kenneth M. Endicott, Administrator of the Health Resources Administration, has assigned responsibility to the National Center for Health Statistics (NCHS), working closely with the Bureau of Health Planning and Resources Development (BHPRD), for assisting State and local health planning agencies in such matters as locating appropriate sources of data for health planning and in using statistical techniques for developing and analyzing data.

One of the well-recognized, serious needs of State and local health planners is for compendia of useful in-State sources of data. Agencies located within the respective States are in a good position to identify and evaluate each of the within-State data sources, to prepare the data sources publication, and to keep the compendium up-to-date after its initial publication.

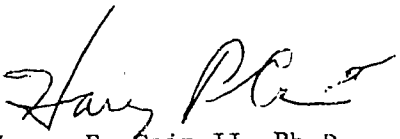
NCHS believes that it could best serve State and local health planners in this effort by preparing guidelines which would help State and local agency staff to conduct their own inventories of data sources and by offering to provide technical assistance to the State and local planning agency staff as they prepare for and conduct their own inventories.

This report presents the recommendations of the Center concerning methods for compiling inventories of State data sources. We hope you will find these "Guidelines" helpful. We especially hope that through the efforts of the State Health Planning and Development Agencies, the Health Systems Agencies, and others, there will soon exist a library of data sources inventories for health planners in all 50 States, the District of Columbia, the Commonwealth of Puerto Rico, the Virgin Islands, the Trust Territories of the Pacific Islands, and American Samoa.

The "Guidelines" form a companion piece to two other products of the NCHS which were prepared in response to Dr. Endicott's

charge. The first is the publication, Selected National Data Sources for Health Planners, a loose-leaf, annotated compendium of national data sources believed to have special value to health planners. The second is a series of methodological papers entitled, Statistical Notes for Health Planners, which are designed to instruct health planners on useful statistical techniques. Both of these products are dynamic sets which will be altered and added to from time to time as the need arises.

These "Guidelines" were written by Robert H. Mugge, Ph.D., Assistant to the Director, NCHS. Helen Thornberry of BHPRD and Garrie Losee of NCHS provided valuable consultation and assistance as the "Guidelines" were being developed.



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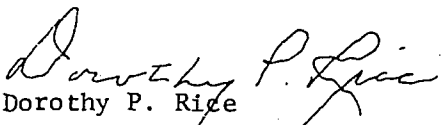

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Director
National Center for
Health Statistics

INTRODUCTION

The first function mandated to health systems agencies (HSAs) by P.L. 93-641, The National Health Planning and Resources Development Act of 1974, is that of assembling and analyzing data. This does not suggest that the development of data is the most important function of HSAs, but it does imply that Congress considered the acquisition and use of appropriate data to be a necessary prerequisite for the other functions of the agencies, i.e., the development of health plans and review of projects for the health service areas. Appropriate data must be assembled to design the health plans for the health service areas and also the State health plan prepared by the State Health Planning and Development Agency (referred to below as the "SA" for State Agency). It clearly behooves SAs and HSAs to obtain and study all relevant information which it is feasible to get before making decisions affecting the health services programs in their areas.

State Agencies and HSAs must be as efficient as possible in their acquisition and use of data. Some data that would be highly desirable to have to support the planning process will be found to be too costly to obtain, especially if it would involve conducting a special survey. On the other hand, there is a great deal of data that can be obtained free or at small expense, which would be very useful for planners, especially if these data are used with a good deal of imagination and ingenuity. Some data, currently available from national sources, that should be useful to local health planners, have been described in the National Center for Health Statistics (NCHS) publication,

Selected National Data Sources for Health Planners.[1] Explanations and descriptions of data sources are also contained in two publications of the Bureau of Health Planning and Resources Development (BHPRD), the Guide to Data for Health Systems Planners and the Guide to the Development of Health Resource Inventories.[2]

There is another group of rich depositories of data which no SA or HSA can afford to overlook; these consist of various agencies and organizations within the State itself. In many instances such offices will have data that are more up-to-date, more inclusive, more detailed, and/or for smaller geographical areas than the comparable data in national sources. The SAs and HSAs should, therefore, always make sure that there are no better State data available to meet their requirements before using the national data.[3]

But, of course, if planning agency staff makes a special search through all possible State sources every time some data are needed, or if SAs and HSAs or two or more HSAs duplicate one another's efforts in searching for the same kind of data among all the possible State sources, valuable resources are wasted.

1/ Selected National Data Sources for Health Planners, (USDHEW, HRA, NCHS) DHEW Publication Number (HRA) 76-1236. Rockville, Maryland 1976.

2/ Guide to Data for Health Systems Planners (USDHEW, HRA, BHPRD, NHPIC) DHEW Document No. (HRA) 76-14502. Rockville, Maryland 1976 and Guide to the Development of Health Resources Inventories. (USDHEW, HRA, BHPRD, NHPIC) HEW Document No. (HRA) 76-14504. Rockville, Maryland 1976.

3/ On the other hand, if particular kinds of data are needed for planning purposes, but these data are not available in the State, the planners should not set out to undertake special data collection efforts without first determining whether there are data available nationally which might be used as proxies or surrogates for the needed State or local data.

Clearly, what is needed in every State is to have some capable individual(s) make a careful and thorough investigation of all State-level sources of data potentially useful to health planners, catalogue their findings in a convenient, systematic manner, and duplicate and distribute the State's data sources compendium, which would be similar to Selected National Data Sources for Health Planners. Although the SA appears to be the most logical agency to guide the development of the data sources inventory, in some States HSAs may have had more extensive experience in conducting surveys of this type and could, therefore, develop the inventory more efficiently. Regardless of which agency takes lead responsibility for preparing this inventory, all agencies and organizations in the State having an interest in health planning statistics should be encouraged to become actively involved in this effort.

This State compendium, once completed, would then be available for daily use in all HSAs in the State and in the SA. It would also be very useful to other health planners, administrators, and researchers in this and other States--especially adjoining States. Thereafter, someone would be needed to review and update the list and descriptions of data sources from time to time in order to prevent the State's compendium from becoming obsolete.

The purpose of this report is to attempt to stimulate the preparation and publication of a "Compendium of State Data Sources for Health Planners" for each State, and to offer suggestions as to how such a project might best be carried out. If agencies agree that this is an important activity, they are urged to follow the procedures described below for planning the project and to seek the cooperation of the State Cooperative Health Statistics System (CHSS) agency in the planning effort.

This report has been prepared in the National Center for Health Statistics with direct cooperation and assistance from the Bureau of Health Planning and Resources Development. Local, State, and regional staff may well have more and better ideas on the subject; if so, NCHS will be glad to receive them and consider them for use in a revision of this report.

PLANNING THE PROJECT

Health planners do not need to be reminded that if the data sources compendium is to be thorough and of high quality, if it is to be completed as quickly as possible, and if it is to be produced at minimum cost, the entire project must have very careful advance planning. There are many points to be considered, many problems to be anticipated and solved or avoided, and many persons to be consulted.

Much of the work required to search out and catalog the data sources may already have been done. The State's HSAs and the SA may have begun to compile information on data sources. The State's Cooperative Health Statistics System agency, other agencies, or university- or foundation-based health statisticians, may have been systematically compiling health data sources. The former Comprehensive Health Planning "a" and "b" agencies, or the Regional Medical Program agency, may also have developed such information. The various individuals who would know about such present and former work should be contacted and such information elicited from them. To the extent that such information is accurate and not out-dated, it should be used in order to avoid duplication of effort. In some places, editing and up-dating may be all that is required.

If the data sources compilation for the State has not already been done, the program necessary to produce one may be very extensive and complex depending upon the size of the State and the number of agencies that should be involved, as well as the organizational relationships of these agencies.

It may well be advisable, early in the development of the "source survey" project, to hold a meeting of all those persons having an important interest in the survey, in order to insure that there will be full and effective awareness of and cooperation in the project by all agencies having responsibility for the assemblage and analysis of statistics, representatives from the State CHSS agency, and any other agencies, schools, and research centers in the State having a special interest in health planning statistics. The group should take up and seek to resolve the following questions:

- What work has already been done to list and describe sources of data in the State that are useful in health planning?
- What kinds of data are needed for health planning in the State?[4/]
- What agencies and organizations are there in the State which are known or believed to produce data useful to health planners?
- How can full cooperation be obtained from these agencies?
- Who will conduct the survey of data sources?
- What kinds of information will be compiled on each data source?
- Who will publish and distribute the compendium?
- Will agencies share in supporting the project financially?
- Are there potential outside sources of support for the project?

4/ For valuable discussions of this question see the Guide to the Development of Health Resource Inventories (op. cit.) pages 17-20, 39-42, 55-56, 83-85, 93-94, 101-107, and 130-133.

- Will charges be made for copies of the compendium to help cover costs of the project?

- Who will carry responsibility to maintain the compendium after its initial publication, preparing and distributing revisions and additions as these are found to be needed?

It is implicit in this suggestion that all of the suggestions contained in the Guidelines should be reviewed at the meeting; the group should decide to what degree the specific recommendations contained here are appropriate for their State. If the meeting does not achieve consensus in finding answers to these questions, then additional meetings will be required.

Prior to conducting the survey, the head of the agency making the survey should make contact with the heads of all of the agencies which may have useful data, explaining the project and requesting their cooperation. Each agency head should also be asked for the names and phone numbers of those persons who have special knowledge of the agency's data and, therefore, should be interviewed in the survey. The surveyor should then visit or telephone these persons in order to make appointments for the interviews.

TECHNICAL ASSISTANCE AVAILABLE

Technical assistance in planning and conducting the data sources survey is available from NCHS. Requests for such assistance should be directed to the Chief, Technical Assistance Branch, Division of the Cooperative Health Statistics System, NCHS, HRA, 5600 Fishers Lane, Rockville, Maryland 20852. A copy of the request should be sent to the NCHS Regional Liaison Officer, Office of the Regional Health Administrator at the HEW Regional Office.

KINDS OF DATA NEEDED

The kinds of data which health planners need in order to shape the health plans and determine which kinds of projects should be supported are outlined in P.L. 93-641 (Section 1513(b)(1)):

> "The agency shall assemble and analyze data concer
>
> (A) the status (and its determinants) of the of the residents of the health service area,
>
> (b) the status of the health care delivery system in the area and the use of that system by the residents of the area,
>
> (C) the effect the area's health care delivery system has on the health of the residents of the area,
>
> (D) the number, type, and location of the area's health resources, including health services, manpower, and facilities,
>
> (E) the patterns of utilization of the areas' health resources, and
>
> (F) the environmental and occupational exposure factors affecting immediate and long-term health conditions."

The kinds of data needed by health planners may be classified as being of three general types: (1) the "numerator" data on conditions in the health area, including data on health status, health resources, and levels of health care utilization; (2) the "denominator" data on base populations and their characteristics which are necessary to develop the rates that will place the numerator data in proper perspective; and (3) the "background" data on environmental and occupational conditions.

The scheme used to classify data sources in Selected National Data Sources for Health Planners is also recommended for the State compendia, as it provides useful rubrics for all health planning data sources. If the State compendium

follows the same outline as the familiar national compendium, the convenience of using both publications in conjunction with one another would thereby be enhanced. This outline is as follows:

A. General Health Statistics. *These are data sources which include two or more of the major area listed below, and none is predominant.*

B. Health Status and Problems. *Morbidity, mortality, and natality statistics.*

C. Health Care Resources--Manpower. *General manpower data sources, and special sources on associated health professions, dentistry, medicine and osteopathy by specialty, nursing, optometry, pharmacy, podiatry, veterinary medicine, and other. Include data on persons being trained for such occupations.*

D. Health Care Resources--Facilities. *Hospitals, nursing homes, clinics, and other health care agencies and their staffing, beds, equipment, and the like.*

E. Utilization of Health Care Resources. *Hospital care, ambulatory care, nursing home and long-term care.*

F. Health Care Programs. *Medicaid, vocational rehabilitation, mental health, and other health care programs. It may be advisable to set up subclassifications for each major program area.*

G. Health Economics. *Employment, incomes, health care expenditures, health personnel costs, welfare recipients, insurance coverage, and related topics.*

H. Demographic Data. *Special population censuses and estimates, migration, marriage, divorce, and school enrollment data.*

I. Environmental and Occupational Health. *This is not yet a part of the national compendium but is a planned future addition. It may include levels of air and water pollutants, findings in food inspections, occupational illness and injuries, employment in occupations known to be hazardous, and so forth.*

Data sources in the mental health area would be classified into the above areas.

Statistical sources are often not found pure in one or another of the above areas. When this is the case, the data source should be assigned to the area of its predominant application, with cross-references to that data source shown for the other areas that are relevant to the source. If no single area predominates, the source should be assigned to the "A" area, with cross-references to the source under each of the other areas which applies.

The above outline, while providing a classification scheme recommended for the State's health planning data sources compendium, also outlines the kinds of statistical information which it is believed may be useful in the health planning processes, and therefore the kinds of statistics that should be sought out in the data sources survey.

THE FORMS OF DATA SOURCES

Data sources useful to health planners may take several different forms; none of them should be overlooked. The sources may be said to be of three general types:

1. Publications. To be included, a publication should contain some systematic statistical tabulations. The "publication" could consist of a printed booklet or a mimeographed or

multilithed report. It could even be in the form of a table or a set of tables that are available for photocopying.

2. Machine-readable Files. Agencies being surveyed may have files containing some types of information, in standard form relating to a known universe of persons, such as patients, physicians, or other practitioners, or of establishments, such as hospitals, nursing homes, emergency clinics, or the like, which could be used to produce [illegible] tabulations needed in health planning. It may be of crucial importance whether the file is in machine-readable form, i.e., on magnetic tape or disc, on punched cards, or on paper tape; if so, the data can be readily entered into a computer for tabulation that could be done quickly and at small cost.

3. Other Files. There may be systematic information on a known universe that is available for tabulation but not in machine-readable form. The records would have to be tabulated by hand or converted to machine-readable form for computer tabulation, which would likely take longer and cost more than if the data were already in machine-readable form.

DATA ACCESS CONSIDERATIONS

Data that are not truly accessible to the health planning agency--even though they are potentially very useful--should not be listed in the compendium. Known data may for some reason be protected by the agency holding them, not to be released for any outside purposes. Similarly, agency files would not be considered as potential sources of data for health planning purposes unless there is a reasonable likelihood that staff of the health planning agency could

be permitted to have access to the files, or that arrangements could be made to have special tabulations run from the files to meet the health planners' needs.

STANDARDS FOR INCLUDING DATA SOURCES: QUALITY AND UTILITY

Not all data that are neatly laid out in internally consistent tables in professionally printed publications are necessarily of value to the health planner--or to anyone else for that matter. Serious errors can creep in at various points in the processes of planning and designing statistical programs and in the collection, editing, tabulating, interpreting, and analysis of the statistics. If the errors are sufficiently gross, the final results may not be what they purport to be; they could in fact be very misleading. Bad statistics, which are far more prevalent than most people realize, are far worse than no statistics at all, because they are more likely to lead to poor decisions. Using erroneous data will increase the vulnerability of agencies to challenges and loss of public credibility.

How does one recognize "bad statistics," since they seldom carry that kind of label? There is no foolproof way, but there are some well-accepted standards which should be applied to evaluate any set of statistics before it is used for any serious purposes. To be acceptable for inclusion in a compendium of data sources for health planners, a set of data--in addition to being accessible and relevant for some aspect of health planning--must meet the following criteria:

1. The set must include systematic data, with all elements having been obtained in a uniform and objective manner. It should be possible to obtain a clear and detailed statement of the methodology employed in obtaining the data. There should not

have been any strong motivation for subjects of the study to falsify their answers, either to gain favor or avoid troubles.

2. The data set must consist of one or more statistical tables, or of descriptors of individual units which are capable of being aggregated.

3. The data must relate to a well-defined universe, such as the entire population of the State, county, or group of counties, or all clients of a given program, or all children under 18 years of age, or all patients in a hospital during a particular month.

4. The data must be sufficiently timely to be currently useful, and not just "ancient history." Timeliness is especially important for planning, since decisions must be based upon assumptions about the future. But expectations on timeliness of data are often unrealistic; with some kinds of statistics it is impossible to keep data very up-to-date, and the analyst often needs to consider how he may obtain useful results from older data, such as through observing trends and projecting them to the present, or using relevant recent data as a clue to the applicability of older data to the present. However, it may be useful to set up general rules as to the required timeliness of data, e.g., that no data over 10 years old are to be used, and, in an area which is changing fairly rapidly, data over 5 years old should be used only with caution. Still, exceptions to these rules may have to be made in certain instances. An older file, for example, may be useful in exposing interrelationships among

characteristics, even though the parameters of characteristics found in the earlier study no longer apply.

5. If the data set does not include approximately 100 percent of the cases in the universe to which it refers, then it should have been based upon a scientifically drawn, representative sample of that universe. Also, for data based upon a sample, there must have been a high response rate for the set to be useful. If there is a low response rate the results are probably biased and do not accurately describe the universe. One useful rule of thumb is that the responses must total at least 75 percent of the sample; some experts would require much higher response rates. (This requirement should vary with the importance of the decision to be based upon the data; where a great deal is at stake, higher st ndards should be applied).

Attention should also be given to the probable errors involved in estimates based on samples; in other words, estimates should be based upon sufficiently large samples so that the sampling errors are relatively small.

6. Good sources of data should involve quality control programs which assure the high quality of data acquisition and processing activities; however, quality control is actually quite rare in statistical programs and not usually to be expected. If the data were collected without quality control, health planners should at least apply whatever appropriate tests of reason might be available before using any data set, making sure that the data appear to be valid and reasonable in relation to other

comparable data. If there are large differences between a set of data and one's reasonable expectations based on general knowledge, and there are no ready explanations for the differences, then the data should perhaps not be used. This determination must largely rest on professional judgment.

Even after carefully following these rules on quality requirements for data sources, it may still be difficult in given cases to determine whether data sources should be included. One way to approach this problem would be to form an interagency committee of experts to pass on the quality of all data sets proposed for the compendium and decide which sets meet the standards for inclusion.

AGENCIES AND ORGANIZATIONS TO BE SURVEYED

Every effort should be made to include in the data sources survey all those agencies and organizations in the State which are likely to have sets of data that would be useful to health planners. There are great differences among the States in terms of the names given to agencies, the organizational relationships of agencies, and the organizational placement of different kinds of program responsibilities; therefore, no single list of agencies would be appropriate and adequate for all States. The following list is intended to be suggestive of the various kinds of agencies which may appropriately be contacted to determine whether they can provide useful data. Only key words likely to be included in the names of the agencies are given; these key words, given below in alphabetical order, may be found in names of agencies identified as bureaus, departments, offices, divisions, administrations, agencies, sections, and the like:

Adolescent health
Adult health
Air pollution
Alcohol abuse
Alcoholism
Birth and death records
Child abuse
Child care
Child health
Child neglect
Clinics
Colleges
Communicable disease
Communicable disorders
Community health
Dental health
Dental services
Drug abuse
Drug control
Drug treatment
Education
Emergency medical services
Employment security
Employment services
Environmental health
Environmental protection
Epidemiology
Examiners (health professions)
Family planning
Geriatric health
Health
Health facilities
Health statistics
Higher education
Home care
Hospitals
Human resources
Immunization
Infant health
Institutional care
Institutions
Licensing (health professions)
Manpower
Maternal health
Maternal services
Medicaid
Medical assistance
Medical social services
Mental health
Mental hospitals
Mental hygiene
Narcotics treatment
Occupational health
Public assistance
Public health
Public instruction
Public welfare
Radiological health
Sanitary engineering
Sanitation
Schools
School health
Social services
Social welfare
Tuberculosis
Universities
Venereal disease
Vital statistics
Vocational rehabilitation
Welfare
Youth health

Additional key words will probably be found. Using these key words, a comprehensive list should be prepared of all State government agencies which may have data useful in health planning. Then it may be ascertained through initial inquiry that certain agencies on the list do not in fact possess any useful statistics, and these agencies would be eliminated. The agencies then remaining on the list would be included in the survey of data sources.

There may also be nongovernmental organizations which maintain systematic statistics of the kinds that are useful in health planning and which meet

the acceptability criteria described above. Examples of such organizations might be associations of professional practit and associations of hospitals, nursing homes, other health care providers, or university departments involved in health data compilation. They should also be included in the data sources survey.

INFORMATION TO BE OBTAINED ON EACH DATA SOURCE

The following kinds of information should be obtained for each identified data source (publication or file) and included briefly but clearly, in the published compendium. Comments on each type of information are given in parenthesis:

1. Source Code Number. (For easy reference purposes, a code number should be given to each data source listed in the compendium. It is strongly suggested that the codes in Selected National Data Sources for Health Planners be used, as this will greatly enhance the usefulness of both data source books. The code number should begin with a letter which identifies the subject matter area; in the national compendium, "A" relates to "General Health Statistics," "B" relates to "Health Status and Problems," "C" to "Health Care Resources—Manpower," and so forth. If there are numerous sources in a particular area it may be advisable also to set up numbered subcategories; thus, C1, C2, C3, and so forth, would refer to different major categories of health manpower.

   Within the subject-matter areas, sources would be numbered sequentially, so that each source ends up with a unique

number designation. The sources would then carry code numbers such as A-1, A-2, A-3, B-1, B-2, C1-1, C1-2, C2-1, C2-2, and so forth.

2. Title. (The title, if a publication, or the subject, if a file. If a publication, give the complete reference as well as the title, including the author, agency, publisher if different, and the city and year of publication).

3. Form. (Indicate whether the source is (1) a publication, (2) a machine-readable file, or (3) other file).

4. Location. (Give the name and address of the agency or organization which developed and/or maintains the data).

5. Availability. (Are there limitations on the availability or usefulness of the data? Is the publication out of print? What does it cost? Is special permission required for use of the file? Can the agency maintaining the file provide services in processing the data? At what cost? Answer any such questions that are important in relation to the use of this particular data set).

6. Date of Data. (Period or point in time to which data refer).

7. Frequency of Report. (One-time, annual, quarterly, monthly, other).

8. Geographic Area Covered. (The entire State or a specified part of it)?

9. Smallest Geographic Unit for Which Data are Reported. (Regions, counties, towns, townships, zip code areas, census tracts, local addresses).

10. Data Contents. (List the major data elements included).

11. Person to Contact for Further Information. (Give the name, title, and telephone number of the person designated by the agency as the contact person to provide information on this data set).

PUBLICATION AND DISTRIBUTION OF THE COMPENDIUM

These suggestions are made:

1. Each data source is begun at the top of a new page of the compendium. Most sources will occupy only one page.
2. The data sources are given in order according to their Source Code Number. The table of contents provides a listing of all the data sources.
3. The compendium is published in loose-leaf form, so that subsequent revisions and additions to the references can be entered in their appropriate places.
4. Have sufficient copies of the compendium printed to meet a demand that is probably larger than first anticipated. Those who will need copies will include not only all the HSAs and the SA in the State, and in nearby States, but also the CHSS agency and various other health statisticians working on the State. Please also print and send two copies each to the National Center for Health Statistics liaison officer and the Bureau of Health Planning and Resources Development representative in the HEW Regional Office, the Director of NCHS, and the Director of BHPRD.