# THE DESIGN AND ORGANIZATION OF A GUAM HEALTH INFORMATION SYSTEM

A REPORT TO THE

GUAM HEALTH PLANNING & DEVELOPMENT AGENCY

ANDREW N. WHITE, PH.D.

PLANNING CONSULTANT,

ROBERT MYTINGER & ASSOCIATES, INC.

JULY 1981

#### **PREFACE**

Health care delivery has become an increasingly complex endeavor in the last two decades. From the nostalgic picture of the family physician or the roving public health nurse and the stand-alone hospital that might have characterized an earlier era, modern society has seen the emergence of a diverse set of health agencies, health professionals, specialty services, health care markets and activities, both public and private. In the Territory of Guam, the health care system has grown beyond the simple public health service provided by the U.S. Navy, to include at present a Public Health Department with branches dealing with epidemiology and vital events, maternal and child health, environmental health, public health nursing services and the like; a government-run hospital authority with two hospital facilities (for short-term and longterm care); two major health maintenance (health insurance) organizations; several private medical clinics; pharmacies, private physicians, and additional public agencies dealing with community mental health care, drug abuse services, and alcohol abuse services; and other voluntary and social agencies which provide a range of health and related services from cancer prevention to homehealth care.

But past this thumbnail sketch of the island's health care system, what can be said about it? What are the health problems that should be addressed by this system? How are people affected by these problems? What resources are available? What manpower is engaged in what kinds of activities? What money is spent and where? Who is served by the system? Who uses the services that are provided? How efficient is this system or the component services of health care? And how effective is the care that is provided?

These questions and similar ones require specific answers rather than generalities. They therefore require <u>information</u> that can be assembled to support, document, and justify a particular position or statement of the factual conditions characterizing Guam residents or the services offered to them. Information about Guam's health care system is the key to

rational consideration of alternative approaches to getting the job done, to rational evaluation of issues of efficiency or effectiveness, and to rational discussion of just what exists and what does not exist in terms of health status or health care on Guam.

But health information on Guam is presently scattered throughout the multiplicity of agencies responsible for individual services. And only recently has thought been given to the desirability and the benefits of having a single organization in which might be assembled, stored and analyzed a variety of data and information, all pertaining to health care and the health care system on Guam. Such an organization can most appropriately be identified as a <a href="health information system">health information system</a>, once its design and organization are identified and characterized. Such a system seeks to obtain a comprehensive set of health and health-related data, to systematically store, retrieve and process the data, and to provide all interested parties in the Territory with meaningful and reliable health information.

This document's sole intent is to lay out in as much detail as possible the design and organization of a health information system suited to the needs, resources, and health care context on Guam. It is a Report that arises out of, and in fact provides a capstone to, a two-month effort to establish the foundation for an operating Guam Health Information System during the summer of 1979. Since that time, the author has had the opportunity to observe the gradual development of the system and at the same time document the structure and activities that are most feasible for this system to adopt.

This Report thus presents a rationale, a blueprint, and an operating guide for a Guam Health Information System (H.I.S.). At the present time, this System exists in a rudimentary form as an activity linked to the Guam Health Planning and Development Agency. Whether or not this System proves viable and valuable for Guam in the long run is a question that only time and motivation on the part of staff associated with GHPDA and the H.I.S. can answer. But whatever the immediate outcome, it is hoped that the present Report serves to alert anyone interested in information system development to the necessary elements and principles that must be considered in order to design and implement such a data processing activity on Guam.

The Report is organized in three Parts as follows. The first Part is devoted to basic information system principles, in terms of broad rationale and specific justification for a Guam system. The second Part presents essential design principles, identified in terms of output, input and processing activities. The third and final Part of the Report discusses several organizational issues, including the cooperative nature of the system, personnel requirements, and management responsibilities. Following a concluding comment, an Addendum provides a brief set of reccommendations for future efforts by H.I.S. staff.

\* \* \* \* \* \*

This Report has been written by one author who was also the single consultant contracted to initiate a Guam Health Information System for GHPDA in 1979. But this document, and the H.I.S. development effort, could not have been undertaken or completed without the help of a variety of individuals and agencies. To begin with, appreciation is extended to the Guam Health Planning and Development Agency and its staff, who were extremely cooperative and congenial during the period of on-site work, and who were patient as well in waiting for this final product to be delivered to them. The on-site work was undertaken with the diligent assistance of Keith Cernak, a graduate student from the School of Public Health, University of Hawaii, at the time. Other individuals closely involved with the project and selected portions of this Reportinclude: Sally Coy, computer programmer for the Guam Bureau of Planning; and Brandt Stickel and Donna Feeley, also from the School of Public Health, University of Hawaii. Individuals in the data community on Guam who were particularly helpful with this project include: Julie Santos, Vital Statistics, Laurent Duenas, Public Health Nursing, and Robert Haddock, Epidemiology, all within the Department of Public Health and Social Services. But right beside these individuals are a much larger group of individuals in a variety of agencies and offices, all of whom proved to be receptive to the idea of a new information service on Guam , and cooperative in the effort to begin one. It is to this Guam data community as a whole that this Report is dedicated.

## TABLE OF CONTENTS

	Page
PREFACE	į
PART I. FOUNDATIONS FOR A HEALTH INFORMATION SYSTEM	
SECTION A. DEFINING A HEALTH INFORMATION SYSTEM	1
1. Information and Data	1
2. Describing a Health Information System	3
3. A Guide to the Contents of this Report	6
SECTION B. FOUNDATIONS FOR A GUAM SYSTEM	8
1. The Rationale for a Guam H.I.S.	8
2. Issues and Assumptions in H.I.S. Development	13
3. An Overview of H.I.S. Development	19
4. An Input-Output System Paradigm	2 1
PART II. DESIGN PRINCIPLES AND COMPONENTS	
SECTION C. THE OUTPUT OF A GUAM H.I.S.	22
1. The Nature of Information Products	22
2. The Information Product Tableau	25
3. Uses and Destinations of Information Products	35
4. Product Destination Classifications	38
5. The Preliminary Information Product Inventory	40
6. Alternative Arrangements of Information Products	42
SECTION D. THE INPUTS TO A GUAM H.I.S.	44
1. Issues in Data Acquisition	44
2. Data Availability and Inventory Procedure	45
3. Data Quality and Evaluation Procedures	46
4. Database Documentation	51
5. Data Acquisition	52
6. Summary: Database Phasing	54

	Page
SECTION E. THE PROCESSING OF DATA & INFORMATION	55
1. Flows of Data and Information	55
2. Data Acquisition and Transmission	57
3. Storage and Retrieval: H.I.S. Filing System	59
4. Physical Facilities for Storage and Retrieval	68
5. The Basis for Computerized Data Processing	68
PART III. ORGANIZATIONAL REQUIREMENTS AND RECOMMENDATIONS	
SECTION F. THE COOPERATIVE ORGANIZATION OF H.I.S.	71
1. Cooperative Philosophy of Guam H.I.S.	71
2. The Administrative Locus	73
3. Coordination of the Guam H.I.S.	74
4. Cooperative Agreements for Data Sharing	75
5. The Nature of Communication Among Participants	76
6. Protocol for Confidentiality and Privacy Assurances	78
7. Policy Guidelines Regarding Access to and Use of H.I.S. Data and Information	79
SECTION G. PERSONNEL REQUIREMENTS & STAFF INVOLVEMENT	82
1. Staff Positions and Functions	82
2. Specific Tasks Related to Essential Staff Functions	83
3. Recommended Personnel Positions and Qualifications	91
4. Supplementary Personnel	94
SECTION H. GUAM H.I.S. MANAGEMENT	97
1. The Central Role of the Data Manager	97
2. Key Responsibilities in Management	98
SECTION I. A FINAL NOTE	103
ADDENDUM. SELECTED RECOMMENDATIONS	105
1. Agency database Revisions	105
2. H.I.S. Newsletter	106
3. Health Data Users Workshop	106
4. Staff TRaining Needs	106
5. Special Studies	108
6. Historical Data Recovery	108

		<u>Р</u>	age	
APPENDI	[X]	I. A SERVICES TAXONOMY FOR THE HEALTH SYSTEM	109	
APPENDI	[ X ]	II. GHPDA HEALTH INFORMATION SYSTEM FILE ORGANIZATION FOR THE PHYSICAL FILE SYSTEM	118	
APPENDI	[ X ]	III.EXAMPLE MEMORANDUM OF AGREEMENT FOR COOPERATION IN DATA AND INFORMATION SHARING	123	
APPENDI	IX I	IV. FRAMEWORK FOR GHPDA POLICY ON CONFIDENTIALITY AND PRIVACY PROTECTION	126	
LIST OF TABLES AND FIGURES				
TABLE	1.	INFORMATION PRODUCT TABLEAU	27	
TABLE	2.	INITIAL INVENTORY OF AGENCY SOURCES OF DATA ON GUAM	47	
TABLE	3.	RECOMMENDED DATABASE DEVELOPMENT PHASING	53	
TABLE	4.	RECOMMENDED LIST OF SERVICE FILE HEADINGS	64	
FIGURE	1.	DIAGRAM OF DATA & INFORMATION FLOWS IN H.I.S. DATA PROCESSING	56	

#### PART I

FOUNDATIONS FOR A HEALTH INFORMATION SYSTEM

# SECTION A. DEFINING A HEALTH INFORMATION SYSTEM: AN INTRODUCTION

#### 1. INFORMATION AND DATA:

What is an Information System?

An information system is an organization and a set of procedures for the orderly collection and processing of raw data from one or more data bases, in order to generate a body of information for a common set of analytical or administrative purposes.

An information system is not just any collection of data, First, the data must be <u>collected</u> for a defined set of purposes. Second, the data must be <u>processed</u> to yield information which fulfills these purposes.

Two words must be more carefully defined before proceeding further: information and data.

What is information?

There are several ways to define this concept, ranging from the technical to the common-sense. Fundamentally, information is "informed" and interpreted data. Information has meaning and use; it is meaningful and useful communication. Its meaning and utility lie in its information content. (Scientists have actually devised measures of the information content of various kinds of inetrpreted data, but these measures are not discussed here.)

What is data?

Data are counts and codes which are collected as indicators of phenomena of interest.

Data consists of discrete observations or facts that, when aggregated, provide simple descriptions of events, or the characteristics or attributes of people, things, or places. When tabulated in some purposeful way,

<sup>\*</sup> Data is the plural term for datum, a single count.
Data are multiple counts.

particularly so that differences and variations are illuminated and questions are posed or answers provided, the aggregated data constitute information.\*

For example, if we wish to know something about the use of a hospital by island residents, then we decide what in particular might indicate various features of hospital utilization. Suppose that we decide that the following features are important:

- (a) number of people who are admitted for treatment,
- (b) number of days spent in the hospital by a patient, and
- (c) how many hospital beds are occupied.

The numbers that we collect as counts are measures of these features in numerical form; they constitute our data. But what do the raw counts mean? What does 140 as a count for feature (a) in a given month mean? When we compare this number with counts from other months, or counts for other hospitals, or when we identify how small or how large this number is relative to a standard number we think should be the count, we are beginning to analyze and interpret the raw counts. The analysis and interprettation of raw data provides meaning to the numbers and hence yields information.

Data are organized into data bases. A data base is a collection of one or more measurements for a defined set of entities (such as hospitals or people), where specific procedures have been followed to make such measurements. The An information system is thus more properly envisaged as a collection of one or more data bases, the combined data of which are processed and analyzed jointly in order to produce specific, useful types of information.

Why distinguish between data and information? We make this distinction and continue to emphasize it throughout this Report in order to make the point that data must be <u>processed</u> in order to be understood, to be informative. Data by themselves are meaningless. They contain, in fact, only potential meaning; the actual meaning comes as a result of individuals using the data: manipulating, analyzing and interpreting them to yield information.

<sup>\*</sup> Quote from Kerr L. White, "Priorities for health services information", Health Services Reports, Vol.88, No.2 (1978):pages 110-111.

<sup>+</sup> A data base is sometimes referred to as a data system, but the latter term is not employed in this Report.

Note must be taken of an important clarification of the distinction that is drawn between data and information.

Information is interpreted data, data that has been processed in a given, specified manner. Suppose one agency (a census bureau) surveys a population, collects data on the population, and produces demographic tables of statistics on this population (for example, age distributions). Information has clearly been generated from raw data (raw counts). Now suppose another agency (a health planning agency) exemines these tables and then uses the statistics for its own purposes of generating information on groups at risk of certain diseases, and groups to be targeted for specific health programs. Because a different and added use of the demographic tables, and a different analysis and interpretation of the statistics were made by the health planning agency, information has again been produced.

We can either say that one user's information is another user's (potential) data, or say that information that is re-analyzed and re-interpreted produces new information. In either case, it is important to bear in mind that any agency's information system may actually collect and compile both raw data and "processed data": statistics and information produced by other agencies. Whether we refer to the content of United States census reports as census data or census information is less important than the realization that such reports are used and analyzed by many different agencies, researchers, and analysts who generate many new kinds of information from such reports. This kind of re-analysis of published reports and documents is an important function of an information system.

#### 2. DESCRIBING A HEALTH INFORMATION SYSTEM:

Now a subsequent series of questions must be answered concerning the nature of an information system.

What kinds of information system are there? What kinds of data are collected? What purposes are served by an information system? And how can information that is organized, interrelated and generated by such a system be used?

To answer these questions, we must first identify the type of information system being considered. There are urban information systems, land use information systems, housing and real estate information systems; and there are health information systems. These are examples of information systems, organized to deal with a certain subject matter (city planning, land use, housing, health). A health planning agency is of course most interested in a health information system. Such a system will serve to generate health information of various kinds and in various forms, in order to permit the agency to plan, regulate, and communicate more effectively.

Any information system can have two basic use-orientations. It can be oriented to enable an agency to monitor its own activities: the work performed, the products produced, the services rendered, the clients seen, the sales and purchases made, etc. In other words, it can help to inform decision-makers of the agency operations in order to help them to better manage and administer the agency. Stress is usually placed on using such information to improve agency efficiency.

Another orientation of an information system is towards analysis. Here the information generated helps an agency to answer research and evaluation questions concerning the nature of problems that people face, the means by which they might be handled, the ways in which they are handled, and how appropriate those means are. Stress is usually placed on using information to explain poorly understood phenomena, to clarify problems, and to help officials to understand the effectiveness of current services offered.

An administrative type of health information system might be found in a hospital or an HMO. In such settings, less interest is shown in what kinds of problems occur to what kinds of people and why, or how effective various procedures are to resolve such problems, and more interest is shown in ensuring proper allocation of resources to meet current patient demands. Examples of such information systems are quite numerous.

An analytical or evaluative type of health information system is more likely to be found in a university research setting or in an epidemiological unit of a public health department. Such an information system is oriented towards examining the nature of current health problems and the appropriateness, quality and effectiveness of current services provided. Examples of

such information systems are few.

If a health planning agency makes the decision to create a health information system, it is more than likely that it will have a dual orientation. That is, the data that is collected will be processed in order to yield information for both administrative and analytical or evaluative purposes. On one level, the health planner may wich to have information describing the operation of various health programs in the territory. Data which serve to generate a profile of service performance may be allocated to help the health planners monitor how health resources are allocated and expended. On another level, though, the health planner may wish to have information which helps clarify the patterns, trends and relationships among health problems in the territory, the most influential determinants of such problems, and the likely resolution to them. The health planner will also want to evaluate the performance of various health programs in terms of whether services rendered actually help solve priority health problems.

What kinds of data - and databases - are assembled into a health information system? The answer to this question depends on first answering another question: What kinds of information are to be produced or generated by a given health information system? And that depends in turn on the specific set of purposes which govern the creation and operation of the particular health information system.

Tentatively we suggest that the kinds of data will most likely include (but will not be limited to): demographic, vital event, socioeconomic, health status, health service, health care utilization, health - financial, and health service outcome data. Such data are drawn from published documents, existing record systems, registration forms, patient records, financial reports, and the like.

The information that is generated will be in various forms: rates, ratios, tables, charts and graphs; or statistics, indicators and indices. They all have one aim: to answer a particular question in a specific way. Some questions are so standard - have been asked in the same way so repeatedly - that standard ways of answering them in the form of fixed indicators have been accepted and produced. Birth rates, infant mortality rates, indices of socioeconomic status, average length of stay in hospital (ALOS), are examples of these health statistics.

Then to what purposes can these statistics and other sources of information be directed? What can an information system for a health planning agency do? The following set of purposes can be suggested as a minimum list that could be easily expanded:

- o health service performance evaluation
- o health resource allocation
- o health status determination
- o health problem priority setting
- o health project grant screening
- o health service operations monitoring
- o health care utilization behavior assessment
- o health status determinants identification

These purposes are directly in line with the major planning and regulation activities that any health planning agency undertakes, and it is simply a matter of characterizing these purposes in enough detail, that is in terms of the quantitative information that would facilitate them, in order for a health information system to be appropriately motivated. This characterization and this motivation will be discussed at length in this Report.

#### 3. A GUIDE TO THE CONTENTS OF THIS REPORT

The rest of this report is organized as follows: After discussing the rationale for a health information system for Guam and identifying source of its major purposes to be served by it, this report will document the structure and function of the Guam Health Information System as well as its management by data staff of the Guam Health Planning and Development Agency. Section C will in fact proceed by identifying desirable outputs of a Guam H.I.S. These outputs will be items or discrete units of information which will be henceforth referred to as information products. Such a term emphasizes the fact that information is indeed a product of some type of analysis or processing of data. Section D will in turn identify what inputs are

required in order to generate these information products. This discussion will entail an inventory of data sources and agencies who are potential data donors. Section E then describes in detail the necessary procedures for collecting, organizing, editing, storing, retrieving and analyzing the data inputs to the H.I.S. in terms of two complementary components: manual, file-based processing and automated computer-based processing. Part I of this Report concludes with this section.

Part III is concerned with the administration of the Guam H.I.S. and separate sections address the issues of cooperative organization, staff requirements, and data management and information reporting.

# SECTION B. FOUNDATIONS FOR A GUAM HEALTH INFORMATION SYSTEM

In order to fully understand the structure of the Health Information System outlined herein, it is necessary to first review the rationale for collecting and processing data for health planning purposes, as well as to identify major issues raised and assumptions made concerning the development of such a System for Guam.

#### 1. THE RATIONALE FOR A GUAM H.I.S. :

#### a) Legal Mandate:

Current health planning is governed by two federal One is P.L.93-641, passed as the "National Health Planning and Resources Development Act of 1974". The other is P.L.96-79, which consists of various amendments to P.L.93-641. Embodied in these two laws are a philosophy and an approach to health planning which is population based, needs and problems oriented, and specific to local areas and their health service systems. The problem-oriented approach to health planning means that goals, objectives, and reccommendations made by a local health planning agency are tied to resolving or at least addressing locally identified priority problems. Much health planning is premised on the efficient allocation, distribution and use of scarce health care dollars and physical and labor resources. Health services and health care delivery systems in a given area or territory should be designed to respond to identified pro-Problems with health services are critical problems only insofar as they impede the resolution of health problems of the population in the area. The health status of the population is thus improved by conscious organization and re-organization of health care resources and health interventions.

Health planning today must therefore ensure that health services are not only efficient but also effective and equitable. An efficient health care program is one which provides a given amount of care or service at minimum cost and resource expenditure. An effective health care program is one which addresses and alleviates particular health status problems or problems which impinge on health status. And an equitable health care program is one which provides services in a non-discriminatory manner by distributing care across all groups in need or all groups faced with the same problem.

In order to monitor and guide a health care system towards more effective, efficient and equitable health care delivery, a health planning agency must repeatedly assess, evaluate and act on information of three kinds:

- information on the planning area's people and their environment;
- (2) information on the people's health status and health problems; and
- (3) information on the organization, operation, and development of the health care system and its various activities and services.

The broad nature of the information requirements faced by a U.S. health planning agency including Guam Health Planning and Development Agency requires an extensive range of data to be collected and analyzed. The mandate for this data collection is contained in P.L.93-641. Specifically, in Section 1513(b) of this law, it states that

"In providing health planning and resources development for its health service area, a health systems agency shall perform the following functions:

- (1) The agency shall assemble and analyze data concerning -
  - (A) the status (and its determinants) of the health of the residents of its 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, types, and location of the area's health resources, including health services, man-power, and facilities,

- (E) the patterns of utilization of the area's health resources, and
- (F) the environmental and occupational exposure factors affecting immediate and long-term health conditions."

A substantial proscription is placed on the agency seeking to generate data through its own efforts such as by survey procedures, without first seeking special authorization:

"In carrying out /the above duties, the agency shall to the maximum extent practicable use existing data (including data developed under Federal health programs) . . ."

Under enabling legislation passed in Guam as Guam P.L. 14-150, the Guam Health Planning and Development Agency was given a clear mandate for data collection and information production:

"/ $\overline{S}$ ection 9852.(7) $\overline{7}$ 

The agency shall coordinate its activities with all entities in the territory involved in general or special purpose planning, development or regulation which may have impact upon the health delivery systems of the territory. The Agency shall, as appropriate, secure data from them for use in the Agency's planning and development activities, enter into agreements with them which will assure that actions taken by such entities which alter the territory's health system will be taken in a manner which is consistent with the Guam Health Plan and the AIP in effect and, to the extent practicable, provide technical assistance to such entities.

/Section 985.2(9)7

The agency shall require by regulation that providers of health care doing business in the territory shall make statistical and other reports of such information prescribed as necessary by the Agency in such form and manner as the Agency may prescribe on a regular basis, which shall include but not be limited to:

- (a) Periodic reports from holders of Certificate of Need respecting developments of the proposal for which Certificates have been issued,
- (b) Master plan feasibility studies, and other long range plans and studies,
- (c) Financial information,
- (d) Utilization information, and
- (c) Manpower inventory."

While the above wording provides a specific mandate for health information generation by the Agency at the present time,

it should be understood that any comprehensive health planning of a specific nature must be based on a technical documentation of current conditions, problems, resources, costs and benefits, and the like. And the need for this kind of documentation in turn demands the acquisition and interpretation of data of various kinds according to the information requirements of the Agency. What are these Agency information requirements?

P.L.93-641 is very specific about what kinds of data are to be collected and analyzed but says little about how the data is to be used. The use of such data, and the information that results, depends precisely on the technical, data-oriented activities that a health planning agency undertakes and the kinds of reports and documents that it produces.

b) Information-oriented Activities

Given the emphases of P.L.93-641 (and its amendments) as well as statements by the Bureau of Health Planning in Washington D.C., along with published guidelines and supporting technical documents, seven basic "packages" of information are required to be assembled by a health planning agency.

- 1. GUAM HEALTH PLAN (Long Term, 5-Year Strategic Planning Perspective)
- 2. GUAM ANNUAL IMPLEMENTATION PLAN (Short Term, 1-Year Tactical Planning Perspective)
- 3. GUAM MEDICAL FACILITIES PLAN
- 4. APPROPRIATENESS REVIEW
- 5. PROJECT REVIEW
- 6. CERTIFICATE OF NEED
- 7. COORDINATING COUNCIL AND COMMUNITY SUPPORT

The first three "packages" are plan documents.\* The fourth package is a different type of report whose contents has been clarified only recently. Both Project Review and C.O.N. activities require a special kind of health service operations and utilization data which enables health planners to judge the suitability of proposed projects and programs. And a more gen-

<sup>\*</sup>The Medical Facilities Plan is now permitted to be an integral part of the Guam Health Plan, which does not have to be produced annually; rather, the GHP must be updated at least every 3 years.

eral and adhoc type of supporting information must be produced to educate the public and inform the Council of important issues and specifics.

How will a Guam Health Information System help meet these information requirements? Through the provision of an orderly procedure for collecting various kinds of data from multiple sources - public health department, hospitals, clinics, water and environmental quality bureaus, and general economic and social planning agencies, for example - and subsequently producing a particular range of "information products" which are targeted to meet specific information requirements of the health planning agency. Guam H.I.S. will at the minimum ensure that fully knowledgeable and carefully researched, non-arbitrary, and justifiable decisions and reccommendations are made by agency staff. Moreover, properly designed and managed, a Guam H.I.S. will enable all health care providers and participants to coordinate their decisions, reach agreements concerning mutually acceptable courses of action, and in general to share data and information for the greater enlightenment of all,

The minimum potential of such a system, when fully implemented and utilized at least by the health planning agency is to elevate the role of the agency to chief repository and resource for all territorial health information. Finally, one source might be called upon for minor accessing costs to provide objective and timely information to promote more intelligent agency decisions as well as to promote more intelligent agency and government debates.

The <u>maximum</u> potential of such a system, when full participation is achieved and requisite management and analytical skills are acquired and utilized, is for the future development of Guam's health care delivery to be guided by the judicious examination of health status, health resources, health services, and health care utilization information by <u>all</u> providers and participants and for such information to be freely contributed to and freely accessed by <u>any</u> agency or entity (provider or consumer). For a health planning agency to achieve even the mini-

mum potential of a health information system, grandiose thinking and idealistic design schemes must be avoided in favor of a methodical approach to the complex task of developing over a considerable span of time such an information resource.

#### 2. ISSUES AND ASSUMPTIONS IN H.I.S. DEVELOPMENT:

The following discussion highlights likely points of debate concerning the nature and operation of a health information system for Guam. These points are drawn from conversations with various officials in agencies on Guam likely to contribute to the development of an H.I.S. A closing discussion will focus on the major assumptions that are being forwarded as operating premises to guide initial development of the Guam H.I.S. These assumptions in effect set the tone for the Report and its remaining content.

Points of controversy likely to surface (and in fact, which have already surfaced) as a health information system is for Guam is discussed, promoted and initially developed, cluster around two actors: the data donor (treated as one entity but actually consisting of multiple agency sources), and the health planning agency. The data donor is any agency or distinct service which collects or maintain an independent database which might prove of use to an H.I.S. The health planning agency, of course, is GHPDA.

#### a) Data Donor Issues:

### (i) Data Donor Management

The development of a health information system for all its flexibility of organization and function, places particular burdens on the agencies which are sources of health and health-related data. Presumably, initial consultations regarding the nature of H.I.S. development and explanation of benefits and costs of participation in such a system impose no additional burden on administrators willing to discuss such issues. But the donor agency must critically assess the extent to which ongoing participation may impose unwanted workload stretch manpower and other agency resources out too thinly, and disrupt normal data operations which, in almost all cases, will be geared to internal agency requirements rather than external service requests. Thus the first issue in H.I.S. development is the very real concern of data donors over the nature and extent of

changes in <u>internal management</u> of data and procedures that might be required of them. Data which can be extracted from or furnished as part of existing reports or tabulations - and hence acquired and processed as part of routine management - will be more readily donated than data which must be in a form that is new to the agency. Unless existing data forms and formats, as employed by the donor agency internally, are used in order for collection and compilation for H.I.S. purposes, either agency participation will not be fully achieved or some compensating benefits must be offered. Such compensation may take the form of monetary reimbursement or may involve assuming certain data processing activities (for example, coding, keypunching, or tabulating).

#### (ii) Donor Benefits

A second issue from the donor's perspective is the nature and ability of information products or other benefits that could be of practical value to the donor agency. This issue cannot be easily resolved prior to extensive consultations with potential data donors and without marked sensitivity to the data needs of such donors; some needs or uses may not be readily apparent to the donating agency itself. It will be necessary for a newly created H.I.S. to "sell itself" and indeed "market" its product and data processing capabilities. This marketing must not be aggressive or inflated. The demonstration of capabilities, rather than claims to that effect, are what will convince agencies to contribute fully and on an ongoing basis.

It is more than likely that such contribution from all health data source agencies will be achieved on the basis of a "bandwagon effect". In particualr, smaller entities (such as clinics and private physician practices) may well join only after the "success" and durability of an H.I.S. have been amply proven. It is well to anticipate that some agencies and providers will not participate at all, since the cost of such participation may well outweigh categorically any benefits that could be derived to small-scale providers.

#### (iii) Regulatory Use of Donated Data

A third issue related to data donors is the latent concern over the health planning agency's use of the assembled data. Given that the Agency is both a planning and a regulatory body with mandate to review, approve or disapprove, and otherwise critically evaluate and comment on grant application project proposals and Certificate-of-Need petitions, and given the gradual adoption of "Appropriateness Review" as a procedure whereby health services are evaluated for their effectiveness, data donors have a real concern that the data provided may ultimately be used against them. Donated data clearly should not be "self incriminating". This issue must be resolved with a straightforwardly established policy and protocol on the part of the H.I.S. regarding the circumscribed uses of health data. Clear limits should be placed on the application of donated data to regulatory and evaluation functions of the agency. Either data donated by private agencies must not be applied to such functions or the applications must be clearly specified as equally affecting all agencies, such that each donor can evaluate for itself what data it is willing to supply on a regular basis.

#### (iv) Confidentiality

A fourth and final issue to be addressed is that of the relevant restrictions that should be placed on the use of donated data sets, which might threaten the primary confidentiality of members and clients. The issue is not one of potential invasion of privacy but rather the steps to be taken to protect confidentiality while using the data to further understand and meet patient or client needs. Clearly, there is no argument to be made for retention of individual and personal identifiers (such as name, social security number, address) in records made available to information systems, other than client code numbers to enable updating of records over time for longitudinal studies. The focus of data collection, however, should be on the aggregation of data in order to establish trends, patterns, and regularities in service delivery, patient utilization of services, and occurrence and causes of major health problems. end, individual records are desirable to the extent that they permit a variety of profile breakdowns and analyses of contingency or correlation among cliant characteristics and conditions.

Another aspect of the issue is the confidentiality that should be extended to agencies - especially private operations - which submit data but do not wish to be identified by name. On one level, it is the job of

the health planning agency, and the Health Information System that provides it with information, to evaluate individual services and to make recommendations for their improvement. Yet on the other hand, it is unlikely that all providers and service organizations will participate in an H.I.S. if data submitted to the system will be used critically. It will be in the long-run interest of the emerging H.I.S. to cautiously move to use data for evaluation purposes; moreover in all such cases, it is highly reccommended that such intended uses be specified and fully recognized by the donating agency.

A final consideration is that since GHPDA is a public agency, data made available to the Agency might be legally accessed by an individual or organization, particularly organizations that may be in competition with the donor. It will be necessary for GHPDA and the H.I.S. to have drafted a well-defined policy regarding public access to agency-maintained data and information, with emphasis placed on the limits to access that are required in order to avoid violating individual or agency confidentiality. The policy should be accompanied by a freely available protocol which outlines what data are available and how such data may be accessed upon request.

#### b) Planning Agency Issues:

### (i) Data Requirements and Information Generation

One of the central issues confronting the health planning agency that sponsors H.I.S. development is the scope of the data system to be assembled for the variety of planning activities to be undertaken. The volume of data, as well as the formats and the manner in which they are collected are in turn a function of the information requirements of the Agency. Thus, one of the first tasks in H.I.S. development is to identify all relevant information which must be compiled and used in the various agency planning activities and documents. The basic "packages" of information required for health planning have been previously identified and in fact represent the appropriate priority of assembly of required information. Based on this ranking, detailed lists of information with associated data requirements should be drawn up to guide H.I.S. development according to a schedule of cooperative agreement signing for data sharing;

data collection; data base storage; and data processing for defined purposes. Such phasing-in of data base development efforts should promote the orderly and manageable growth of the Health Information System.

#### (ii) Database Management

An important issue to bear in mind is that database management problems associated with multiple data sets are far more complex than those associated with individual (internal) agency data sets. The interactive nature of databases within information systems means that data definition, completness, validity, and compatibility are critical assessments that must be made by and for the H.I.S. Data elements must be completely specified and defined. The validity of the measurement procedure used by the source agency must be evaluated to ensure that each data element has a measurement that adequately and consistently represents the definition given that element. And data compatibility must be assured by maintaining consistent definitions, measurements and collection methods over time. A major concern in the area of database management, one which will affect and be affected by efforts to ensure validity and compatibility, is maintaining cooperative agreements with data donors. These agreements - necessary to the effective functioning of the H.I.S. (as detailed in Section F of this Report) - must establish uniform and explicit expectations on the part of GHPDA and each donor agency regarding data collection procedures, information generation and transmittal, and adequate input by participants on the nature of and possible revisions to any and all databases in the H.I.S.

#### (iii) <u>Information System Administration</u>

Related to database management is the issue of appropriate structure of H.I.S. administration. It is clear that since the system is primarily a resource for health system planning, the Guam Health Planning and Development Agency must maintain a direct responsibility for the activities of the System. The extent to which guiding policy, donor participation, and day-to-day operational questions are assumed by the planning agency, or by a Coordinating Committee (which is argued later), or by an autonomous H.I.S. management staff should be resolved as quickly as possible and framed by written policy. The role that H.I.S. staff play

in the control of the System is less important, however, than the necessity to adequately guarantee that suitable skilled staff are recruited, trained, and retained on a long-term basis. At the minimum, an H.I.S. staff will require skills in the areas of database management, system management, and statistical (including computer-based) processing of health data. Specific skill specifications for H.I.S. personnel must be developed and appropriate staff recruitment efforts must be undertaken in order to secure a thoroughly dedicated staff that is committed to developing the Guam Health Information System.

Given this outline of points requiring decisions to be made in order for the complete structure and operation of a Guam H.I.S. to be laid out, the following premises and assumptions have been made as guidelines which have shaped H.I.S. design to the present time.

a) Locus of H.I.S. Administration:

It is assumed that the locus or setting for administration of a Health Information System spanning various public agencies and including the hospitals and HMOs is best found in the Guam Health Planning and Development Agency, with its mandate to plan and coordinate health services delivery, and with its resources available to dedicate to data collection and analysis.

b) Strictly Specified Uses of Acquired Data:

In oredr to alleviate uncertainty in all data donors, as well as to indicate to the health planning agency in advance the size of the undertaking and resources required for H.I.S. development, GHPDA must specify in detail an H.I.S. "charter" which identifies all potential uses to be made of any and all data acquired by the System. It must be clearly stipulated what kinds of analyses of donated data might affect donor or other agencies. Any regulatory use to be made of data should be indicated prior to accessing such data. Any agreement entered into between GHPDA and a data donor agency must specify what information will be generated and how such information will be utilized or communicated.

c) Cooperative Information Sharing:

It is assumed that the most beneficial and mutually compatible arrangement for data to be donated and information communicated is a cooperative and voluntary effort on the part of all agencies involved in health care delivery and planning. It is strongly urged that coercive measures to force compliance with data requests be avoided at all costs. It is further assumed that agencies are most likely to cooperate where direct benefits are regarded as deriving from voluntary participation in and use of such an information system. The benefits most tangibly perceived are the data, analyses, reports and other types and collections of information that can be made available to any agency participating in the Guam H.I.S.

#### d) Incremental and Flexible Development:

A major assumption to bear in mind is that development of a fully useful Health Information System for Guam - a setting where few if any other information systems exist at present - cannot be expected to be accomplished in a short period of time. It is more appropriate to plan and develop this System in stages, where each stage involves acquisition of a particular and limited set of data as well as demonstrated utilization of these data, in order to reveal the benefits of such a System. This incremental development should be tied to specific design and management principles - such as those described in this Report - but must overlook the need on occasion for adaptations or adjustments to meet special operating or constraining circumstances, which cannot be foreseen at the present time.

#### 3. AN OVERVIEW OF H.I.S. DEVELOPMENT

At the outset, GHPDA as well as all other agency participants in a developing information system should be cautioned against developing expectations of quick or easy creation of a fully implemented System. Depending upon involvement, resources, staff, and use and support of the System, a Guam H.I.S. may take from 5 to 10 years to fully mature.

Below are listed major developmental components which must be assembled and maintained in order for a Guam H.I.S. to function properly. It is vital, however, to the creation of any form of an H.I.S. for health planning that staff with the required training and analytical and data management skills be employed, prior to or concurrent with System development. This point cannot be stressed too much: H.I.S. development depends upon the quality of staff dedicated to its creation and management. A Guide to information system development for Guam, such as this, can be done from afar; but the actual development of this System can only proceed after appropriate staff are hired and are committed to implementing all reccommendations laid out in this Report, or similar specifications devised elsewhere.

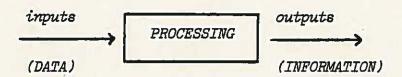
A <u>development</u> scheme for a GHPDA-sponsored Guam Health Information System consists of the following 8 components:

- (1) An information system management staff consisting of two individuals trained and prepared to, first, collect, edit, file, and maintain data; and second, retrieve, process, and analyze and interpret the results of data processing.
- (2) A systematic organization and classification of <u>information</u> and data processing outputs with prescribed features and destination-uses, preferably with sub-sets identified corresponding to priority of generation.
- (3) A documented set of health and health-related databases, along with inventories of data sources and data collection forms, and documentation of database quality.
- (4) A set of specific, routinely scheduled, and clearly understood procedures for processing data which are accessed in order to produce desired information, including computer and non-computer-based computation, statistical analysis, and interpretation of results.
- (5) A physical repository for both incoming data and generated information in the form of a Data and Information Filing System which permits easy access, retrieval, return and storage of all data and information in an organized fashion.
- (6) Active cooperation and participation through implementation and maintenance of Cooperative Agreements of all agencies and individuals providing data or using generated information on a voluntary basis.
- (7) Provision (and revision as required) of an annual schedule for data collection from all participating data donor agencies, for data processing, and for information generation and transmittal to indicated destination agencies, activities, and documents.
- (8) Dedication of adequate monetary resources and budgeted staff time to support all phases of health information system management activities on a regular and continuing basis without interruption.

#### 4. AN INPUT-OUTPUT SYSTEM PARADIGM:

The next three sections of this Report constitute Part II and will address the basic structuring of a health information system for Guam in terms of design principles. It is important to bear in mind, however, that an information system is not any particular physical entity: it should not be confused with a particular configuration of hardware. Rather, an information system should be thought of as an organizing principle which, when explicitly characterized, identifies how a particular set of data is transformed into a particular set of information.

As the clearest guide to the following presentation, the notion of a health information system as an input-output or processing device is emphasized. Such a device is pictured as producing one or more outputs or products as a result of some transformation or processing of a set of inputs. This can be conveniently diagrammed.



The clearest way to characterize a given system is to identify what it produces; that is, what its outputs or products are.

Then we can ask what was required to produce them, or what were the system's inputs. And finally we can ask how these outputs were produced from the available inputs, or what kinds of transformation and combining of inputs took place to generate the products.

This input-output system paradigm is what can be referred to, to help clarify the relationships between data and information in general, and between the components of a health information system for Guam, which are presently discussed. In fact, henceforth, conscious use of the term information products will be used to emphasize the essential output of such a system. These products will be discussed next.

#### PART II

DESIGN PRINCIPLES AND COMPONENTS

# SECTION C. THE OUTPUT OF A GUAM H.I.S. THE ORGANIZATION AND CLASSIFICATION OF INFORMATION PRODUCTS

This section describes in detail the manner in which the outputs of a health data processing system have been organized and classified, along with the tasks involved in establishing any sub-range or any further expansion of the information product list described here.

In order to understand what a health information system can do it is necessary to identify what can be and what should be produced by the system. Thus, discussion begins with an examination of the nature of information products and subsequently describes their organization and the classification schemes employed to permit easy access and interpretation of different sub-sets of such products.

#### 1. THE NATURE OF INFORMATION PRODUCTS:

Information product is a term used to describe what is generated by data processing activity. An information product may be a single count, indicator, or statistic (such as Guam infant mortality rate for a given year); or a single figure or chart (such as a map indicating the infant mortality count for each Guam village district, or a chart indicating the relationship between calendar year and infant mortality rate on Guam for the past 15 years); or even a table or cross-table (for example, a table showing village infant mortality rates for two different years, or a cross-table or cross-tabulation of infant mortality rates by age of mother and month in which the first prenatal care visit was made).

An information product can be identified by a range of attributes. More importantly, an information product has (i) a label to describe it; (ii) a specific output or product form, which includes the means for interpreting the product as information; (iii) a known source of data; and (iv) a means of producing, i.e., computing, the product from the data. This represents a minimum list of attributes or features for identification and description of any information product. (This list can be easily expanded and is done so shortly.) In order for information products to be communicated and understood by health professionals and health care providers, its is necessary that these minimum attributes be known.

\* \* \*

#### SOME EXAMPLES:

Example 1. Product Label: Crude Civilian Death Rate, Guam 1980

Product Form: Rate: Guam civilian deaths per 1000 Guam civilian population

Data Source: 1980 Vital Statistics on civilian

deaths (Death Certificates) and

1980 civilian population estimate

Computation: (Total 1980 Deaths + 1980 population)

x 1000

Example 2. Product Label: Crude Birth Rate, Guam 1980

Product Form: Rate: 1980 Guam live births per 1000

Guam population

Data Source: 1980 Vital Statistics (Birth

Certificates) and 1980 Estimated

Guam population

Computation: (Total 1980 Guam live births

+ Total 1980 Population) x 1000

Example 3. Product Label: 1980 Guam Live Births by Weight

and Gestation Period

Product Form: Cross-Table: Live births by birth-

weight in ounces and gestation

period in weeks

Data Source: Vital Statistics (Birth Certificates)

Computation: (prior computation and publication

in DPHSS Annual Report)

Note that in Examples 1 and 2, the products are known, standard health statistics. The attributes thus codify what is largely already known about the nature of these crude rates. The problem, if any, to be had in computing

these rates is the acquisition of appropriate and reliable population estimates. In Example 3, note that the product is actually a set of numbers or counts arranged in cross-tabular form. In fact, such a format is published in the annual statistical compilation report based on summary tables produced by the Vital Statistics branch of the Department of Public Health and Social Services. Earce no further computation or processing of the data is required. Moreover, it is often the case that the means for producing a given information product, as well as the manner in which it is to be interpreted are known in advance and thus it is not necessary to explicitly state them.

Note that in all three examples, the product informs us about some aspect of health on Guam. The three products are illustrations of health status information products; but products descriptive of health services or the general population or environment can also be (and have been) formulated. The information in some products is only latent: it is actually provided by examining a series of such products, or by comparing the product value with an already established standard or desired value. The GHPDA may have decided that a crude death rate comparable to the State of Hawaii's is a desirable standard, and comparison of Guam's rate with Hawaii's rate would then yield the actual information. But it should be apparent that all numbers or values that are calculated cannot stand alone; they must be compared in order to derive any information value from them. In Example 3, the numbers are arranged in a format that lends itself to just such comparison and resulting informativeness.

\* \* \*

An information product should not be thought of as a definitive item of information. Its specification at a given point in time reflects only what is felt, at the time, to be an appropriate item to utilize in a document or an activity. It may not be an appropriate description or characterization once other types of information or new ways of analyzing data are introduced and adopted.

Even an information product's current characterization is not exhausted by a few attributes. In fact, the preliminary listing of four features of an information product, just described, are <u>not</u> sufficient to permit the kind of organization and indexing of the wide variety of

products that are likely to be called upon to fill just health plan documents. (The Guam Health Plan alone has upwards of 100 information products contained and discussed in it.) To maintain a flexible information system in which different products can be maintained, stored and assembled over time; where products are called upon for various uses at different points in time; and where different agencies may request acquisition of different but overlapping sets of information products at any time; it is necessary that each and every information product be unambiguously described and characterized with an extensive set of features (attributes) which may be indexed and subsequently referenced.

To meet this requirement for flexibility of referencing, each information product that is considered for inclusion in the Guam Health Information System is described by 13 features, each of which will be discussed shortly. However, it is here noted in passing that this information product indexing scheme was not arrived at arbitrarily. Nor is the selection of information products that form a Preliminary Inventory of Health Information for Guam a random assemblage. This initial Inventory referred to is based on a complete documentation of all information that was incorporated in the Preliminary Guam Health Plan, and a careful expansion of this initial list to cover information deemed essential for inclusion in any revised edition of Guam's principal health planning document. From this tentative inventory as a start, the total list of information products has slowly been enlarged to incorporate desirable items and computations which would be of value to a more complete range of health planning documents and activities. Undoubtedly, the Preliminary Inventory can be enlarged still further. It can also be "pruned" quite easily. The important point to bear in mind is that this Inventory rests on the complete documentation of every information product contained and listed in it. It is thus, at once, an inventory, a dictionary, and an indexed reference guide to all health planning information in use or of use on Guam.

#### 2. THE INFORMATION PRODUCT TABLEAU:

The 13 features that serve to characterize each and every information product at present, are collectively termed an "Information Product Tableau". This tableau serves as the template

for constructing complete documentation on any (old or new) information product. The tableau indicates for any product; where it can be found in the Information Product Inventory; what it can be referred to by name; what computational form it takes for display or discussion; what characteristics are imbedded within the product; where the product can be utilized and what source is referenced for raw data for it; and what rationale in general it carries for its use in health planning.

In order, the features or attributes listed in this Tableau appear in the accompanying display (next page). In use, this Tableau is a separate list for each information product.

It should be noted immediately that many of the terms attached to particular features (as their descriptors or qualifiers) refer to different code schemes and classification systems. It is easiest to take each of the features along with their implied coding schemes in turn, to make sure that all the information contained in the Information Product Tableau is properly understood.

- (1) ID. Sequential Identification Number:
  This is a number ranging from 00001 upwards and it uniquely identifies each information product for easy reference in a sequential search of the Inventory as a whole.
- (2) PC. Product Code:

  This is a three-part coding of the type of information product according to how and where it would be filed and from where it would be retrieved in the H.I.S. Filing System. The Filing System is discussed later (please refer to Section E, part 3).
- (3) PL. Product Label:
  This is a short-phrase label that identifies the information product. It is its "name" as a particular statistic, rate, index or table.
- (4) PS. Product Statement:

  This is a longer-phrase label that describes the information product in more detail. It often serves to clarify what has been expressed in "shorthand" in the Product Label.
- (5) PR. Priority:
  This is a coding scheme consisting of numbers: 1, 2, and 3 are used presently.
  Priority indicates the relative value or

TABLE 1.

#### GUAM HEALTH INFORMATION SYSTEM

## INFORMATION PRODUCT TABLEAU

Prefix	Description
**	Initial Product Separator
ID.	Sequential Identification Number
PC.	Product Code
PL.	Product Label
PS.	Product Statement
PR.	Priority
CF.	Computational Form
AT.	Attributes
PF.	Product Format
PD.	Product Destination
DS.	Data Source Report Code
RA.	Rationale
us.	Use
sv.	Service -
OT.	(Other - blank at present)
CC.	(Comments - optional)
\$\$	Final Product Separator

importance attached to the computation and use of the information product. It helps identify subsets of information products that should be generated in temporal order. A value of "1" equals highest priority; a value of "2" means recommended development; and a value of "3" implies suggested but not urgent development.

- (6) CF. Computational Form:
  This identifies how the information product is actually calculated or computed, or condensed from raw data. Often it specifies a mathematical equation or formula to be used in computing the product's value.

  The form also indicates the units or dimensions in which the product is measured.
- (7) AT. Attributes:

  This term identifies one or more qualifiers in a standard set of attributes which the information product might reference. This standard set consists of two types of qualifiers, actually: demographic and temporal. The following terms and codes are referred to:

Demographic		ic	Temporal		
Age	=	A	Weekly	=	W
Sex	=	S	Monthly	=	M
Ethnicity	=	E	Quarterly	=	Q
Village	=	v	Semi-Annual	=	¥
Occupation	=	0	Annual	=	Y
			Periodic	=	P

The demographic attribute codes thus identify what features or sub-groupings of the population are or could be or should be referenced by the product. The temporal qualifiers on the other hand identify how often or at what interval the information product is or should be generated.

(8) PF. Product Format:
This indicates one or a combination of several different formats in which numerical information is presented. The list of formats and acronym codes used to identify them are as follows:

acronym	product format
no	number
ra	ratio
ra	rate
fg	figure
mp	map
gr	graph
ta	table
ct	cross-table

(9) PD. Product Destination:
This identifies in what document or in what activity (within or outside of the health planning agency) the information product will be used. (These destinations will be discussed presently (part 3 and 4 of this Section). In terms of current coding scheme, however, the following list

has been devised:

GHP Guam Health Plan		
GAR GUAIN REALCH FIAM		
AIP Annual Implementation	Plan	
MFP Medical Facilities Pla	n	
PRV Project Review		
CON Certificate-of-Need	Certificate-of-Need	
HIS Agency Information		
HCC Coordinating Council		

- (10) DS. Data Source Report Code:
  This refers to the coding scheme which identifies existing documents or reports which contain the data used to construct the information product. The code scheme is tied Directly to the Data Source Inventory, which is discussed in a subsequent section (please refer to Section D, part 2).
- (11) RA. Rationale:
  This feature refers to a standard set of labels which serve to indicate in capsule fashion the reason(s) for generating the particular information product. After much discussion among assisting staff, a set of descriptive phrases for rationales were devised for health status, health service, and population/environment types of information products. For each of the three sets,

a two-digit numbering scheme was used to code each rationale, so that multiple rationales, where appropriate, might be identified for a given information product. These sets of rationales and their code values are presented in the following table (please refer to the next page).

- This indicates the analytical or planning or administrative use(s) that might be made of the information product that is generated.

  These uses also reference the specific kinds of analytical or planning types of activity that are facilitated with this information. Such uses as priority-setting, needs assessment, resource estimation, agency planning, and evaluation are among those uses that are listed and coded according to the accompanying guide (please refer to the next page).
- This identifies the type of health service program or activity that might benefit from study or other use of the information product. The services listed are identified by standard federal service classification code, which is a four-digit number indicating one service from a comprehensive and exhaustive listing of possible health services, including health planning. This service listing is discussed shortly (please refer to part 4 of this section).

The construction of this Information Product Tableau for each and every health information product can now be seen to be an elaborate undertaking. It may perhaps prove to be cumbersome at times, given its multiplicity of codings which must be referred to repeatedly. However, one distinct advantage lies in the use (if even only partial use) of this Tableau: every information product is fully characterized and rationalized. The tableau descriptions in fact <u>fix</u> any product in the overall health information system without ambiguity.

AN EXAMPLE:

An example information product and its associated Tableau should help clarify the last point made above. Consider the commonly used statistic known as "crude birth rate". How is it 'fixed' in the Guam H.I.S. by its Tableau descriptors?

### INFORMATION PRODUCT USE CODES:

Designated Use	
Priority Setting	
Needs Assessment	
Forecasting & Projection	
Epidemiology	
Statistical Analysis & Inference	
Resource Estimation	
Resource Allocation & Utilization	
Determination of Appropriate Program	
Monitoring	
Regulation	
Planning, General	
Planning, GHPDA	
Planning, Public Health	
Planning, Hospital	
Planning, Agency or Clinic	
Planning, Consumer	
Evaluation: Efficiency	
Evaluation: Effectiveness or Outcome	
Evaluation: Equity	
Evaluation: Other Impact	
Reporting & Documenting	
Public Awareness	

## INFORMATION PRODUCT RATIONALE CODES: Health Status Products

Code	Designated Rationale
01 02	Comparison with National/International Figures Comparison among Populations:Civilian,Military;State, Territorial
03 04 05	Comparison among Groups: Age, Sex, Ethnicity, Occupation, Class Comparison among Locations & Areas: Villages & Districts Comparison among Risks or Exposures
06 07	Comparison among Problems & Conditions Association, Contingency or Correlation Testing
08 09 10	Identification of Risk Groups & Areas Identification of Target Groups & Areas Determination of Priorities
11 12 13	Determination of Impacts Analysis of Trend or Pattern in General Mortality/Morbidity Analysis of Trend or Pattern in Cause-Specific Mortality/
14	Analysis of Trend or Pattern in General Vital Events
15 16 17	Analysis of Trend or Pattern in General Condition Analysis of Trend or Pattern in Needs or Demands Analysis of Trend or Pattern in Utilization
18	Baseline Assessment or Profiling

(Continued next page)

## INFORMATION PRODUCT RATIONALE CODES: Health Service Products

Code		Designated Rationale
01 02 03 04 05 06 07 08 09	(SUPPLY) M A I I I I I	General Service/Program Description General Resource Description General Resource Description General Resource Description General Resource Description Gode/Setting/Affiliation Getive/Non-Active/FTE Graining/Schooling Gicensing/Certification Gistory/Duration Gocation/Distribution Ghysical Condition/Character
11 12 13	(DEMAND) C	Public/General Need Consumer Demand Provider/Supplier Demand
14 15 16 17 18 19	(COST) S	Overall Cost Resource Cost Service Cost Consumer Cost/Pricing Payment Source Revenue Source
20 21 22 23 24 (CO) 25 26 27 28 29 30	E E MPARISON)E E E E E	by Setting/Mode by Specialty/Position by Location by Facility/Service by Service Type by Consumer/Client Type by Provider Type by Reimbursor/Payor by Training by Private/Public Operation by Problem/Condition
32 33 34 35	I E P A LUATION) A E E P C	Change/Development in Service Income/Revenue Ifficiency/Cost-Benefit Productivity Iccessibility to Location Iccessibility: Financial Iffectiveness/Outcome/Impact Iquity/Disadvantaged Problem Complications/Dissatisfaction Iontinuity Ivality

(Continued next page)

Code	2	Designated Rationale
42		Number Clients Served
43	(USE)	Resources Expended
44		Referrals
45		Service Time/Waiting Time/Delays

# INFORMATION PRODUCT RATIONALE CODES: Population & Environment Products

(none currently designated)

ID. 0001

PC. 00/AA/01

PL. Birth Rate - Crude

PS. Total Live Births per 1000 Population

PR. 1

CF. (Live births + Population) x 1000

AT. A,E,V (mother),Y

PF. RA/GR

PD. GHP/F. IV.1

DS. VS-1-m

RA. 01,03,04,05,08,09,14,16

US. 02,03,04,11,12,13 SV. 2140,3100,7100

#### EXAMPLE PRODUCT TABLEAU: "Crude Birth Rate"

The tableau descriptors to be found for Crude Birth Rate give the product a unique identification number and product code (which translated stands for, "general health status/natality/birth"); identifies a product label "Birth Rate - Crude" and elaborates this in a short statement; and assigns a high priority ("1") to computation of this information product. The computation form states explicitly how to calculate this rate and tangentially indicates what kind of data is required for the calculation. The attribute list suggests that crude birth rate should be specified for age, ethnicity, and village categories for the mother giving birth, and that the rate should be computed annually. The product format is a rate, but is to be presented in graphical form in its chief destination document: the Guam Health Plan (where it is found in Figure IV.1). The data for this rate is derived from Vital Statistics monthly reports which have been aggregated. The multiple rationales for generating this statistic include: comparisons with national rates, comparisons across age ethnic and village groupings, identification of "risk" and target service areas, identification of general vital trends or patterns and of demands for service. The uses to be made of this rate include need assessment, population projection, epidemiology, and various types of planning. Services which are likely to benefit from use of this information include maternal/child health care, family planning, and health and hospital planning.

\* \* \*

#### 3. USES AND DESTINATIONS OF INFORMATION PRODUCTS

Information products are intended to serve the planning requirements of GHPDA, as well as to provide Guam's health and health-related agencies and the public at large with quantitative information. Such information can be used for the purposes of:

- (a) general education and public awareness;
- (b) agency planning;
- (c) agency monitoring of activities, resources, utilization, and needs or demands; and
- (d) justification of funding requests or resource allocations.

These purposes are fulfilled by making available information in three broad classes: (1) information on the health status of the population and sub-groupings of the population, by charting major causes of death, types of diseases, and reasons for and impacts of hospitalization and physician or clinic visits; (2) information on the nature and performance of the range of health care activities undertaken on Guam, including charting the availability, accessibility, acceptability, continuity, quality and cost of services provided on- and off-island to Guam residents; and (3) information on the characteristics and behavior of the population, and sub-groupings of the population (such as ethnic groups and villages), and features of the physical environment and modifications made to it.

There are, of course, multiple destinations for information products, even within the health planning agency. This is tied to the multiple functions and purposes that GHPDA serves. The federal-level Bureau of Health Planning currently identifies such broad agency functions as:

Agency Management, Plan Development, Plan Implementation, Plan and Project Review, Data Management, and Public Involvement and Education. Each of these functions calls upon some form of data and generated information, not all of which are quantitative or numerical in character.

The uses to which a Guam H.I.S. can be put have been alluded to before briefly. On closer inspection, moreover, it is possible to specify not only the <u>priority</u> that should be given to agency activities

in terms of effort allocated and significance of the report produced or the decision that is made, but also the range and types of information that must be channeled to each activity. It is maintained here that the principal activities of a health planning agency are its information and coordination roles which are accomplished through document generating activities. These activities focus on three separate documents, each of which calls for special sets of data to be analyzed. These three documents are: the Health Systems Plan (Guam Health Plan), the Annual Implementation Plan, and the Medical Facilities Plan. Three additional activities can be expected to demand their share of data, particularly financial forms of data, but are less straightforwardly specifiable. These activities are Project Review (including PUFF Review), Certificate-of-Need Review, and Appropriateness Review. Herein we briefly discuss the information requirements of the three major planning documents, as a guide to the nature of the information function in health planning.

#### a) Health Systems Plan:

The information content of the Guam Health Plan as a planning document is the most straightforward of the content requirements. Expansion of the scope and detail of data collected for and the information and statistics embodied in the Guam Preliminary Health Plan document is needed in order to improve the utility and integrity of the plan document. But the information base for the basic plan document is firmly established.

The Guam Health Plan incorporates three major informational components: (1) Description of the territory in terms of geography, environment, and population; (2) characterization of the health status, and ideally the health behavior and health conditions, of the population; and (3) assessment of the components and services of the health care delivery system (facilities, resources and manpower) along with its utilization by the population. Due to inadequate records and data reporting procedures, not all morbidity and disability data that are desirable are capable of being assembled; nor have major areas of health services delivery been adequately covered (for example, dental, nursing and village clinic services, and mental health, drug and alcohol, and maternal/child health programs). In many cases, there is

need for data to evaluate the effectiveness of services delivery in terms of standard criteria: availability, accessibility, acceptability, continuity, quality and cost. These information needs should be of major concern to the planning agency. Subsequent attention should shift to developing a forward-looking perspective on health status and health care system development. The information requirements to fulfill such a perspective revolve around trend determinations and the ability to project or forecast population and health profiles based on the current developmental tendencies and potential of the system of health care.

#### b) Annual Implementation Plan:

The AIP provides a yearly prioritization of Health Systems Plan objectives for health status and health system improvement, along with specific, tactical reccommendations for resource allocation and deployment for maximum anticipated improvement. AIP actions identify: (i) the population and /or geographic area affected, (ii) the type of health service or program affected, (iii) the type of facility affected, (iv) the expected effects, impacts and outcomes for health status change and health system improvement, (v) the agency organization responsible for implementing the specified action, (vi) the resources nad costs that are imposed in order to undertake action, and (vii) the existence of any documented commitments or agreements which would facilitate implementation. As far as resource estimates are concerned, the detail includes: location, number and type of facilities, beds, or equipment involved; number and type of manpower; overall cost; and type and source of financing. Finally, the AIP must assess the implications of the action reccommendations it sets forth, with particular attention to the overall impact of the plan on cost-containment as a general health planning issue.

#### c) Medical Facilities Plan:

The State Medical Facilities Plan is intended as the detailed work plan to guide the implementation of physical facility planning objectives which will meet the needs of the population. In addition, the Plan serves as a guide to prioritizing assistance and specifying the type of assistance to be allotted to various medical construction or conversion or closure projects. As such, the MFP

calls for a detailed inventory of existing medical facilities; a survey of need for medical facilities and beds; and a specification of the minimum requirements for maintenance and operation of facilities receiving public assistance funds. The inventory consists of: (1) a count of medical facilities and facility beds, along with their location; (2) a listing of services offered per facility or institution; (3) a determination of the utilization of each facility: (4) general information concerning the organization's status and accreditation or certification; and (5) an assessment of conformance with standards regarding appropriate supply, distribution and organization of health resources (facilities) as specified in the National Health Planning Guidelines.\* The survey of need involves a determination of the extent of modernization or conversion to new uses of existing facilities, or closure, that is required; the need for new facilities; and a drafting of priorities, consistent with Health Systems Plan goals, objectives and reccommendations, to guide the allocation of assistance to various projects.

#### 4. PRODUCT DESTINATION CLASSIFICATIONS: DOCUMENTS & SERVICES

How might information product destinations be accounted for?

For the health planning agency itself, it is rather simple to draw up a list of destination documents and activities which would be targeted for specific information products. Included in the Information Product Tableau is provision for just such a listing (referenced by "Product Destination"), coded according to the scheme outlined earlier. It is also rather easy to expand this listing at any time. For example, it may be possible in the future to identify documents, reports and activities of agencies other than GHPDA to which H.I.S. information products would be sent.

Of similar value is the ability to identify what health service or class of service might benefit from information products generated by the System. Such an identification is possible with the use of an exhaustive classification system, first suggested by the federal

<sup>\*</sup> These standards cover the following areas:general hospital bed supply, hospital occupancy rate, obstetrical service, neonatal special care units, pediatric service beds, pediatric inpatient occupancy, open-heart surgey, cardiac catheterization, radiation therapy, CT scanners, and end-stage renal disease services. The Guam Health Plan discusses these standards at length.

Bureau of Health Planning and later modified by the State of California. Were each information product to have codes indicating what services would benefit from using it, then it would be possible to identify sets of information products which a given service could make use of.

The Health Service coding system used here depends on a three-level classification of all present and potential health services on Guam.

Together, these classifications form a Taxonomy of Health Services.

The first level in this taxonomy refers to eight major categories of health service provision; these categories are identified by a code value in the "thousands", that is from 0000 to 7000.

Code	Category of Services			
0000	General Health System (non-specific)			
1000	Community Health Promotion & Protection			
2000	Prevention & Detection			
3000	Diagnostic & Treatment			
4000	Habilitation & Rehabilitation			
5000	Maintenance			
6000	Personal Health Care Support			
7000	Health System Enabling			

These categories correspond to those levels of health service which the federal government (Bureau of Health Pjanning) has promoted as a guide to systematic description and evaluation of the entire service spectrum in a given area.

For each health service category, it is possible and desirable to refine the classification further by identifying broad <u>clusters</u> or sub-categories of health services, and to refer to these through means of specific labels as well as numerical codes in the "hundreds", ranging from 000 to 900. For example, under the general health category of Community Health Promotion and Protection Services (coded 1000) are identified six sub-categories (please refer to the complete Taxonomy appended to this Report as Appendix I). These sub-categories are:

<sup>\*</sup> The value "0000" is reserved for non-specific reference to health services in general, or to the health care system as a whole.

Health Education Services (1100), Environmental Quality Management (1200), Food and Drug Protection (1300), Occupational Health and Safety (1400), Radiation Safety (1500), and Biomedical and Consumer Product Safety (1600).

In turn it is feasible to identify individual services at a third level of classification for each and every sub-category of health service. These individual health care services can be coded in the "tens" from 00 to 90 (and provision can be made for additional two-place symbol codes in cases where more than nine specific services are subsumed under a sub-category). For example, under the general category of Community Health Promotion and Protection Services (coded 1000) and its sub-category Health Education Services (coded 1100), are to be found the distinct services of School Health Education (1110), Community Health Education (1120), Positive Health Behavior Promotion (1130), and Emergency Health Education (1140).\*

It is readily apparent that individual health care service codings of the third-level classification identify both the second-level health service clusters and the first-level general service categories they are subsumed under. Thus the coding scheme is at once quite specific and generalized. It is possible to identify all information products that pertain to a given service, to a given service sub-category, or to a given general category of health care delivery. By this scheme, it is also possible to identify information gaps, that is, services, sub-categories or even categories for which insufficient information is presently available. Measures could then be taken to access the appropriate data to generate needed information products. At present, however, it is enough to have the Health Service Taxonomy available by which to code health services for easy reference in an Information Product Tableau.

#### 5. THE PRELIMINARY INFORMATION PRODUCT INVENTORY

Having elaborated the design and coding schemes employed in characterizing each health information product, it is only necessary at this juncture to identify how the overall set of information products is

<sup>\*</sup> It should be noted that a "ones" place, with values from 0 to 9, has been reserved for still further sub-classification. This fourth level could possibly reference individual programs or budgeted activities, if someone were enterprising to inventory all such activities in a given planning area.

organized and maintained. It should be understood that the generation of individual information product descriptions is in response to the need to be as specific as possible about the nature of information to be generated by a Guam Health Information System and to be used in various GHPDA and other health agency activities. The clarity of specifying individual <u>outputs</u> of data processing activities should be apparent - it leaves no ambiguity as to what kinds of data acllection and processing efforts must be undertaken to generate needed information.

At this early stage of H.I.S. development, it cannot be expected that the full potential to access different sets of information products inmultiple ways can be achieved; yet some of this potential will be indicated shortly. At the outset, a straightforward inventory of all information products of use to GHPDA is a suitable reference document.

This Preliminary Information Product Inventory was initially developed during the summer of 1979 on Guam. It is divided into three blocs of information and further grouped into separate sections and subsections which correspond to the manner in which both data and information products are organized in the physical Filing System (discussed in Section E, part 3). The three main information and data blocs identify the three main types of information required in health planning:

BLOC I Health Status Information

BLOC II Health Service Information

BLOC III Population & Environment Information

Two forms of information product inventory have actually been devised. The original inventory was documented on 8 x 14-inch tables, which amounted to 30-odd pages of information product inventory. This initial inventory, while fairly complete in its listing of all desirable information products of use in a Guam H.I.S. to begin with, did not provide complete Tableau descriptions; only 6 features were in fact identified. Subsequently, a more complete Tableau for information product description was devised (as described earlier in this Section), and individual cards were employed where each card represents one information product. The latter, card system

<sup>\*</sup> These 6 initial features were: Product Code, Product Label, Features, Product Format, Product Destination, and Data Source Report.

for the Information Product Inventory is unfortunately unfinished as of this writing. A major portion of Bloc II Health Service information products have yet to be more completely described. However, all products are described according to the initial set of six features. This initial Inventory forms a separate document a copy of which is maintained by GHPDA. A copy of the incomplete expanded-feature card system is also retained by the Agency.

#### 6. ALTERNATIVE ARRANGEMENTS OF INFORMATION PRODUCTS

By way of summarizing, attention is drawn to the initial but quite definitely developmental work of establishing the content of a Guam Health Information System. The general rationale for such a system is to have in one physical repositaory all information which would benefit health planning activities. The large amount of information that health planning calls upon requires some systematic means of identifying and classifying individuals items or products. Thus, it is necessary to not only specify and characterize each information product as a unique output of an H.I.S., but to order these products for easy storage, retrieval and assembly. The Information Product Tableau, while quite cryptic and symbolic, serves to present a standardized format for describing and coding each product. The Information Product Inventory (in its dual formats) helps arrange products in one straightforward scheme corresponding to how such information - and their related data inputs - are to be physically stored in a filing system.

But it should be apparent that, given the nature of the Tableau and its variety of coding schemes, it is quite possible to organize the variety of information products into several alternative systems or packages. Several of these arrangements are noted below.

#### a) Priority:

At the minimum, it would be of value to separate information products according to their priority (1,2,or 3) of use. Obviously, all information products coded "1" should be generated first.

#### b) Product Attributes:

It may be of value to a data analyst to work with all data which will produce information keyed to one or more particular attributes or qualifiers (demographic or temporal), such as age-groups, males and females, ethnic groups, or villages. Thus all information products which identify village, for example, might be collected for quick reference.

#### c) Product Destination:

It would certainly be desirable to assemble all information products targeted to particular documents, such as the Guam Health Plan or the Annual Implementation Plan. This sorting of products would facilitate health planning activities when all attention is turned to the production of a single document and emphasis is thus placed only on those products that comprise that document.

#### d) Data Source:

Assembly of information products according to the data source called upon for processing to generate them would aid in communications with data donor agencies concerning what exactly is being requested and what will be computed from the requested data.

#### e) Service:

As discussed more fully later, it may help promote cooperation in a common H.I.S. development effort if all health agencies are aware of the nature and range of information which might be produced by the System and that could be tapped by the agencies. Thus, sorting of all information products by individual service, or by service sub-category (as mentioned before) would enable GHPDA to communicate the concrete information benefits of H.I.S. participation. Such collections would also indicate what services lack appropriate information.

# THE ORGANIZATION OF DATA AND INVENTORIES OF SOURCES AND COLLECTION FORMS

#### 1. ISSUES IN DATA ACQUISITION:

This section outlines the nature and organization of data which is to be acquired for the Guam H.I.S. in order for the system to produce desired information products as itemized in the Preliminary Inventory. The data referred to are the raw counts and numbers, and in some cases already-computed statistics and rates, which are processed by the information system to generate specific information outputs. It should be clear from the outset that any contemporary government and modern society (developed or developing) collects far more data than are ever processed as information. Much of this data has been and is still collected according to routine administrative procedures. Other data are collected only periodically in the form of surveys. Some data are generated by forms that are filled out at the beginning or at the conclusion of a particular type of activity. Some data are collected for services or agencies or departments which are treated as single entities. Much more data, of course, are collected on individuals at various times and in various settings.

It is the task of a health information system whose supporters desire certain sets of information products to search for and collect the necessary data often from <u>multiple sources</u>. Two cases should illustrate this fairly clearly.

In order to obtain current birth rate statistics, a health planning agency must access not only birth counts for a given period from the personnel in charge of vital statistics, but also population estimates from the office charged with producing such figures, usually a central government planning office or a university research arm. On the other hand, in order to obtain total hospitalization or hospital admission rate statistics, a health planning agency must access both admissions counts

from hospitals in the territory and similar population data, often disaggregated by age and sex distributions.

It is obvious that information products cannot be produced without requisite data. Yet what total set of data actually exists in the territory may be far from clear. Furthermore, of the data known, to be available, some may prove to be of little value in use. Thus, two issues must be addressed in discussing data inputs: the issues of data availability and data quality.

#### 2. DATA AVAILABILITY AND INVENTORY PROCEDURES:

It has been stressed throughout that the development of an H.I.S. proceeds from an initial specification of what uses an H.I.S. is to be put to, followed by an itemizing of all information products that are desirable according to the uses which will be made of them. This itemizing in the form of an inventory was the subject of the preceding section. But all such information products may not be feasible to generate, simply because the data necessary to generate them may not be available. Thus, the third "step" in developing an H.I.S. is to identify all health and health-related data available in the territory. This step involves another inventory effort.

The effort to inventory available data for an H.I.S. is most suitably achieved by seeking to identify what each agency, or other data-producing entity, in the terrirory has to offer. This <u>Inventory of Data Sources</u> is a systematic lissting of data available by source agency. If these data prove to be of value in creating desired information products, and if the data source agencies prove cooperative in permitting access to the relevant data, then these source agencies will become <u>Data Donors</u>.

The detailed procedures involved in a complete and systematic inventory of data sources have not been elaborated, largely because the task may prove to involve various efforts and strategies. Formal or informal contacts are usually the starting point for conducting the inventory. Ultimately, the purpose of the inventory is to identify all relevant data,

according to discrete databases, which can be conveniently and cooperatively accessed from each agency. The agencies to be involved are both public and private, but it is rightly assumed that public agencies contain the bulk of regularly maintained data.

In the summer of 1979, an effort was made to contact the majority of public agencies on Guam, including military sources, in an attempt to identify all available health and health-related data. This initial effort resulted in the following list (in alphabetical order) of agencies with known data sets (see accompanying table, next page).

Each of these agencies or offices on Guam has one or more sets of data which could be of value in generating desired H.I.S. information products. It is an extensive list and suggests the large supply of data that exists on Guam. But is all of the data of equivalent utility? Can it all be handled in the same manner and with the same level of confidence?

#### 3. DATA QUALITY AND EVALUATION PROCEDURES:

Whether or not two sets of data which both happen to be available to GHPDA are equally valuable and useful is more than simply a matter of what information products they may generate. The quality of the information is only as good as the quality of the data employed to generate it.

The information will be worthless, and no confidence can be placed in it, if the data which generated it was not collected in a systematic manner according to standard measurement protocol. The utility of data actually revolves around the issue of data quality. Data quality refers to the validity and the reliability with which data are collected. Any measurement is a procedure to quantify a given phenomenon. The success with which one actually measures what one intends to measure is called validity. In turn, the ability to consistently measure a phenomenon accurately with a rigorous, standardized and unvarying procedure is called reliability. To be useful, data must be both vaildily and reliably measured.

TABLE 2.

#### INITIAL INVENTORY OF AGENCY SOURCES OF DATA ON GUAM

AGE		OF AGENCY SOURCES OF DATA ON GUAM
CODE	NAME	DATA AVAILABLE
AAFB	Anderson Air Force Base USAF Clinic	Outpatient Data; Periodic Reports
BBM	Bureau of Budget and Management	GovGuam Budget, Expenditures; Federal Grants
BP	Bureau of Planning	Guam Economy, Land Use, Social Statistics
DOC	Department of Commerce	Demographic, Commerce, Import-Export Figures
DOE	Department of Education	Special Education Program Enrollment
DOL/BLS	Department of Labor/ Bureau of Labor Statistics	Labor Force Statistics, Population/Labor Survey
DPHSS	Department of Public Health and Social Services	Medicaid Statistics; Licensed Health Manpower, Health Facilities Data
/EH	Environmental Health Branch	Inspection and Sanitation Data
/EP	Epidemiology Branch	Infectious-Communicable Disease Reports, School Absenteeism, Computer Data Base
/PHN	Public Health Nursing Branch	Public Health Nurse Visit and Clinic Reports, Outpatient Visits, Public Health Program Data, Computer Data Base
/vs	Vital Statistics Branch	Birth, Death, Infant and Fetal Death, Marriage and Divorce Data, Computer Data Base
DPS	Department of Public Safety	Crime and Accident Data, Computer Data Base
DVR	Department Vocational Rehabilitation	Disabled and Rehabilitation Program Data
FHP	Family Health Program	Federal Annual Reports on Visits, Programs, Enrollment; Client Data Available
GCMHC	Guam Community Mental Health Center	Mental Health Program Data, Client Data Available, Computer Data Base (in preparation)
GEPA	Guam Environmental Protection Agency	Air Quality Reports
GMH	Guam Memorial Hospital	Hospital Inpatient Admissions and Discharge Data, Outpatient Visits, Procedures Data, Computer Data Base (in preparation)

AGI	ency	
CODE	NAME	DATA AVAILABLE
GMHP	Guam Memorial Health Plan (HMO)	Annual Federal Reports on Visits, Program Data; Client Data Available, Computer Data Base (partial) and Output
GTA	Guam Telephone Authority	Telephone Calls and Hook-ups Data
GVB	Guam Visitor's Bureau	Visitor Statistics
HML	Health Maintenance Life (HMO)	Annual Federal Reports on Visits, Clients
MHSAA	Mental Health and Substance Abuse (Single State) Agency	CODAP-Based Data on Drug and Alcohol Abuse
NRMC	Naval Regional Medical Center	Hospital Use Data, Client and Referral Data
PUAG	Public Utilities Authority of Guam	Water Quality and Sewage Data
RT	Revenue and Taxation	Government Revenue and Taxation Data, Vehicle Registration Data
SDA	Seventh Day Adventist Clinic	Outpatient Visits and Clinic Program Data (Private Clinic: Limited Access)

There are many ways in which data quality may suffer. Different individuals may record measurements differently. Someone may copy data from coding sheets onto permanent file copies inaccurately or sloppily, or with impermissible latitude in interpretation. Clinicians often forget to fill out client forms immediately after a patient contact, and poor memory may forc them to guess in filling out specified items. Often problem or clinical diagnoses are vague because a client presents a unique problem which does not admit to easy identification. In many instances, administrators simply forget to fill in all items on a coding form.

In general, administrative records are less reliable than clinical records, and clinical records are poorer in overall quality than individual sets of data obtained from one-shot or periodic surveys. It is generally true that surveys are conducted with careful attention to ensuring maximum quality, hence interpretability, of the data. However, in some cases, public agencies undertake surveys that are poorly designed, use inadequately trained interviewers, and do not provide proper safeguards or edit-checks on data quality. However, it should be pointed out that some administrative programs collect highly reliable data, usually motivated by one of two aims: billing and reimbursement, or research and evaluation.

A fundamental, required activity of any H.I.S. program effort is to assess the quality of the data that are being accessed to generate information products. There can be no assumptions made by an H.I.S. staff that available data is reliable. It cannot be concluded that since the information must be generated the data necessary to generate it must be accepted without comment or qualification. Information products are only as valuable and valid as the data that go into their creation.

As of this writing, an unfinished task for the Guam H.I.S. to undertake and complete is an inventory of all data sources deemed desirable for H.I.S. acquisition in terms of data quality. Such an inventory, at the minimum, must seek to document each and every data source, and give answers to the following questions:

<sup>\*</sup> This is related to the fact that surveys collect data on <u>samples</u> of individuals in the total population, and survey results try to generalize information computed to the whole population. Accurate generalization depends on accurate and complete sample data.

- i) How long has the data been collected in its present form?
- ii) How many cases or records are currently stored?
- iii) How often is the data coded for stored records?
  - iv) How many copies of this data set or of individual data records are made on a regular basis?
  - v) Who or what groups code the data?
  - vi) What training is given to data collectors and coders?
- vii) Are there independent edit procedures to check the completeness, accuracy or reliability of the codings?
- viii) Who is covered by this data set who is "eligible" to be coded?
  - ix) Is there a Procedures Manual available as a reference for how to code the data and interpret questions and answers?
    - x) How is the data used by the agency?
  - xi) How often is the data manipulated, aggregated, processed or analyzed?
- xii) Who or what groups use the data or statistics generated from it?
- xiii) How many items (questions) are to be filled out on a given case in order to have a complete record of data for that one case?
- xiv) If the data pertain to individuals (clients), what personal characteristics or attributes are asked for (examples: age, sex, income, ethnicity, village)?
- xv) How is the data (if personal) protected in its confidentiality? Who is allowed to review or examine the data?
- xvi) How and by what procedures are the data collected, stored and retrieved?
- xvii) What physical system is used to store the data?

An H.I.S. staff member should consult any standard reference to data collection or survey methodology in order to identify further questions which should be raised in the process of documenting each and every data set.

#### 4. DATABASE DOCUMENTATION:

What has been presented here in admittedly outline form is the manner in which data that are to serve as inputs to a Guam Health Information System should be inventoried. This inventory procedure consists of both an enumeration of data available and an evaluation of data quality. At the very least, the result of this inventory will be better knowledge of what each data set can do and how each can function in the H.I.S.; that is, what kinds of information, and of what quality, can be generated from it.

It is best to frame this "input" portion of H.I.S. development as a systematic atte,pt to document individual databases. It will be recalled that a database refers to a data set (a collection of one or more measurements for a defined set of cases or observations) and the specific procedures which have been followed to permit such measurements. More exactly, a data set is a collection of measurements on different variables (for example, name, age, sex, ethnicity, disease diagnosis) for each and every case or observation (for example, an individual client or survey subject). And the set of procedures are simply the rules and circumstances under which measurements are allowed to be made and recorded. The nature and quality of the measurement procedures are summed up in answers to the list of questions just presented.

Emphasis on database documentation means that more than the nature and quality of data, and measure procedures, are described. In addition, such documentation involves identifying individual variables which may be of use to the H.I.S. This assessment is best handled in two ways. First, the utility of the data can often be evaluated by listing and obtaining copies of the reports and information product documents that are produced by the data collecting agency or other agencies which tap the database of interest. An <u>Inventory</u> of <u>Data Reports</u>, at the very least, may help save H.I.S. staff time by indicating what desired information products may already be on hand or regularly calculated by other agencies. Second, a companion activity to help assess data availability is for H.I.S. staff to obtain copies of

<sup>\*</sup> Variables are simply discrete features or characteristics which are measured. Observations or cases are the entities each of which has the characteristics to be measured.

all original data collection and coding forms used to collect and compile each of the indicated databases. This latter task of producing an <a href="Inventory">Inventory</a> of <a href="Data Forms">Data Forms</a> is in fact not time-consuming at all, and is usually non-threatening to the data source agencies.

A final note helps to point out the obvious. Information systems and databases are the products of people, and it will aid any H.I.S. development effort to make contact with this data collection and database management staff on an informal basis. At the least, it will aid in future ease of communicating importnat requests or other memoranda if particular individuals in data administration positions are known and are involved in and informed of all data acquisition efforts.

#### 5. DATA ACQUISITION:

The culmination of any database documentation activity should be the decision to access or not to access the available data. If the decision is affirmative, then it is necessary to involve GHPDA and the potential data donor agency in formal proceedings leading to a lending or a donation of specific data to the H.I.S. for purposes of information product generation. Such proceedings involve negotiations concerning the data to be acquired, the products which will be generated from them along with the uses to which such products will be put, the circumstances under which data will be accessed, and any reciprocal flow of data or information from the H.I.S. that will be made - in short, the substance of a Cooperative Agreement for Data Access and Information Sharing between GHPDA and the data donor agency. The content of this kind of Cooperative Agreement is addressed in Section F of this Report; however, it is stressed here that the priority given to particular data source agencies which are negotiated with first may well hinge on more than just the priority given to certain sets of information products. In general, it will be advisable to acquire those data which, with acceptable relaibility and utility, are in the most suitable form for easy data processing. In particular, computer-based datasets are the easiest to manipulate for newly designated ends, that is, new types of information products; already routinely

TABLE 3.

RECCOMMENDED DATABASE DEVELOPMENT PHASING

PHASE/DATABASE	INPUT FORMAT *
I. PHASE ONE: "CORE H.I.S."	
1. PUBLIC HEALTH NURSING/VILLAGE CLINIC DATA	computer
2. VITAL RECORDS	computer
3. EPIDEMIOLOGY-MORBIDITY REPORTS	computer
II. PHASE TWO	
4. GUAM MEMORIAL HOSPITAL MEDICAL RECORDS	output report
5. GUAM MEMORIAL HEALTH PLAN (HMO)	output report
6. FAMILY HEALTH PROGRAM/HEALTH MAINTENANCE LIFE (HMO)	report
III. PHASE THREE	
7. MENTAL HEALTH & SUBSTANCE ABUSE DATA	sample/report
8. AIR & WATER QUALITY DATA	output report
9. FOOD ISNPECTION & SANITATION DATA	output report
10. NAVAL HOSPITAL RECORDS	report/ sample
11. ANDERSON AIR FORCE BASE CLINIC DATA	report/ sample
IV. PHASE FOUR	
12. EMERGENCY MEDICAL SERVICES DATA	output report
13. HIGHWAY SAFETY/ACCIDENTS DATA	output report
14. DEPARTMENT SOCIAL SERVICES RECORDS	report
V. PHASE FIVE	
15. BUREAU OF LABOR STATISTICS POPULATION DATA	report
16. DEPARTMENT OF COMMERCE ECONOMIC DATA	report
17. FINANCIAL/BUDGETARY DATA	report
18. VOCATIONAL REHABILITATION RECORDS	report/sample
19. SEVENTH DAY ADVENTIST CLINIC DATA	sample

<sup>\*</sup> Explanation of "input format" terms: computer = data available on computer tape or diskette, can be processed with aid of programmer; output report = data processed by computer and presented as computer output, often according to requested displays; report = existing agency report; sample = data can be accessed by obtaining a sample of agency records and analyzing this subset.

generated data or statistical <u>reports</u> are nearly as valuable; and sets of raw coded data forms, unprocessed in any way by the source agency, are the least "congenial". (In this last case, if the data proves to be essential to H.I.S. activities or for priority planning documents, then the best procedure is for a representative <u>sample</u> of the data to be taken, and data processing done on this smaller, more manageable set.)

#### 6. SUMMARY: DATABASE PHASING:

This section has outlined the nature of what is clearly an ongoing activity to identify, document, and ultimately collect available data which are desired by an H.I.S. It is readily apparent that extensive documentation is in fact called for. At a minimum the following inventory activities are advisable:

- 1) Inventory of Data Source Agencies
- 2) Inventory of Individual Databases (including documented data contents and quality)
- 3) Inventory of Data Reports and Documents
- 4) Inventory of Data Collection and Coding Forms
- 5) Inventory of Database Management Staff

Due to the size of the overall task involved, it is highly reccommended that complete database documentation be undertaken in several phases, which may be separate or overlapping in their actual scheduling. The suggested phasing is presented in the accompanying table (next page). This phasing is reccommended on the basis of limited staff resources available to GHPDA and the collective desire for selected databases to be acquired as quickly as possible and for the planning or related use of such acquired data to be demonstrated soon after acquisition. Of course the ability to demonstrate utility of such acquisition is highly dependent upon the manner in which data processing activities are defined and organized within GHPDA, the subject of the next section of this Report.

# SECTION E. THE PROCESSING OF DATA & INFORMATION IN A GUAM H.I.S.

#### 1. FLOWS OF DATA AND INFORMATION IN AN H.I.S.:

The key to ongoing operation of an information system is the processing of data into information products. At the outset, it should be understood that data processing refers to much more than simple computations of an arithmetic sort. Indeed, data processing encompasses a variety of manipulations of data, many of which are simply managerial or logistical in nature. Thus, at least two kinds of data processing activity should be initially distinguished: computation and "handling".

It is difficult to specify <u>computational</u> processing procedures in any detail, for the simple reason that each type of data/informatio transformation is often unique. Furthermore, the actual computational processing format is usually straightforward and is adequately summarized in the Information Product Tableau (Section C). No further guidance to arithmetic, computational processing of data is offered here.

Guidance is required, however, in properly understanding the structuring of <a href="logistical">logistical</a> processing activities, and in understanding the extent to which data processing is more of a logistical problem than a computational one. To picture this adequately, it is best to consider the various <a href="flows">flows</a>
of health data and information into and out of an established information system. The range of flows is roughly pictured in the accompanying figure (next page). This diagram indicates that there are complex flows of data and information into, out of, and within the processing component of an information system. Data from a source (donor) agency "arrives" at the H.I.S., there to be initially edited and evaluated for its quality. It is subsequently compiled or rearranged into suitable storage formats prior to be actually stored. (In this same storage repository are also to be found information products, arranged in a physical filing system shortly to be described.) Upon request - and by agreement - certain "raw" data sets may be accessed by other agencies on Guam for their own use, hence may be

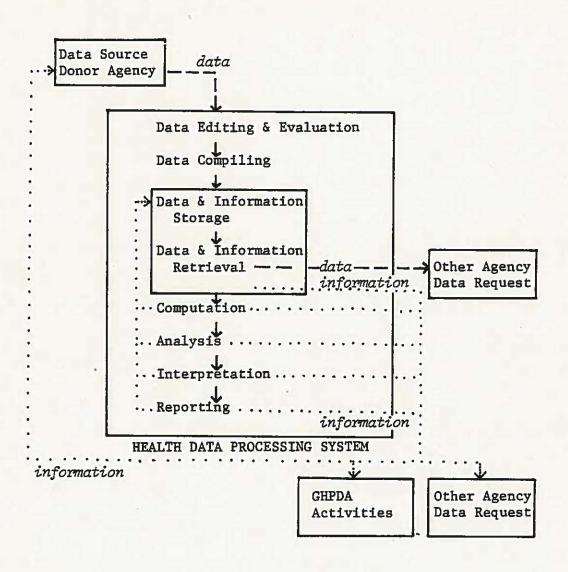


FIGURE 1. DIAGRAM OF DATA AND INFORMATION FLOWS IN H.I.S. DATA PROCESSING

retrieved (i.e., copies made) and sent in response to the request. At appropriate times, portions of the stored data are removed to undergo computational data processing. Subsequent to such computation are the follow-on activities of analysis, interpretation, and the narrative documentation of or reporting on the results of analyses performed. The final product - the information which results form computation - actually is a product in various stages of finishing: computed, analyzed, interpreted, or documented. All are accepted as being various kinds of information products. These products are either stored again (in appropriate files), or flow to final-destination uses. The destination may be within GHPDA in some plan activity, or may be to another agency which has made a request to the H.I.S. for specific products. The request may obviously come from the data source agency itself. In fact, added emphasis should be placed on servicing all data processing requests of data donors. Source agencies should receive lists or reports involving all information products that are generated using their data.

#### 2. DATA ACQUISITION AND TRANSMISSION:

The diagram is sufficient to indicate the kinds and directions of data and information flow, but it cannot suggest the manner in which data and information may be sent. A brief word is in order here on these modes of transmission.

Data may be acquired as:

- a collection of individual case-files, with unedited, manually recorded raw data contained within them (e.g., client files);
- (2) a collection of manually coded administrative forms (e.g., CODAP drug abuse client service forms);
- a set of automated, punched records, such as a computer card deck;
- (4) a magnetically encoded computer diskette or disc of case data (such as vital events data);
- (5) a magnetically encoded computer tape;
- (6) a summary or compilation of original case data, presented as as series of aggregate or average statistics (e.g., average clinic visits per week);

- (7) a compilation of data and statistics in tabular or graphic form (e.g., DPHSS Annual Statistical Report or Guam Annual Statistical Abstract); or
- (8) a public or private report on a study or an agency program report or grant proposal, with data and statistics incorporated in such reports.

It will be the task of the data management staff to appropriately handle the acquisition and processing of any one of these data transmission modes. For the foreseeable future, it is more than likely that computer-based data submissions will be limited to a few key sources: Vital Statistics, Public Health Nursing, and Epidemiology Branches. In the main, data summaries (Type #6) or data reports or abstracts (Type #7 and 8) will be the expected formats. For certain central agencies (Guam Memorial Hospital, the Health Maintenance Organizations, major health clinics, for example), it is likely that raw records may have to be tapped in order to produce needed information. In such cases, H.I.S. management staff will better maintain data processing schedules by selecting suitable samples of records to be subsequently processed, both logistically and computationally.

In turn, it is well to note that information, upon being produced, may be transmitted to appropriate destinations in various formats. It is to be expected that in the short run, a hand-tabulation with adequate analysis and interpretation will be the commonest form of product to be transmitted. However, H.I.S. staff, and GHPDA staff as a whole, should be aware of the vast increase in efficiency that can result if suitable computer or micro-computer facilities are directly accessible to automatically (computationally) process data into desired computer output formats. The difference between handtabulating data on age-sex population distributions by village on Guam and having a computer-based statistical routine (program) produce the same tabulations should be readily apparent. The variety of outputs that can be quickly generated by a computer from a given computerized data base (such as Guam's Vital Statistics data) is one of the basic assets of this data processing medium. It will take much preparation, staff training, and investment of resources to fully activate such a means of producing and transmitting a range of information products.

#### 3. STORAGE AND RETRIEVAL - THE H.I.S. FILING SYSTEM:

The task of accommodating various types of dataset submittals to an H.I.S. and transmitting various products to destinations is rather straightforward compared to the task of organizing and maintaining easy access to the vast range of data and information that will be assembled by the data management staff. If data were to be instantly processed, computed, and transmitted as information at the time of its acquisition, there would be less or no need for careful structuring of internal data and information flows. But the schedule which is followed to acquire relevant datasets on a periodic basis will never match the schedule that is established to periodically produced desired information products - let alone handle 'ad hoc' requests for information. Thus, a means for physically storing data, for knowing where different datasets are at any time, and for quickly accessing different combinations of data in order to computationally process data into information products demands a classification scheme attached to a physically filing system.

The criteria governing the establishment of a filing system are that any dataset or information product must have a physical location with an "address" that permits its quick retrieval, and that the set of such addresses be organized in some systematic manner. Since the entire system of health information is oriented to information generation, it is nearly intuitive that the filing system should be mapped and indexed to correspond to the types and destination uses of such products.

A classification scheme for information products should meet several criteria of its own. The classification of products according to use or information content should be as detailed as possible, in order to permit different datasets to be physically separate yet easily identified and retrievable. The classification scheme should be organized to correspond to the three main groupings of health information (health status, health services, and population and environment); but under each of these general headings should be further subject or content specification of types or classes of information. And the classification scheme should permit

straightforward accessing by way of an indexation of two main types of subject matter of health planning: (1) health status problems, and (2) health service activities.

In response to these requirements, the classification scheme which is presented as an Addendum to this section (see has been adopted. And this scheme serves as the organizational "road map" to the physical filing system. In fact, this classification scheme has a coding system incorporated within it which enables each and every information product, for which a Tableau is constructed, to be indexed according to its place in the filing system. The actual organization is as follows:

- (1) The H.I.S. File Classification Framework consists of three levels of identification. The first level identifies <u>Data Blocs</u>: Health Status, Health Service, and Population-and-Environment blocs.
- (2) Each data bloc consists of a series of Files and Folders. For both Health Status and Health Service data blocs, there is one Special File and a set of Main Files, within either of which are to be found an ordered series of Folders. The Folders contain data and information pertaining to various Topics. For the third data bloc, Population and Environment, there are no Files but only Folders, each of which has its own set of topical data and information.
- (3) For the <u>Health Status data bloc</u>, the most important organization of data and information is according to priority (i.e., prioritized) <u>health status problems</u>, which the agency determines are important (and feasible) enough to warrant attention and planning analysis and reccommendations by the agency.
  - a) The <u>Special File</u> for the Health Status data bloc is a file for collecting all data and information which documents general, overall, or comparative

health status of Guam's population without reference to any one health status problem. (The General Health Status special file would thus contain data related to life expectancy on Guam, for example.)

- b) The Main Files for the Health Status data bloc are precisely files on individual health status problems. Each Main File consists of data and information, inserted in various folders within the file, on a particular health status problem. Such problems might include Diabetes, Infant Mortality, Cancer (or a particular form), for example.
- c) The coding scheme employed for the Health Status data bloc Files uses a two digit number to identify individual files. A code of "00" identifies the Special File on general health status. Codes from "01" to (potentially) "99" are available to identify individual health status problems. The Guam Health Plan, 1979-1980 edition, identifies the priority ordering of thirty critical Guam health status problems; hence corresponding files would be numbered "01" to "30".
- d) For the Health Status data bloc, individual Files are further organized internally by Folders and Topics. Folders identify the <u>subject area</u> of information being dealt with. The subject areas include: Natality, Life Expectancy, Mortality, Morbidity, Injury, Disability, Discomfort, Risk-Groups, and Health Behavior. Information products or raw data pertaining to one of these subject areas would thus be stored in and retrieved from the designated Folder bearing the appropriate title.

<sup>\*</sup> In actuality, the subject area lists for Special and Main Files differ; the Addendum list identifies the differences.

- e) Individual Folders (subject areas) are referenced by a letter code, which correspond to an alphabetical ordering of subject areas. Special File subject areas are distinguished from Main Files and their subject areas; the former are coded by a doubly repeated letter, while the latter are coded by a single letter. This coding is joined to the right of the data bloc File code number separated by a slash mark. Thus, a code of "12/C.." refers to health status problem number 12 as a File, perhaps labelled "Pneumonia", and to the subject area of Mortality as indicated by the letter C. mortality data of a general, crude or comparative nature to be assembled, it would likely be stored in the Special File and hence would have a coding of "00/CC..". Important to note here is that a complete set of Folders (subject areas) for a given health status problem (in a given Special File) is not likely or expected to be constructed. subject areas will simply not be relevant to a given health problem. (Suicide, for example, if identified as a numbered Problem File, is unlikely to require a "morbidity" subject area Folder!)
- f) Topics are further specifications (classifications) of the data or information content of a Folder.

  Topics are not another physical receptacle; and again they need not form a complete set in a given Folder. Topics as lables (with associated codes) simply permit a more detailed classification and indexing of data entries as well as information products. A complete list of Topics for the health status data bloc is presented in the Appendix.

- g) The coding of Topics is simply a two-digit number (see Addendum). A complete coding of the information product labelled "Pneumonia crude death rate" might thus be "12/C/01". The "12" would here indicate the priority attached to pneumonia as a health status problem; the "C" identifies the Mortality Folder; and the "01" identifies the folder Topic heading "crude and aggregate" which refers to the type of mortality statistic, i.e., crude death rate due to pneumonia.
- (4) For the <u>Health Services data bloc</u>, the most important organization of data and information is according to the range of <u>health services</u> which the agency is mandated to monitor, evaluate, regulate, and plan for. This range of service types is quite large, but as noted before, a useful three-level service classification scheme withaccompanying four-digit coding system has been devised to identify any and all such services.
  - a) The health services data bloc is thus arranged into a <u>Special File</u> and many <u>Main Files</u>. The Special File is reserved for data and information about the health care system as a whole. The Main Files are files of data and information compiled on individual health services on Guam that are to be documented by GHPDA.
  - b) It is highly reccommended that Main Files be created for service groups (i.e., the "hundreds"-level of coding). Roughly thirty (30) such files would thus be created, and individual services or programs could be documented by means of insertions of data and information within such Files. At the risk of repetition, the complete set of Service File headings and codings are displayed in the accompanying table (please refer to next page).

### COMMUNITY HEALTH PROMOTION & PROTECTION SERVICES

- 1100 Health Education Services
- 1200 Environmental Quality Management
- 1300 Food and Drug Protection
- 1400 Occupational Health and Safety
- 1500 Radiation Safety
- 1600 Biomedical and Consumer Product Safety

### PREVENTION AND DETECTION SERVICES

- 2100 Individual Health Protection Services
- 2200 Detection Services

### DIAGNOSTIC AND TREATMENT SERVICES

- 3100 Maternal and Infant Health
- 3200 Medical-Surgical Services
- 3300 Diagnostic Radiology Services
- 3400 Therapeutic Radiology Services
- 3500 Clinical Laboratory Services
- 3600 Emergency Medical Services
- 3700 Outpatient Services
- 3800 Dental Health Services
- 3900 Mental Health Services
- 3\*00 Substance Abuse Services
- 3+00 Special Medical Services

#### HABILITATION AND REHABILITATION SERVICES

- 4100 Medical Habilitation and Rehabilitation Services
- 4200 Therapy Services
- 4300 Mental Habilitation and Rehabilitation Services

#### MAINTENANCE SERVICES

5100 Long Term Care

#### PERSONAL HEALTH CARE SUPPORT

- 6100 Direct Patient Care Support Services
- 6200 Administrative Services

#### HEALTH SYSTEM ENABLING SERVICES

- 7100 Health Planning
- 7200 Resources Development
- 7300 Financing
- 7400 Regulation
- 7500 Research

#### TABLE 4. RECCOMMENDED LIST OF SERVICE FILE HEADINGS

- c) The coding scheme employed for health service data bloc Files employs the four-digit service classification code outlined earlier. The Special File is indexed by the code number "0000", while the Main Files are coded by the numbers associated with the service groups, as listed (on the previous page).
- d) For the health services data bloc, individual
  Files are futher organized internally by Folders
  and Topics. Folders identify the service group
  subject areas. These subject areas include:
  Programs & Objectives, Manpower Resources, Budget Resources,
  Facilities & Equipment Resources, Utilization, and Evaluation
  for Main Files; and the above headings plus
  headings for service "settings" for the Special File:
  Hospital, HMO, Public Health Clinics, and Private Clinics.
- e) Individual folders are referenced by a <u>letter code</u>
  (a double repeated letter code for the SpecialFile,
  a single letter code for the Main Files) according
  to the scheme given in the Addendum.
- f) Individual folders may be further organized by the

  <u>Topic headings</u>. These topics are not another physical
  receptacle and they need not form a complete set in
  a given folder. The topic headings are convenient
  labels, with associated number codes, which permit
  a more detailed indexing of data and information
  products about the subject areas of services. A
  complete list of Topic headings for the health service
  data bloc is found in the Addendum as part of the
  classification scheme for the Filing System.
- g) The coding of Topics is simply a two-digit number (see Appendix ). A complete coding of an information product labelled "Mental Health Clinic Admissions" would identify the service group "Mental Health

Services", coded 3900, the subject area as being Utilization, coded E, and the topic under this heading being clientele, coded 01; hence the abbreviated coding for this information product would be listed as "3900/E/01".

- 5) For the <u>Planning</u> and <u>Population Environment</u> data bloc, the kind of data and information being referenced does not directly deal with health. However, all such data and information collected is essential background and supporting material. For this data bloc, then, the organization is only in terms of <u>Files</u> and <u>Folders</u>; no Topics are provided.
  - a) For this data bloc, <u>Files</u> correspond to one of six "Environmental Subject Areas": *Physical*, Demographic, Social, Economic, Political, and Hazard.

    There are no Special Files required or designated.
  - b) The Files are <u>coded</u> by roman numerals, I through VI.
  - c) Each File, corresponding to an Environmental Subject Area, is further subdivided into special subject areas represented by individual Folders. For example, for File II (Demographic), the Folder headings are: population distribution, population trends and dynamics, and population projections. There are Folder headings unique to each File (see Addendum list).
  - d) For this data bloc only, Folders are coded by a single letter (no double letter being required). An example of a complete characterization of an information product labelled "Guam Population Projection: 1985-2000" would thus be to identify the file referenced as "Demographic", coded II, and the subject area as "population projection", coded 03. Thus the abbreviated coding for this information product would be "II/03".

6) It should be noted in conclusion that any information product, or set of data being physically stored in the Filing System has a quite detailed Index Code attached to it. For information products, this is the same as the Product Code. For incoming data entries to the System, the code can be considered a "Data Code". It is a three-part code in either case (with the exception of the third data bloc which omits coding Topics). In general the parts indexed are File/Subject Area/Topic.

When data on births are collected from the Vital Statistics Branch of DPHSS, then the data sheets can be individually coded for insertion in the appropriate location in the Filing System, according to the index code "00/AA/01" for example. The data is thereby to be inserted in the Folder for subject area "natality" (code AA) in the Special File "Overall Health Status" (code 00), with reference made to the fact that the topic it relates to is "birth". When the information product "Crude Birth Rate" is generated and then to be filed, it is given the Product Code "00/AA/01" as well and inserted alongside the raw data.

\* \* \* \* \* \*

It should be understood that this organizational and coding scheme for the Physical Filing System for health and health-related data and information in the H.I.S. has been designed with comprehensiveness in mind. However, it has also been designed in some respects as an ideal system which has not been fully tested in actual use. It is not expected, therefore, that the system, with its coding schemes, will be used in its entirety. (Topic headings and their codings, in particular, may be easily omitted if their level of detail is not appropriate at present.) It is also expected that, once in use, the Filing System may well be modified in organization or in terms of classification or coding. Certainly additional Files and Subject Area Folders can be added to the present system. But the present design allows a health information system to identify, code, store and esily retrieve a wide variety of data and information from a physical

repository or archive. Thus, it is to be reccommended as one of the first steps towards organization and development of a Guam H.I.S.

### 4. PHYSICAL FACILITIES FOR STORAGE AND RETRIEVAL

Whether or not computer-based data processing eventually incorporates all health data and information on Guam - something quite unlikely to actually to have implemented - there will always be a necessity for a <a href="https://process.org/physical">physical</a> repository for paper output at least. Under current conditions, whereby only a few databases are computer-based, there is of course much more justification for carefully designing the physical facilities for storage and retrieval of data and information.

As alraedy partially implemented by GHPDA at this writing, the reccommendation is for three office file cabinets to be used, one file
cabinet for each data bloc in the information system. Office files and
folders are also to be employed as the physical receptacles for data and
information. Note should be made of the fact that the Filing System's
File corresponds to a large, pocketed, expandable office file or folder,
within which the Filing System's Folders (each with its own set of data
and information) can be inserted. These Folders could be thinner, office
manila files, for example. The principle of inserting data/information
sheets into "Folders", several of which are inserted and bound in each of
several "Files", which in turn are stored in designated File Cabinets, is
what should guide the acquisition and use of particular storage media.

### 5. THE BASIS FOR COMPUTERIZED DATA PROCESSSING:

Brief mention has been previously made of the potential for computer-based data processing for a Guam H.I.S. In reviewing the proposed schedule of databases to be acquired and maintained, it was reccommended that three databases currently based on computer-coded records should receive priority. Vital Statistics, Public Health Nursing, and Epidemiology (Infectious Diseases) are these three databases.

At present, Guam has a limited yet quite adequate supply of computer facilities. These facilities include an old IBM unit maintained privately; a Burroughs computer operated by the Department of Public Safety, another

Burroughs computer operated privately for contract and corporate accounts, and some (minor) analytical or survey projects on an ad hoc basis; and a newer-model IBM computer with an extensive set of peripheral equipment and data-management and data-analytic software located in GovGuam's Data Processing division. The University of Guam has a mini-computer system for instructional purposes (a PDP model). After reviewing these computer "options", it has been concluded that the most suitable facility for computer-based H.I.S. development for the short term at least is GovGuam's central Data Processing division. While all government computer divisions tend to be heavily biased, in terms of time allocation, towards fulfillment of budgetary and payroll types of data processing demands, there is sufficient capacity and off-peak computational time available at present for utilization by a Guam H.I.S. In particualr, GovGuam's Bureau of Planning has a computer programmer available who is skilled in the use of data management and statistical software at the disposal of GovGuam's computer facility.

During the last quarter of 1979, and during 1980 as well, a formal agreement between GHPDA and the Bureau of Planning was implemented whereby the Bureau's programmer was placed in charge of compiling, keypunching, editing and maintaining computer files for Vital Statistics and Epidemiology data. The DPHSS Public Health Nursing Branch has independently contracted with GovGuam's Data Processing division to process data collected on public health nurse visits and services forms. As part of the formal agreement, the Bureau of Planning's programmer was to acquire a remote data processing terminal linked to the central IBM computer in order to facilitate data management and analysis activities; this acquisition has now been made. As a final portion of the agreement, the programmer is responsible for producing requested computer outputs, using available statistical software, as GHPDA and the H.I.S. data management staff periodically call for.

Both the programmer and remote terminal and the contract for computerbased data processing are highly desirable and represent a highly beneficial arrangement for a GHPDA-sponsored H.I.S. to maintain for the foreseeable future. Computer programmers are difficult to recruit on Guam with the statistical and computer skills necessary to analyze computer-based data of interest to the H.I.S. There is little possibility that GHPDA would be able or could afford to hire a programmer for the H.I.S. on a full-time basis. It will be quite sufficient for the H.I.S. data management staff to maintain contact with the Bureau of Planning's computer programmer concerning computer databases and desired computer outputs, as well as to formulate a work plan for computer-based data processing activities for each contract period, at least for the short term.

After some time has elapsed to enable the emerging H.I.S. staff to comfortably handle essential manual and current computer-based data sets, it will be possible to consider the potential for converting additional record systems, currently in manual or paper form, to computerized form. An initial acquisition, of course, are the data processed by the Guam Memorial Hospital Authority. A second priority are the HMO client data sets. It must be stressed once more, however, that computer-based data will never be able to fully substitute for or replace a manual, physical system for classifying, storing and retrieving health information. It should always be kept in mind that computer facilities are a useful, and increasingly valuable adjunct to information systems; but computers can never supply the organizational elements so necessary to the proper functioning of an H.I.S.

# PART III

ORGANIZATIONAL REQUIREMENTS & RECOMMENDATIONS

### SECTION F. THE COOPERATIVE ORGANIZATION OF H.I.S.

With a firm grounding in H.I.S. design principles now provided (through preceding discussions in Parts I and II), it is now appropriate to convey the management principles which should guide development and maintenance of the health information system. Several related issues are addressed in this section. First and foremost, it is argued that a cooperative approach to organizational development and health data donor participation is to be preferred over any mandatory or coercive approach. Second, the appropriate locus of control and operation is briefly discussed in terms of the inherent advantages--and some limitations--of GHPDA sponsorship. Thirdly, the issue of organizational direction and coordination is posed. A fourth topic for discussion is given much attention: namely the most desirable strategy to pursue in order to acquire all datasets required for generating priority information products. This topic is followed, in turn, by three others: the nature and kinds of communication required to sustain involvement; the protection of privacy and confidentiality of certain sets of data (especially agency internal files and client records); and suitable policy guidelines which an H.I.S. should have concerning access to data, processing of data, and use of information products.

## 1. The Cooperative Philosophy of Guam H.I.S.

It is possible for an information system that is created and maintained in the public domain under the sponsorship of some public agency to seek and obtain sufficient legal authority to force compliance from all agencies who maintain source datasets. In fact, a close reading of existing Guam Public Law 14-150 suggests that GHPDA presently has sufficient authority to mandate data transmissions to the health planning agency. It is strongly urged that this legal mandate never be employed or referred to in communications with potential data donor agencies or officials. Every attempt should be made to acquire desired data inputs on a voluntary and cooperative basis.

There are several reasons for recommending a <u>cooperative basis</u> for H.I.S. organization and development. Firstly, it is in keeping with the general public philosophy of information as the basis for rational decision-

making that a publicly promoted health information system be developed with maximal accessibility to any potential information user. Such accessibility to data processed by the H.I.S. serves to promote utilization of the system by other agencies, including data source agencies.

The perception that there are benefits to be had from participation in and contribution to the H.I.S. is likely to stimulate voluntary sharing of data under agreed conditions, more than any set of demands based on forced compliance.

A more direct basis for promoting a cooperative strategy is that while data acquisition under mandate can ensure that data desired is made <u>available</u> to the H.I.S., it can never ensure—and will more than likely jeopardize—data quality. Datasets that are "forcibly" acquired never will be transmitted with apppropriate documentation or with sufficient regard to completeness and accuracy. Furthermore, such "forced" data is easily undermined or distorted. The tactics of evasion, delay, feigned ignorance, and the like are well known to any agency or individual coerced by another. These tactics are well suited for use by agencies or officials not wishing to cooperate. And it is all to easy to have valued data distorted beyond usefulness as a result, without H.I.S. staff aware of such distortion. In coercive information systems, it is data quality and information value that suffer the most, not the coerced agency.

The desirable adjunct features of a cooperative organization of a health information system are, at a minimum:

- a wide agency participation
- data and information sharing with participants and the public
- negotiation and compromise as bases for data and information sharing agreements
- sustained information activities which produce tangible benefits and rewards for participating agencies
- mutually agreed upon protocol for protection of records, processing of data and release of information.

An H.I.S. should not be an exclusive, aloof organization but an "open shop" that encourages full participation of any and all agency--public or private--wishing to access health data or information. Wide participation

will help to ensure that the H.I.S. is perceived by everyone as not belonging to or controlled by a health establishment elite, and that it is recognized as being a useful public agency or entity in its own right. The H.I.S. should be organized as a resource which is not the exclusive property and avoids being exclusively controlled by a particular agency. The perception and the reality should be that an H.I.S. is a resource which is the result of the combined efforts of many agencies pooling their data for conjoined mutually beneficial processing. A policy of maximum acceptable accessibility goes hand in hand with a cooperative philosophy. All data acquired by the H.I.S. should in principle be accessible to any participating agency. In effect, the H.I.S. should assume that donor agencies are motivated by a "quid pro quo" philosophy of participation: data that are donated should be matched by data or information that can be accessed and retrieved from the system. Some data, of course, will be highly confidential and should be carefully protected as such (in order to avoid the withdrawal of agency participation). As far as possible, however, even confidential data can be compiled, aggregated or used in a manner which masks individual identification while providing suitable information. Such aggregated forms of confidential data should be shared where possible. In other words the most tangible benefit to participation that a donor agency can identify is the ability to tap other (donated) databases or generated information which would be too expensive to acquire by its own efforts.

#### 2. The Administrative Locus:

Though already briefly discussed in the prior section, it should be reinterated here that due consideration has been given to alternative administrative settings for a Guam H.I.S. For example, it is possible to envisage a Guam H.I.S. as (1) an independent public authority; (2) a special branch of DPHSS; (3) a special arm of the University of Guam; (4) of the Bureau of Planning, or (5) of the Guam Memorial Hospital Authority; or even as (6) a semi-public nonprofit information system corporation. However, the arguments for delegating Guam Health Planning and Development Agency the responsibility for administering a Guam H.I.S. are too compelling. By legal mandate, GHPDA is the one health agency specifically charged with data assembly and analysis. Federal directives to the Agency concerning required activities and staff

include datamanagement and analysis guidelines. And the Agency has a sufficient yearly budgetary allocation for such functions. No other agency at present has the time, budget, or staff resources to assume administrative responsibility of an H.I.S. for Guam.

GHPDA can also be recommended as an appropriate locus based on its relationship to other health agencies and organizations on Guam. Until quite recently, this agency, as well as its predecessor (Guam CHP), have played background roles which have coordinated and promoted health planning. While there is some indication that the Agency may be prepared to take a more active and directive role in health care delivery in the future, it has so far been able to avoid offending or isolating any other agency, public or private. A Guam H.I.S administratively located in GHPDA thus stands a good chance of establishing the objective, "non-partisan" image necessary to its functioning and of more easily encouraging cooperation and participation with such a non-threatening locus. Thus, it is recommended that the present arrangement, in which the newly emerging Guam H.I.S. has been sponsored and promoted by GHPDA, be continued and formalized, subject to the approval of participating agencies.

### 3. Coordination of the Guam H.I.S.

To ensure wide participation in a Guam H.I.S., the part played by the health planning agency should be purely supportive. This role can be enhanced if activities of the H.I.S. are monitored and to a large extent answerable to a Coordinating Committee. Such a Committee would consist of representatives from all agencies and organizations actively or formally participating in or cooperating with the H.I.S. The Committee would be chaired, most likely, by the senior data management staff person for the H.I.S., who would convene the Committee periodically (possible bi-monthly or quarterly). At the least Committee functions would include review of period activities; consideration of H.I.S. policy guidelines; review of data acquisition and processing functions; review and evaluation of data requests and information sharing; progress in and obstacles to further H.I.S. development; and status and maintenance of cooperative agreements for data and information sharing.

# 4. Cooperative Agreements for Data Sharing:

Organization of the Health Information System as a voluntary, cooperative, and participatory entity does not imply that procedures for data processing or management or relationships between data donors and users should be informal. On the contrary: in a multi-participant setting, there is all the more reason for ensuring that each participant is fully and formally aware of roles and responsibilities.

No relationship is more important to the H.I.S. than that between the H.I.S. administering agency (GHPDA) and the data donor agency. It is only through a careful, balanced, and mutually respectful formal arrangement between these two parties that desired data of appropriate quality can be acquired and processed. The principle vehicle designed for establishing and confirming this relationship is a <u>Cooperative Agreement for Data and Information Sharing</u>.

A Cooperative Agreement serves several purposes. On one level, it is a contract that establishes the kind of transactions that will routinely take place between H.I.S. and donor agency. It specifies (reiterates, in actuality) the general rationale and specific reasons for dataset acquisition and identifies the kinds of information to be produced. On the other hand, it stipulates clearly what the limits to interaction and transaction are and the nature of what is to be transacted. Hence the responsibilities of a donor agency as data provider are laid out in such an Agreement. The use to which the information products resulting from this data processing should be itemized (on an appended list). The donor agency will be formally safeguarded, as desired, and mutually agreed to against breaches of confidentiality of specified datasets. And the donor may be enjoined to provide assistance as necessary to interpret the data, to provide documentation of the databases, and ensure the highest level of data quality. (An example Cooperative Agreement is attached to this Report as an Appendix—Appendix III.)

The Cooperative Agreement should in no way be interpreted as a <a href="legal">legal</a>
instrument. Rather it is a memorandum which establishes the specific purposes, procedures and desired products and outcomes of a voluntary cooperative arrangement. It is to be regarded as a vehicle for establishing specific roles and for reminding parties of their respective responsibilities. The

Cooperative Agreement is best specified for a limited term of one to two years, the completion of which enables review of results and problems, and renegotiation of particulars as may be required. To the greatest extent possible, all interpretations of such Cooperative Agreements should be made with regard to equal partners in a balanced transaction rather than in terms of any superordinate-subordinate relationship.

## 5. The Nature of Communication Among Participants

The twin purposes of H.I.S. communication activities are to provide useful and practical information and to reduce administrative uncertainties. Both of these purposes are complementary to but distinct from the operating objective of providing comprehensive health planning information from collected data. In addition to the content of H.I.S. activities, the H.I.S. process must be communicated. Practical information about how the H.I.S. operates, what procedures and policies are followed, how agencies can access data and generated information are all important for participants and interested parties to be aware of. Such communication helps guide them to make intelligent decisions concerning health information system activities. In a multi-participant and multi-interest group environment, it is equally important that H.I.S. staff work to reduce as much uncertainty in the eyes of others concerning the nature of H.I.S. activities undertaken or outcomes that follow from such activities. Such communication by reducing the unknown, also reduces unfounded suspicions, and uncooperativeness. An additional function of communication efforts undertaken by an H.I.S. is to sustain interest and involvement in an activity which is inherently a long and sustained process. Information products and desired reports of any comprehensiveness are not produced overnight. The period from dataset collection, documenting, evaluation, compiling, processing, analyzing, interpreting and write-up and dissemination may stretch out over six to twelve months (and in some cases longer). Donor agencies and sources of information requests must be alerted to such scheduling and be made aware of the quality product that will be assured at the price of patience. However, such agencies must also be kept informed of developments: both progress and setbacks. On-going communication activities can thus involve: (a) alerting parties to problems and difficulties; (b) discussing methods of data processing and

analysis; (c) resolving issues and problems that are encountered in processing; (d) reporting interim and preliminary results and (e) commending data donors and other participants for valuable forms of aid and cooperation.

Three separate audiences should actually be kept in mind when designing communication strategies. The first audience are all participating agencies, public and private, who are involved in primary H.I.S. activities; in particular: are donating desired datasets. This audience naturally should receive priority attention. The second audience is the wider public which may feel that their privacy is threatened, or may be entirely ignorant of the activities and merit of an H.I.S. This audience should be routinely communicated with via popular media to explain, in non-technical language, the utility of such an operation. The third audience is the government and its political power centers, the Executive and Legislative branches. The most sensitive kinds of communication must take place between the director of H.I.S. activities or the sponsor of the H.I.S. and members of the legislature as well as the Governor and his aides. This communication need not be time-consuming at all. It may amount to being highly responsive to individual requests of an 'ad hoc' or 'quick response' nature. It may involve preparing an annual report which will summarize activities, accomplishments and resources expended for benefits generated. Its principal aim, in any event, is to communicate to decision makers in control of money and influence the value of an H.I.S. for Guam and the governmental support it should merit.

What modes of communication might be employed by the H.I.S. to reach these three audiences? It is enough to identify briefly a range of possibilities. First, it would seem obvious that H.I.S. staff will have a central vehicle for information dissemination when it establishes an H.I.S. Coordinating Committee. This Committee, in addition, will likely be able to furnish additional suggestions regarding desirable forms and audiences for communication. In addition, one-on-one meetings of H.I.S. staff (i.e. Data Manager) with administrators or representatives of data donor agencies, both formally and informally, are an excellent mode to communicate progress, problems, additional requests, and the like. Special workshops and seminars might also be periodically convened with respect to health information themes. Occasional reports or general purpose memoranda might also be

circulated; annual reports (as noted before) might be an excellent means of informing and reminding the public and decision makers of the role of a Guam H.I.S. A last suggestion is that H.I.S. actually produce its own quarterly or semi-annual Health Information Newsletter. Such a newsletter's purpose would simply be to publish notes on available databases and findings or results of particular analyses or data processing activities undertaken.

# 6. Protocol for Confidentiality and Privacy Assurance

One of the central concerns that any data donor will have, upon being approached by the H.I.S. is--apart from what relative costs and benefits are to be derived by participating--is the attitude and ability of the H.I.S. organization and its staff to assure and maintain the confidentiality and privacy of any and all individual records delivered to them. This consideration is perhaps the most sensitive issue that the H.I.S. will face; it will certainly be an issue raised and scrutinized by the public (i.e. certain private citizens) and government decision makers.

Existing Guam Territorial laws give limited authority to certain public agencies to collect and process data for statistical purposes. However, such laws also stipulate that individual privacy must be safeguarded and the confidentiality of data provided by individuals to clinicians, administrators or other officials must never be violated. The spirit of this stipulation has usually been held to mean that such data, while being made available for statistical manipulations, must never be communicated in raw form to any individual. It has further been agreed that certain manipulations which tend to identify single persons geographically and by certain combinations of personal attributes, while still deleting direct personal references (such as name, address, social security number) are also to be considered breaches of confidentiality and are unwarranted.

Standing to some extent at cross purposes to this general public philosophy on privacy is one dealing with citizen accessibility to public documents. As recently as a few years ago there was some doubt as to how any public document, including a private individual's record of personal contact with a public official could be kept from release to those demanding access. At present, it is fairly clear that citizen access to public

records does <u>not</u> include the right to access another individual's private record thus violating his or her privacy and the confidentiality of the transaction. (However, such access <u>does</u> include the right for an individual to see any and all personal data and records maintained by one or more public agencies.)

The issue of suitable policies for an H.I.S. to devise regarding confidentiality go beyond the individual client and his or her service record. Data donor agencies, especially private or semi-private ones which may be in competition with each other, have every right to be concerned about the protection afforded them and the administrative as well as client data they may forward to the H.I.S. for processing. On Guam, the concrete example of this is the data which is desired by the H.I.S. from the three Health Maintenance Organizations (FHP, HML, GMHP). Another case is presented by the totally private Seventh-day Adventist Clinic.

It is in the long-run interest of the Guam H.I.S. to formulate a clear-cut, precise, and binding policy and assurance protocol that will obligate the organization, its staff and its sponsoring agency (i.e. GHPDA) to guarantee the privacy of all individual records and to maintain the confidentiality of all personal and institutional data (or information) as mutually decided between the H.I.S. and the data donor agency. An outline of such a protocol is presented in an Appendix (see Appendix IV) to this Report.

 Policy Guidelines Regarding Access to and Use of H.I.S. Data and Information

It is essential that a full <u>charter</u> for the Guam H.I.S. be established in writing, in order that all interested agencies, officials and other persons may determine for themselves what structure, mission and activities the organization has identified for itself. This charter, in one sense, amounts to a formulation of policies that will govern the internal and external activities of the organization and its staff members. While a variety of such policies must be specified, it is best left for consideration by the sponsoring agency (GHPDA) and any advisory board (such as the Coordinating Committee) that is established to support the H.I.S. However, two

sets of guidelines are worth commenting on here since they have a direct bearing on the data processing philosophy and activities of the organization in a cooperative setting which is being advocated here. The first policy is concerned with access to data by prospective H.I.S. users (including data donors). The second policy is concerned with uses to be made of H.I.S. data and information products by the recommended sponsoring agency, namely GHPDA.

As noted in the previous section, it is presently accepted that the public's "right to know" as expressed in "access to public data" clauses does not extend to personal records (other than records on the person who makes the request).

In fact, the principle of open access to public data does not suffer from this appropriate restriction. However, such access should not therefore be treated uncritically. It should be made clear to both H.I.S. staff and the data requestor that H.I.S. policy on data access involves certain reasonable conditions. These conditions are as follows:

- that all requests for raw data or information products be made in writing and identify specific data items or products desired, and identify requestor by name and affiliation;
- (2) that all data requests will be handled on a first come, first served basis except for stipulated sources of requests (e.g. Legislature, Executive) and that requests will be responded to as quickly as possible without interfering with primary activities of the organization;
- (3) that all requests will be granted and responded to except those seeking individual person or individual private institution or agency (other than own data);
- (4) that release of data is subject to review and approval by the agency or agencies where data originated, unless such power is delegated to the H.I.S.--such approval power to be exercised only with regard to confidentiality stipulations;
- (5) that release of data or information to requestor is subject to prior examination and approval by H.I.S. with respect to inadvertent identification of individual persons or agencies; and

(6) that release of data or information products is done so without guarantee for their validity, reliability or accuracy or any implied H.I.S. (or donor agency) responsibility for or agreement with any interpretation made of the data or products by the requestor.

While the above stipulations to be found in any reasonable access policy of the Guam H.I.S. are intended as forewarning to data users outside the organization, a comparable set of stipulations should be in effect to govern how health and health related data collected and processed for planning purposes by GHPDA areto be used. While the former policy protects GHPDA (as sponsoring agency) and the H.I.S., this latter policy protects data donors in large measure. The minimum stipulations for "GHPDA Use of Donated Data" are as follows:

- that all data to be used by GHPDA will be identified by source agency;
- (2) that source agencies will be informed of information products (including formats) to be generated from agency data;
- (3) that source or donor agencies will be made aware of all intended uses of donated data prior to data acquisition of H.I.S., all such uses to be specified in the Cooperative Agreement signed by the agency and H.I.S. or sponsoring agency (GHPDA);
- (4) that, by agreement, source agencies will have review and concurrent privileges for all information products to be produced for GHPDA uses:
- (5) that use of donated data in planning documents will not be subject to donor agency appeal;
- (6) that use of donated data in GHPDA regulatory functions will be subject to prior notification of and comment by source agency as well as to source agency appeal.

SECTION G. PERSONNEL REQUIREMENTS AND STAFF INVOLVEMENT"

While consultant activities have enabled the initial structure and operations of the organization to be specified in some detail, such activities cannot replace the efforts of a full-time staff assigned to manage the H.I.S. and to carry out all data-oriented and health-information related functions. Central consideration must be given to the appropriate meshing of staff, tasks, and skills, if the Guam H.I.S. is to function at all according to requirements laid out by GHPDA and elaborated in this Report.

In this section, staff considerations are presented under three headings. First, the data management activities and associated tasks are discussed and related to essential staff functions. Second, two realistic personnel positions and the qualifications are identified as being required for the continuing operation of a Guam H.I.S. Third, the recruitment and use of supplementary personnel are briefly considered.

# 1. Staff Positions and Functions

To begin with, a distinction will be drawn between person positions (the number of individuals actually recruited and hired) and person functions (the kinds of activities and skills that are directed towards a basic purpose of H.I.S. operation). Each person-function can be broken down into the various tasks required to be carried out in order to fulfill the coresponding operational purpose. Separation of functions and positions, as will be seen, enables a person-position to be defined based on single or multiple functions which are specified.

The basic recomendation is that, at a minimum, two staff positions be allocated to a Guam Health Information System. These two positions will comprise three person-functions, namely: (i) data base maintenance, (ii) data and information processing, and (iii) information system management.

<sup>\*</sup>This section is a revision and expansion of Memorandum No. 3 to the Administrator of GHPDA from the H.I.S. Development Contract Planning Consultant, dated July 1979.

It is thus possible, depending upon qualifications, for an individual to be hired to data base maintenance and data/information processing functions, leaving the other position to fulfill the information system management function. Alternatively, the latter two functions could be combined in a more technically qualified position. Or, the second person-function, data and information processing might be shared between two staff positions.

In addition to these two full-time staff positions, it is recommended that the Guam H.I.S. maintain regular consultations with public health and hospital data clerks and statisticians, and that a computer programmer and computer analyst be retained in official or unofficial capacity as a necessary staff resource for the conduct of all computer-based data processing activities. It is important that staff allocated full-time to the H.I.S. have H.I.S. functions designated as their primary responsibility. There may well be periods when data-processing/information generation activities will demand less than full-time attention, and consequently may well enable H.I.S. staff to be recruited for other planning or related efforts by GHPDA. However, a properly running Guam H.I.S. cannot function on a part-time or ad hoc basis, lest its carefully scheduled flow of data inputs or information product and report outputs be irreparably interrupted.

### 2. Tasks Related to Essential Staff Functions

The three specified staff functions (database maintenance, data and information processing and information system management) collectively require a minimum of twenty separate tasks to be undertaken. Below, these tasks are listed according to pertinent function. Subsequently, each task is briefly described.

### Function 1. Data Base Maintenance

- Task 1. Data element and reports identification and updating
  - 2. Data element and report acquisition
  - 3. Data source documentation
  - 4. Data element extraction, editing, and formatting

- Data storage and retrieval
- 6. Data compilation and tabulation

# Function 2. Data Information Processing

- Task 7. Information products specification and updating
  - 8. Information products preparation
  - Data manipulation, transformation and classification
  - Statistical, graphical and tabulation procedure utilization
  - 11. Information product and report generation
  - Information product and report compilation, analysis, and interpretation
  - 13. Information product and report documentation
  - 14. Information product and report transmittal

# Function 3. Information System Management

- Task 15. Data donor agency contracts and consultation
  - 16. Cooperative agreements creation and maintenance
  - 17. Staff training and supervision
  - 18. H.I.S. Advisory Group participation and supervision
  - 19. H.I.S. reporting, documenting and inter-agency relations
  - 20. H.I.S. planning, budgeting, scheduling and implementing

Task 1. Data element and reports identification and updating: As a part of the data base maintenance function, it is necessary for an H.I.S. staff

person to gain complete knowledge and understanding of all data elements and their source documents
and reports which the Guam H.I.S. will call upon
for information generation. From time to time,
an inventory and description of all such data
elements and related reports and source documents
will have to be revised and updated.

- Task 2. Data element and report acquisition: This task involves acquiring all required data elements from source (donor) agencies via raw records, documents or reports. Such acquisition should proceed according to a timetable which is mutually agreeable to both donor agency and H.I.S. staff, such timetable indicating how periodically and under what conditions the data will be acquired.
- Task 3. Data source documentation: As a necessary adjunct to data element acquisition, source records, forms, reports and the like must be examined and charac-Hence , a thorough familiarterized in detail. ity with the strengths and limitations of the data donor agency's methods of data collection and storage must be achieved by H.I.S. staff in order to properly interpret (and limit the interpretations made of) any manipulations of the data. Such documentation should, in general, assess the conceptual basis as well as the measurement technique employed to record data for a particular item (i.e. variable); it should also seek to determine the validity and reliability of such measurements as are made use of by the H.I.S.
- Task 4. Data element extraction, editing and formatting:

  It will often be the case that desired data will
  be imbedded in a larger set which is not required
  by the H.I.S. and thus staff must spend some time
  extracting the desired data. At the same time,

the data sets that are acquired may have inappropriate values present or missing values for selected observations which necessitate their deletion. Often times, a correct specification of the format of particular variables or measures is missing and must be determined by H.I.S. staff. "Formatting" refers not only to correctly identifying the value range and significant digits associated with each data element, but also to the recording of acquired data in suitable raw form for in-house H.I.S. storage and use. It is important that all such internal formatting of acquired data be described in writing, possibly in a data log book, since much data will be stored for lengthy periods of time.

- Task 5. Data storage and retrieval: A straightforward task, this involves an H.I.S. staff person in storing data elements or their source forms in appropriate files in the H.I.S. and retrieving data as needed for specific processing or as requested by specific agencies.
- Task 6. Data compilation and tabulation: It will often be necessary to gather together a range of data elements and their measurements for special purpose uses, requests or comparisons and analyses. It is thus necessary for a staff person to assemble required data and to produce special tabular displays of such measurements. This task completes the activities associated with the data base maintenance function.
- Task 7. Information products specification and updating:
  As part of the data and information processing
  function, an H.I.S. staff person must gain complete knowledge and understanding of the full
  range of information products identified and

described for production or use by the H.I.S. From time to time, an inventory of all such products, their attributes, data sources, purpose and uses, and generation procedure will have to be reviewed, revised and updated.

- Task 8. Information products preparation: When an agreedupon schedule calls for a certain set of information products to be generated, data processing
  activity will entail the preparation of materials,
  procedures, time and other resources needed to
  generate the desired products in a timely and
  efficient manner. Such preparation, for example,
  may entail arranging for computer facilities, or
  a block of time to allow for product generation.
- Task 9. Data manipulation, transformation and classification: In order for desired information products to be produced, it will often be necessary for data to be manipulated by one or more mathematical procedures. Data may have to be re-scaled or value ranges may have to be adjusted. (In technical terms, continuous or ratio data may require transformation into interval form.) This task can be looked at as an adjunct activity to that described as product preparation in the previous task.
- Task 10. Statistical, graphic and tabulation procedure
  utilization: Different information products call
  for different data processing activities. Some
  products may simply be the calculation of rates
  or ratios; others will be plots on graphs against
  time or other variables; others will require
  standardization by age, sex or other criteria.
  In some cases, raw data will be converted, aggregated to different observation units, and subsequently presented in new or special tabular forms.

Aggregation of data to new observation units (years, towns, age intervals, etc.) is an important basis for permitting comparisons among different types of data.

- Task 11. Information product and report generation:

  According to a specified schedule which both the Guam H.I.S. and other agencies can refer to, specific (sets of) information products will be generated and made available for analysis and interpretation. Oftentimes a set of products will be assembled, labelled and described as part of a specific report to be published by the Guam Health Planning and Development Agency or by some other agency.
- Task 12. Information product and report compilation,
  analysis and interpretation: Once specific (sets
  of) products are generated they may not only be
  compiled in a particular arrangement but they may
  have to be individually analyzed and interpreted
  by H.I.S. staff. In fact, it will be necessary
  for H.I.S. staff to be aware of all limitations
  and caveats that any product generated by their
  efforts carries with it, and they must be prepared
  to convey these limitations to any agency which
  seeks to use such products.
- Task 13. Information product and report documentation: It will be very important for H.I.S. staff, as part of the processing function, to document all information product (report) generation activities in as much detail as possible. Such documentation should enable other agencies as well as GHPDA to understand how and when data is processed in any particular instance and for any particular purpose. It should serve as a log-book of processing activities and thus permit H.I.S. staff to account

for time spent manipulating data. As such it will be a valuable aid in learning the appropriate resources and activities and step-by-step procedures involved in generating any particular (set of) information products. Such documentation should also stress the limitations and the relative quality (i.e., validity and reliability) of the information products which are generated, inserted in reports, or made available to other agencies.

- Task 14. Information product and report transmittal: As part of the H.I.S. rationale, some products and reports that are generated and assembled are created expressly for transmittal to agencies other than GHPDA. It will be necessary for an H.I.S. staff person to allocate sufficient time to properly convey and discuss with requesting agencies the results of data processing undertaken by the H.I.S. This task completes the set of activities involved in the data and information processing function.
- Task 15. Data donor agency contacts and consultation: As one of the primary management function activities, it will be necessary for an H.I.S. staff person to maintain a regular schedule of contacts, conversations and discussions—including negotiations—with various health and health related agencies on Guam which are linked formally or informally with the Guam H.I.S. Consultations with such data donor agencies will require considerable time and patience and will of necessity involve repeated contacts, reviews of activities, assessments and clarification of activities, procedures and data as well as information products or reports within which they are assembled.

- Task 16. Cooperative agreements creation and maintenance:

  Of course one of the essential tasks of an H.I.S. staff is to secure the necessary formal operating agreements with data donor agencies which specify how and under what conditions data are made available to the H.I.S. and information products in turn are made available to one or more agencies.

  Re-negotiation and updating of such agreements may take as much time and effort as negotiation of initial agreements. Thus this can be considered an on-going activity.
- Task 17. Staff training and supervision; An important task of an H.I.S. managerial person is the training of the other staff person, upgrading of his or her own skills and the supervision of staff in the performance of their activities. In addition, this person may from time to time be called upon by GHPDA or other agency staff to train or assist their own staff in data related activities.
- Task 18. H.I.S. Advisory Group participation and supervision: As recommended in this Report, the Guam H.I.S. should incorporate a broadly representative Advisory Group comprised of data/information staff from pertinent health and health-related agencies on Guam. It will be the non-trivial task of a managerial person to coordinate the meetings of this Group to review and advise on the activities of the H.I.S. This person must be prepared to take a direct if not leading role in the conduct of Advisory Group meetings. He or she must also spend valuable time consulting and communicating with individual members of this Group on important matters.
- Task 19. H.I.S. reporting, documenting and inter-agency relations: Another important managerial task is

for reports and documents to be generated and disseminated concerning the general activities as well as calendar year or other period-related accomplishments of the H.I.S. Other agencies, including executive and legislative offices and officers will more than likely have to be consulted from time to time to explain, justify, or clarify H.I.S. activities.

Task 20. H.I.S. planning, budgeting, scheduling, and implementing: A final task related to the H.I.S. managerial function is the preparation and coordination of future activities of the H.I.S. organi-This involves planning period-specific zation. activities and any special efforts negotiated with particular agencies; preparing an annual budget to cover staff, data processing, and report generation; scheduling activities and tasks to mesh with GHPDA and other agency operations; and of course, implementing all plans and prospective arrangements -- as well as evaluating the results of all H.I.S. activities, in order to find ways to improve H.I.S. performance in the future.

### 3. Recommended Personnel Positions and Qualifications

Corresponding to the three H.I.S. functions identified, three personnel titles can be identified, along with their requisite qualifications. It should be remembered, however, that only two staff positions are recommended for the Guam H.I.S. with which to begin operations, although expansion of activities over time may require an additional person at some later date. Thus, at least initially, the three titles are to be viewed as allocated to two FTE staff positions. These three titles are: Data Clerk, Statistician (or Research Analyst) and Data Manager (or Information Specialist). Recruitment flexibility is thus enhanced by permitting alternate combinations of these three titles to describe the two staff positions, e.g.

Data Clerk/Statistician and Data Manager; Data Clerk and Statistician/ Manager; or Statistician duties divided between Data Clerk and Data Manager.

Realistic job qualifications for these three "functional positions" are as follows:

- 1. Data Clerk: Knowledge of and facility with descriptive statistics acquired through one-semester course in college Statistics (preferably Biostatistics); working knowledge of and experience with health data, databases, and data file systems and filing procedures; and acquaintance with methods and procedures of health planning analysis.
  Preferred additional qualifications include: working knowledge of computer-based files, computer software, and batch-processing of statistical problems; inferential statistics; and work experience with multiple databases (especially Vita series and health related data sets).
- 2. Statistician (Research Analyst): The minimum competence required are abilities assumed by a statistician, and involve: descriptive and inferential statistical analysis and statistics computation for report generation; statistical report writing (documentation, analysis, and interpretation); ability to generate health information products in alternative formats (tables, charts, graphs, figures, maps, and diagrams) for purposes of enhancing data communication and interpretation; ability to design, construct, analyze, and interpret cross tabular arrays of data; ability to generate demographic and service user profiles and to statistically estimate specific target, risk, and client populations from available data sources; ability to analyze basic demographic trends and processes (fertility, mortality, morbidity, migration) along with their determinants, and to produce appropriate rates, ratios, and indices; knowledge, experience and facility with health planning methods and analytical procedures (including: needs assessment; health status problem identification; goal and objective specification and prioritization; health care delivery system inventory, assessment, and evaluation; and health problem and health system analysis and interpretation).

Preferred additional work experience and qualifications are research abilities, which include experience with the conduct of empirical investigations in the health or behavioral science fields, survey design and research methods (including sampling); higher-level knowledge of multivariate statistical methods with applications to research issues in health status determinants, health care utilization, and health care program evaluation, including cost-effectiveness methodologies; and working knowledge of and practice with computer applications of health statistics generation problems including computer programming.

Minimum formal training required for this activity includes at least two college graduate courses in Statistics (descriptive and inferential), preferably Biostatistics or other statistics courses with applications to health data; and one college graduate course in Epidemiology with attention to research design and applications.

3. Data Manager (Information Specialist): Minimum qualifications for a staff person undertaking this activity include experience with and sustained ability to initiate, conduct and follow-up consultations with all agencies and parties which are participating or actively interested in the development and conduct of Guam H.I.S.; ability to draft, negotiate, implement, and update cooperative agreements with participating agencies; experience with health information statistics and other products generation, compilation, analysis and interpretation; experience with statistical report writing; experience and competence in health planning methods and analytical procedure (including needs assessment, health status problem identification, goal and objective specification and prioritization, and health care delivery system inventory, assessment and evaluation); management and supervisory experience with subordinate personnel; ability to plan, schedule, implement, coordinate, and update multiple data collection, processing and information compilation and reporting tasks and activities of the H.I.S. (including scheduling the activities of data collection, editing and storage, data analysis, and information product generation and

interpretation on a timely basis to meet health planning document production and project review deadlines); and ability to coordinate with GHPDA personnel regarding information needs, scheduling and reporting, as well as assignment of priorities for development and maintenance of the H.I.S.

Preferred <u>additional</u> work experience and qualifications are abilities in management information systems development, health or hospital information systems management, and working knowledge and operation of computer-based record and file systems.

Minimum formal training required for this activity includes at least one year work experience with multiple database management organization (preferably health-related), one semester course in graduate level statistics, two semesters of course-work in management, and two semesters of course-work in public administration and planning (preferably health care administration and/or planning).

Again it should be kept in mind that the basic recommendation is for two staff persons to be initially hired and allocated to H.I.S. activities and tasks on a full-time (FTE) basis. Current GHPDA staff position titles include only three levels: Health Planning and Development Specialist I, II, and III. Given only these titles, and their accompanying position work descriptions and skill requirements, the two staff positions recommended for the Guam H.I.S. correspond to the two higher-level Specialists. However, in terms of specific qualifications, competencies and training, the specifications listed above for the three "functional positions" should be adhered to in considering candidates for H.I.S. staffing.

# 4. Supplementary Personnel

This final section briefly draws attention to the kinds of personnel that may, from time to time, need to be called upon to aid H.I.S. staff in the pursuit of their tasks and assignments. In particular, it must be realized that not all appropriate H.I.S. skills can be initially acquired. These skills do exist, nonetheless, in the local community and appropriate individuals can be consulted to assist in specific tasks.

Below three separate kinds of supplementary personnel are identified and characterized in brief: namely, (1) computer programmer, (2) survey interviewers and (3) various statistical and planning consultants.

- (1) Computer Programmer: It is envisaged that for the immediate future. separate computer facilities and programming staff will not be acquired by an H.I.S. organization or its parent agency (GHPDA). However, since the H.I.S. draws upon a large and vital amount of computer-based data, the organization will necessarily require the assistance of a computer programmer. This assistance includes acquiring copies of all health-related computer-based data of use to the Guam H.I.S.; processing the data using computer facilities and software to generate desired outputs; and documenting all computer-related H.I.S. activities. The assistance should be secured and maintained by contract with a single computer programmer with thorough knowledge of Guam computer facilities, statistical and data management software, and computational procedures. the present time, a cooperative agreement/contract is in effect with the Bureau of Planning to secure the part-time services of the Bureau's computer programmer. This arrangement has proven satisfactory for the past two years and should be maintained.
- (2) Survey Interviewers: Occasionally the H.I.S. staff may require consultation with individuals skilled in survey design and analysis. Such consultation may help to establish the limitations of particular (survey-based) data sets and the interpretations which can be made of them. The H.I.S. may also be called upon to assist in survey work itself or to help combine survey data with other sources. It may also undertake its own survey effort or append a questionnaire to an existing survey effort (such as the quarterly Bureau of Labor Statistics labor force survey). In all such cases, the advice of trained survey workers and interviewers will be helpful to H.I.S. staff. Such personnel can be found in the Bureau of Labor Statistics, the Department of Commerce, and at the University of Guam.
- (3) Additional Consultants: Briefly mentioned here are several kinds of resource persons who may provide valuable insights into certain aspects of data or their collection, analysis or interpretation.

Such persons include Epidemiologists and Vital Statistics
Specialists; Economists and Financial or Budget Analysts;
Statisticians; and Health Planner. Guam is fortunate in having
locally employed individuals skilled in these areas, either in
government agencies or in the University of Guam. It is also
possible for H.I.S. staff, through the auspices of GHPDA, to seek
assistance from the Western Consortium or Western Center for Health
Planning based in San Francisco, or from consultant groups with
requisite knowledge of the Pacific island and its developmental
and health care context.

SECTION H. GUAM H.I.S. MANAGEMENT: A SUMMARY VIEW

## 1. The Central Role of the Data Manager

This Report now draws to a close by considering the nature and priority of various activities which are central to the operation of the Guam H.I.S. and which are the responsibility of the H.I.S. Data Manager to undertake. While the previous section has identified the necessary staffing requirements and the series of specific tasks to be associated with the H.I.S., discussion here focuses on identifying how such tasks can meet the data processing requirements as detailed in the first half of this Report. Thus, it is important to identify the key role played by the Data Manager in perpetuating the H.I.S. as a productive and effective organizational component of a health planning function in the Territory. To this end, attention is drawn to four responsibilities of which the Data Manager should be constantly aware in undertaking any assigned task and generally in seeking to make the Guam H.I.S. a viable entity.

It cannot be stressed too much that the operation of the Guam H.I.S., at least in its infancy, will be closely associated with the activities and performance of the Data Manager. This person alone will be engaged in contanst interaction with the data staff of numerous agencies in the Territory, and through such contacts will forge the collective impression of the value and utility of the health information system enterprise. It is important that the Manager be visible, communicative, and cooperative in all interactions with these agencies. It is also important that the Manager not assume that any other individual or agency is in a position to render assistance or support on a continuing basis; in other words, the Manager must be willing to assume a great deal of independence and individual initiative for the initial development of the system. To this end, it is advised that the Data Manager be aware at all times of the nature of his or her responsibilities in a broad philosophical sense. These responsibilities are discussed below.

# 2. Key Responsibilities in Management

The previous Section of thisReport has identified six tasks which should be undertaken by a Data Manager role in order to fulfill the H.I.S. function of "information system management". Those six tasks include:

(1) data donor agency contacts and consultations, (2) cooperative agreements creation and maintenance, (3) staff training and supervision, (4) H.I.S. advisory group participation, (5) H.I.S. reporting, documenting and inter-agency relations, and (6) H.I.S. planning, budgeting, scheduling, and implementing.

In examining the basis for assigning these six tasks to the Data Manager, and in providing a rationale for the Data Manager to administer the H.I.S. as an organizational entity, what stand out are four basic responsibilities which go with this staff position. These responsibilities are the essence of management, insofar as a health information system are concerned. They may well in fact appear so obviously a part of a manager's role as to require no special mention. However, at the risk of overstatement, it is worth identifying each of these responsibilities, if only to emphasize the strategic means by which a Guam H.I.S. can be - in fact must be - promoted in the governmental and administrative milieu on Guam. The key responsibilities which stand out include: (a) assessment, (b) planning and scheduling, (c) coordination, and (d) communication. Each responsibility is briefly clarified below.

# a) Assessment:

TheH.I.S. clearly is not at the present time a vital or central organizational component of health care delivery or health care planning; otherwise, this organizational function would long since have been established. The health care sector on Guam is in a state of transition at present. It can be characterized broadly as a multi-functional, public-private system which has a less than ideal amount of organization and coordination. Apart from straightforward questions concerning why the present leadership or responsible administrators have not been able to

select or impose a developmental path, the question of why individual branches or components of the system have not been able to plan or organize their services better must be raised. And while partial answers may lie in identifying weak administrative skills or organizational conflicts or inadequate policies and regulations, it is quite clear that no agency or branch has been able to formulate a clear-cut, comprehensive assessment of problems, resources, opportunities and desired strategies. What is apparent that the agencies and branches are much too involved in daily operations and routine service or administrative tasks and do not have sufficient staff expertise to devote appropriate time and resources to this assessment function. This situation holds equally for all Public ealth branches as well as for the Guam Memorial Hospital and its various services. In addition, no other governmental agency is in a position to identify and document th problems and options related to the entire system of health crae delivery for Guam.

By foresight or by default, the Guam Health Planning and Development Agency is in a unique position to sponsor a health information system which can provide the entire Territory with not only a comprehensive, organized collection of health and health-related data, but also the capability to analyze, evaluate and document problems and alternatives. The assessment function is therefore critical to the proper reception of the Guam H.I.S. as a new activity. And this assessment function must be the responsibility of the manager of the H.I.S. who alone will respond to requests for particular studies or evaluations, or will initiate such studies as a positive and constructive step towards assisting Guam's health agencies to plan and coordinate their services better.

## b) Planning and Scheduling:

Assuming that the H.I.S. will become actively involved in collecting health and health-related data for Guam and will apply this data to selected analyses and evaluations (assessments) of various health problems and health care activities in the Territory, it is essential that the H.I.S. manager carry out all data processing activities in an orderly manner. The usefulness of data is obviously time-dependent, and the value of health care information for planning and evaluation purposes is clearly

limited to the rather narrow time-frame within which the need for such information is identified and its application is determined to have a bearing on decisions or actions to be taken. Given the broad variety of actors and agencies participating in health care delivery on Guam, including the health planning agency itself, it is essential that all activities of the H.I.S. be thoroughly planned, sequenced, and scheduled for periods as long as a year in advance. It is just as clear that the Data Manager is the only staff person who can assume responsibility for this planning/scheduling function. Such a staff person must also bear in mind the conditional nature of all such planning and scheduling and be prepared and willing to reorder priorities and re-schedule various activities and tasks in order to meet new demands. The plan and the schedule that are assembled by the Data Manager must be specific and be available as a concrete document at all times for review by all interested agencies. There should be no hidden agenda and no activities or tasks confined to memory or simply assumed to be the purview of a particular individual. The H.I.S., if it is to gain credibility as an organization, must be able to document its own activities as well as or better than its ability to document any other part of the health care system.

### c) Coordination:

Public agencies in any government are not generally known for their ability to coordinate activities with each other. But an information system for health planning and analysis must seek to coordinate its activities with other agencies within both public and private sectors for its very survival. The GUam H.I.S. is not a management information system. Such systems are usually confined to one organizational domain and serve the single administration of that domain. The Guam H.I.S. will answer to and seek data from a multiplicity of agencies and organizations; it will in fact serev the entire health care system on Guam. In such a capacity, the H.I.S. manager must spend a considerable amount of time consulting with various agency heads - as well as agency data staff - understanding the often changing agency activities, determining what data is desirable and feasible to acquire and what information can be efficiently generated for joint use, and, overall, assessing how agency administrators and officials can best be served and motivated to contribute to the mission of the health information system.

Coordination is more than simply a matter of joint identification of needs and resources and scheduling of activities. It is also, and more importantly, an approach to management which necessitates a frequency and openness of communications; solicitation of opinions and recommendations; willingness to revise plans, to accept different points of view and even less-than-optimal recommendations on actions to be taken, to assume the role of initiator, prodder and promoter of all joint activities. This responsibility for coordination inherent in the nature of the management function of the Guam H.I.S. in fact demands a special kind of person to fill the role of Data Manager, and may well have to be accorded the status of a separate job qualification in order to ensure the proper staffing of the information system activity.

#### d) Communication:

Much of what has been said about the manager's responsibility to coordinate diverse activities and actors applies equally well to consideration of the need for strong communication skills in order to support the H.I.S. All formal communications to and from the H.I.S. must be channelled through the Data Manager, yet this stipulation cannot preclude the manager from employing more diverse and informal means to convey the messages from the H.I.S. Again, the managerial responsibility for effective communication at the same time points up a critical skill which the manager must have initially or must acquire rather quickly. There must be absolutely no reticence in speaking with or writing or responding to actors and agencies ranging from individual line staff in Public Health and individual physicians in private or independent clinics to directors of public agencies or legislators or the Governor, or key figures or Region IX officials in the federal government. Appropriate and often overlapping use of informal and formal communications, reminders and memoranda, letters and reports, telephone conversations, lunchtime meetings, official appointments and conferences must all e thought of as available means of conveying various messages. These messages may include specific data requests, requests for monetary or other assistance, notifications of meetings, decisions, options, and findings, and reports or delivery of information by request or voluntarily provided as a means of indicating what is and available or valuable product of the H.I.S. effort.

While no specific combination of messages and communication skills can be established here as the appropriate strategy which the Data Manager should employ, it is important for the manager to understand that communication is the primary means by which the end of health information use is to be achieved.

#### SECTION I. A FINAL NOTE

At this time, there is no singular conslusion as such to be drawn out of the discussion presented in this Report. The Guam Health Information System was given an initial stimulus in mid-1979 and is at present still in a formative stage. The contents of this Report on the design, organization, and activities of this newly created entity (with newly established functions) provide a guide to the architecture of the system and to the operation of its components. It remains for individuals as staff to fully "occupy" and actually run this system. As such, a detailed blueprint has been created, a handful of suggestions and recommendations for staff activities has been proferred, and now the advocacy from afar must give way to hands-on application, learning by doing, and indeed ultimate revision and adaptation of the blueprint to account for realities and constraints that can only be discovered through system implamentation.

Thus no forecast is offered as to the likely future of the Guam Health Information System. Nor are any final words of advice needed at this point. Enough has been detailed to allow any health planning staff to conscientiously consider what is at stake in designing and operating a health information system for planning and analytical purposes. Enough arguments have been presented to arm future H.I.S. staff or H.I.S. promoters to help them negotiate with line agencies and officials in order to obtain the degree of cooperation and assistance needed to make the system work. It is a simple principle indeed: that how health agencies operate is a function of the health information they employ, and that this information is only as good as the nature, amount, and quality of the data collected and the manner in which it is processed and utilized. And for all the seeming intricacy or detail with which certain components or activities of the Guam H.I.S. are specified, it is a rather simple principle that governs its operation: that the commitment and the abilities of the staff of the Health Information System and the individuals who support it will ultimately determine its success.

It will be the dedication and steadfastness with which the aim of more informed health care planning and health care delivery is pursued that will see the H.I.S. become an integral part of the Territory's health care system or will see it neglected and even abandoned for older, more piecemeal approaches to data processing of a limited sort. Time and the people involved will tell which path is chosen and to what extent this blueprint is able to chart the future course for data-related activities for better health care for the Territory of Guam.

#### ADDENDUM. SELECTED RECOMMENDATIONS

This short attachment to this Report serves to identify a variety of specific recommendations for facilitating the development and the viability of a Guam H.I.S. These recommendations are neither systematic in nature nor comprehensive in their elucidation here. They are presented more in the way of stimuli as discrete developmental projects which have been suggested by people involved with the initial development of the H.I.S. or have occured as possibilities to the author. Six such projects have been identified, as follows: (1) agency database revisions, (2) H.I.S. newsletter circulation, (3) health data user workshops, (4) staff training in statistics and computer programming, (5) special studies, and (6) historical data recovery. Below, each project recommendation is discussed separately.

#### 1. Agency Database Revisions:

The Guam Health Information System has been configured to generate information products initially which depend only upon current data elements available from agencies and their current databases. This is a pragmatic approach to immediate information product set generation, but it does not address the issue of optimal or desirable health information for planning, administrative, or other purposes. Thus, at some point in the near future, Guam H.I.S. staff may wish to approach selected health service agencies, or branches, to identify what information ideally would be useful and what data should be, rather than is currently, generated. Such an effort is equivalent to a "zero-based" approach to information product specification, and it will require considerable time in planning database development, in revising data element and information product inventories and report formats, and in designing, testing and adopting new data collection forms and data processing procedures. Yet this approach is ultimately what every agency feeding data to the Guam H.I.S. should take. And while the time perspective will of necessity be rather long, there is no reason why every agency and data source cannot eventually reassess its data collection and database maintenance activities, with the assistance of the GUam H.I.S. staff.

#### 2. H.I.S. Newsletter:

As the Guam H.I.S. struggles to establish itself in the first few years of operation, one of the critical aspects of the developmental program will be to communicate to skeptical agencies and officials the existence and the value of the Health Information System as a health information producing entity. This activity can be promoted most conveniently by means of actual satistical compilations and small-scale demonstrations of health data use which are circulated to all health and health-related agencies. The nature of this circular should be a newsletter which is concise, didactic as well as informative, and periodic. A Guam H.I.S. Newsletter is a suitable vehicle by which to convey the health information producing value of the organization on a rimely basis; as different sets of information products are generated, they can be summarized and discussed in small "information articles" in such a newsletter. Topical reports on selected diseases and disease statistics, health care sector activities, survey findings, broad comparisons of health statistics from Pacific territiries, and short essays on the nature of the H.I.S. or its component activities or on the activities (and data) of participating agencies would all be appropriate material for such a newsletter. newsletter could be conveniently produced semi-annually or even quarterly.

#### 3. Health Data Workshops:

Another promotional strategy, as well as a directly valuable means of fostering greater awareness of health data and their uses, is for the Guam H.I.S. to sponsor and conduct one or more data user workshops. Such workshops would bring together data gatherers, record-keepers, statisticians, and data users on Guam to discuss selected topics of common interest concerning health data and health information. A data user workshop could help provide a forum for Guam agency personnel to present statistical findings, report on data collection methods and problems, and discuss common strategies for data collection or data use in the future. Such forums are obvious vehicles for fostering greater participation and cooperation among data source agencies and their staff.

### 4. Staff Training Needs in Statistics and Computer Programming:

Two skill areas are more than likely to be underrepresented in the training background of any staff brought on-board a Guam H.I.S., namely

statistical methods for a lower-level Data Clerk position, and computer programming for the upper-level Data Manager or Analyst position. If only to ease the computational and analytical burden placed on the senior H.I.S. staff member, it is strongly recommended that ppropriate training in statistical methods be given to the lower-level staff person. This training should not be acquired through any short-term statistics training course, such as offered by ASTI (Applied Statistics Training Institute). It is all too apparent that such training offers minimal benefits for the money and time invested, since the training period is too short to allow participants to fully adopt, apply and feel comfortable with material which is conveyed during the training seession. Rather, it is far more suitable for a staff person to enroll in a semester-long night school course or even be allowed time off during regular working hours to attend a daytime one- or two-semester course in statistics in which applications are emphasized.

For the senior staff position, the statistical methods proficiency is assumed to be acquired, and the predictable skill deficiency is more likely to be in the area of computer programming and computer database For the near future, it is advisable for this staff management. person to concentrate on central management responsibilities, while a computer programmer (such as employed by Bureau of Planning) is retained under contract to handle the computer-based health data of the Territory (Public Health Nursing data, Vital Statistics, Epidemiology data, and eventually Hospital data as well). At some point, however, it will be of use to the Analyst/Data Manager to be able to access all available datasetsmanual or computer-based - for analytical purposes, and this will necessitate his or her understanding of computer facilities, programming, and principles of computer-based data management. Actually, the two computer skills of (1) software utilization for statistical analysis and tabulation of data and (2) computer-based data compilation, filing, storage and retrieval, are separable, and priority should be placed on acquiring the former skill. Again, longer-term training courses are the most advised route, although conceivably the computer programmer in the Bureau of Planning could be contracted to transfer some of the computer software useskills to the Analyst.Manager,

#### 5. Special Studies:

Similar in intent to the production of a newsletter is the initiation of specific, data-oriented special studies by Guam H.I.S. Such studies should be carefully selected to be supportive of and compatible with the issue-areas and priorities of the GUam Health plan or to immediate and relevant requests for investigation, analysi or evaluation by the Legislature or the Executive office. Such studies might focus on individual health status problems; braod analysis of trends in the pattern or changes in health problems considered as a set; individual health care services; or pecific target groups (e.g., youth) or target areas (e.g., southern Guam). The approach of any particular special study should be to assemble, display, analyze and interpret a range of data that bear on specific issues. The study need not be massive in time expenditure or page length. In fact, it is more appropriate initially to demonstrate the analytical and reporting capabilities of the H.I.S. by tackling small data analysis projects. Such projects should be carefully scheduled well in advance and published for wide distribution and a general audience.

### 6. Historical Data Recovery:

A longer-term project which would be of use only to an information producing organization that has established itself in the health care/ health agency community would be an effort to extract historical records and data. Such records should be compiled from years prior to 1975 in order to stretch the longitudinal base of any trend studies undertaken in the course of data processing. For example, it is known that Vital Statistics, Epidemiological (disease reports), and hospital admission and discharge records are available in paper form for a considerably longer period of time than have been compiled and summarized in currently available public documents. A Guam H.I.S. is in the unique position, once confidence in its organization, staff, and procedures has been established in data source agencies, to offer these agencies the service and benefit of recovering and editing their archived records. Such historical data, in all cases, should be coded and keypunched for computer-based data storage and retrieval, rather than risk having a manual set of "rejuvenated" historical data get lost or discarded inadvertently.

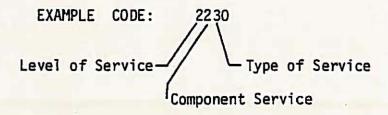


#### APPENDIX I.

#### A SERVICES TAXONOMY FOR THE HEALTH SYSTEM

FOR HEALTH PLANNING & DEVELOPMENT AGENCIES

The following is a coding system for use in referencing and classifying health services and programs for areawide health care systems. The coding scheme employs four digits to code the Level, Component, and Type of service or program available. The Level of service is indicated by the first digit (0 through 7). The Component service category is indicated by the next digit (hundreds: 0 through 9 and two additional symbols, \* and +); a 0 indicates no specification of a Component. Finally, the Type of service or program is indicated by the third digit (0 through 9, where 0 indicates no specification of Type). The fourth digit is not utilized at the present time, but is available for sub-classifications of Service Types.



#### HEALTH SERVICE SYSTEM SERVICES TAXONOMY FOR GUAM

#### 0000 OVERALL HEALTH SYSTEM

#### COMMUNITY HEALTH PROMOTION AND PROTECTION SERVICES 1000

1100 Health Education Services

1200 Environmental Quality Management

1300 Food and Drug Protection

1400 Occupational Health and Safety

1500 Radiation Safety

1600 Biomedical and Consumer Product Safety

#### 1100 Health Education Services

1110 School Health Education

1120 Community Health Education

1130 Motivating Positive Health Behavior

1140 Emergency Health Education

#### 1200 Environmental Quality Management

1210 Water Supply Treatment & Wastewater Disposal

1220 Solid Waste Disposal

1230 Air Pollution Control.

1240 Noise Control

1250 Housing and Residential Hazards Control 1260 Vector Control

1270 Recreational Area Hazards Control

1280 Highway Safety 1290 Pesticide Control

#### 1300 Food and Drug Protection

1310 Sanitation

1320 Safety

1330 Nutritional Quality

#### 1400 Occupational Health and Safety

1410 Construction

1420 Transportation and Utilization

1430 Manufacturing, Service and Others

#### 1500 Radiation Safety

1510 Industrial Radiation

1520 Medical Radiation

#### 1600 Biomedical and Consumer Product Safety

Drugs and Medical Devices

#### 2000

#### PREVENTION AND DETECTION SERVICES

2100 Individual Health Protection Services 2200 Detection Services

#### 2100 Individual Health Protection Services

2110 Immunization

2120 Well-Person Maintenance

2130 Dental Prophylaxis

2140 Family Planning

### 2200 Detection Services

2210 Condition-Specific Screening

2220 Multi-Phasic Screening

2230 Contact/Collateral Follow-Up

3100 Maternal and Infant Health (Obstetric/Pediatric) 3200 Medical-Surgical Services 3300 Diagnostic Radiology Services 3400 Therapeutic Radiology Services 3500 Clinical Laboratory Services 3600 Emergency Medical Services 3700 Outpatient Services

3800 Dental Health Services 3900 Mental Health Services 3\*00 Substance Abuse Services 3+00 Special Medical Services

### 3100 Maternal and Infant Health (Obstetric/Pediatric)

3110 Diagnosis and Treatment of Prenatal Complications

3120 Labor and Delivery Care

3130 Post-Partum Care

3140 Neonatal Care

3150 Pediatric Care

#### 3200 Medical-Surgical Services

3210 Inpatient Surgery

3220 Post-Operative Recovery Care

3230 Post-Surgical Care

3240 Anesthesiology

3250 Special Intensive Care

3260 Ambulatory Surgery

### 3300 Diagnostic Radiology Services

3310 General Roentgenography

3320 Contrast Radiology

3330 Computerized Transaxial Tomography

3340 Nuclear Medicine

3350 Angio-Cardiology

3360 Ventriculography

## 3400 Therapeutic Radiology Sérvices

3410 Megavoltage Therapy

3420 Orthovoltage Therapy

3430 Interstitial Radium Therapy

### 3500 Clinical Laboratory Services

3510 Hematology

3520 Chemistry

3530 Histology

3540 Microbiology 3550 Serology

3560 Basal Metaboloism

3570 Bacteriology 3580 Parasitology

### 3600 Emergency Medical Services

- 3610 Emergency Communications
- 3620 Emergency Transportation
- 3630 Emergency Medical Treatment

#### 3700 Outpatient Services

- 3710 Emergency Outpatient Services Department
- 3720 Organized Outpatient Services (Clinic)

#### 3800 Dental Health Services

- 3810 Dental Resoration
- 3820 Periodontics
- 3830 Oral Surgey
- 3840 Examination

#### 3900 Mental Health Services

- 3910 General Psychiatric Services
- 3920 Crisis Intervention
- 3930 Community Mental Health Services
- 3940 Outpatient Services
- 3950 Partial Hospitalization

#### 3\*00 Substance Abuse Services

- 3\*10 Detoxification
- 3\*20 Counseling

#### 3+00 Special Medical Services

- 3+10 Clinical Diagnosis, Prescription. & Medical Care Management
- 3+20 Specialized Diagnostic Procedures (EEg/EKG).
- 3+30 Renal Dialysis
- 3+40 Burn Care Center
- 3+50 Inhalation Therapy

4100 Medical Habilitation and Rehabilitation Services

4200 Therapy Services

4300 Mental Habilitation and Rehabilitation Services

#### 4100 Medical Habilitation and Rehabilitation Services

4110 Specialized Treatment and Care (Inpatient Care for Nursing and Custodial Patients)

4120 Intermediate Care for DEvelopmentally Disabled

4130 Children's Long Term Care

#### 4200 Therapy Services

4210 Physical Therapy

4220 Occupational Therapy

4230 Recreational Therapy

4240 Prosthetic/Orthotic Service

4250 Communication Therapy (Speech/Hearing)

4260 Social/Psychological Therapy

#### 4300 Mental Habilitation and Rehabilitation SErvices

4310 Aftercare and Support Services

4320 Vocational Services

4330 Community Living Care

5000

MAINTENANCE SERVICES

5100 Long Term Care

### 5100 Long Term Care

5110 Chronic Disease Care

5120 Skilled Nursing Care 5130 Intermediate Nursing Care

5140 Sheltered Care

5150 Day Care Services 5160 Mental Health Hospitalization

#### 6000 PERSONAL HEALTH CARE SUPPORT SERVICES

6100 Direct Patient Care Support Services 6200 Administrativ Services

### 6100 Direct Patient Care Support Services

- 6110 Pharmacry Services
- 6120 Tissue Services
- 6130 Blood Bank Services
- 6140 Medical Social Work Services
- 6150 Medical Records Services

#### 6200 Administrative Services

- 6210 Management and Supervision of Medical Care Resources
- 6220 Facility Maintenance and Housekeeping Services

#### HEALTH SYSTEM ENABLING SERVICES

7100 Health Planning

7200 Resources Deelopment

7300 Financing

7400 Regulation

7500 Research

#### 7100 Health Planning

7000

7110 Data Assembly and Analysis

7120 Goal Determination

7130 Action Reccommendation

7140 Implementation Strategy

7150 Evaluation

#### 7200 Resources DEvelopment

7210 Manpower

7220 Facilities

7230 Equipment

#### 7300 Financing

7310 Third Party Rēimbursement

7320 Public and Direct Public Expenditure for Service

7330 Construction Loans and Loan Guarantees

7340 Philanthropic Grants and Payments for Services

#### 7400 Regulation

7410 Certificate of Need

7420 Manpower Licensure and Certification

7430 Facility Licensure and Certification

7440 Rate Regulation

7450 Insurance Regulation

7460 Association Accreditation

7470 SAA 1122 Agreements

#### 7500 Research

7510 Biomedical

7520 Behavioral

7530 Technological

7540 Organizational and Services Delivery

#### APPENDIX II.

GHPDA HEALTH INFORMATION SYSTEM (H. I. S.)
FILE ORGANIZATION FOR PHYSICAL DATA FILING SYSTEM

#### DATA BLOC I. HEALTH STATUS

SPECIAL FILE: OVERALL HEALTH STATUS (00)
MAIN FILES: (Specified) HEALTH STATUS PROBLEMS (01 - 30)

### SPECIAL FILE

Subject Area		Topic Heading	
Natality	(AA)	Birth Fertility Birthweight Illegitimacy	01 02 03 04
Life Expectancy	(BB)	Years Remaining Years of Life Lost	01 02
Mortality	(cc)	Crude & Aggregate Infant Mortality Neonatal Mortality Fetal Mortality Cause-Specific Mortality Leading Causes	01 02 03 04 05 06
Morbidity	(DD)	Notifiable & Infectious Acute Chronic Mental Other	01 02 03 04 05
Injury	(EE)		
Disability	(FF)	Disability (Days) Restricted Activity (Days) Work Loss (Days) School Loss (Days) Mental Developmental Other	01 02 03 04 05 06 07
Discomfort	(GG)		

(H)	Pregnancy Obesity Hypertension Diabetes Cirrhosis Occupational Non-Immunized Genetic	01 02 03 04 05 06 07 08
(1)	Alcohol & Drug Tobacco Nutrition Exercise Other	01 02 03 04 05
	Topic Heading	
(A)	Crude & Aggregate Cause-Specific	01 02
(B)	Notifiable & Infectious Acute Condition Chronic Condition Injury Other	01 02 03 04 05
(C)	Physical Mental Developmental	01 02 03
on (D)		
(E)		
(F)	Alcohol & Drug Tobacco Nutrition Exercise Other	01 02 03 04 05
(G)		
	(A) (B) (C) (D) (E) (F)	Obesity Hypertension Diabetes Cirrhosis Occupational Non-Immunized Genetic  II)  Alcohol & Drug Tobacco Nutrition Exercise Other  Topic Heading  (A)  Crude & Aggregate Cause-Specific  (B)  Notifiable & Infectious Acute Condition Chronic Condition Injury Other  (C)  Physical Mental Developmental  On (D)  (E)  (F)  Alcohol & Drug Tobacco Nutrition Exercise Other

#### DATA BLOC II. HEALTH SYSTEM

SPECIAL FILE: OVERALL HEALTH SYSTEM (0000)

MAIN FILES: (Specified) HEALTH SERVICES (1110 - 7300)

### SPECIAL FILE

Subject Area		Topic Heading	
Programs & Objectives	(AA)		
Manpower Resources	(BB)	Core Practitioners Skilled Allied Personnel Unskilled Allied Personne	01 02 103
Budget Resources	(CC)	Revenue, Income, Reimbursement Expenditures Fee Schedule Health Insurance	01 02 03 04
Facilities/Equipment Resourc	es(DD)	Facilities Equipment (\$150,000) Equipment (\$10,000 - \$150,000) Operating Equipment*	01 02 03
Utilization	(EE)	Clientele Services Rendered Duration of Service Outcome	01 02 03 04
Evaluation	(FF)	Availability Accessibility Cost Quality Continuity Acceptability Cost-Benefit Cost-Effectiveness Impacts Need Documentation Problem Reduction	01 02 03 04 05 06 07 08 09 10
Health Intervention System	(GG)		
Hospital	(HH)		
нмо	(11)		
Public Health Clinics	(11)		
Private Health Clinics	(KK)		

# MAIN FILES

Subject Area		Topic Heading	
Programs & Objectives	(A)		
Manpower Resources	(B)	Core Practitioners Skilled Allied Personnel Unskilled Allied Personnel	01 02 03
Budget Resources	(C)	Revenue, Income, Reimbursement Expenditures Fee Schedule Health Insurance	01 02 03 04
Facilities/Equipment Resources	(D)	Facilities Equipment ( \$150,000) Equipment (\$10,000 - \$150,000) Operating Equipment*	01 02 03
Utilization	(E)	Clientele Services Rendered Duration of Service Outcome	01 02 03 04
Evaluation	(F)	Availability Accessibility Cost Quality Continuity Acceptability Cost Benefit Cost Effectiveness Impacts Need Documentation Problem Reduction	01 02 03 04 05 06 07 08 09 10

## DATA BLOC III. PLANNING & POPULATION ENVIRONMENT

No Special Files

Main Files Correspond to: Environmental Areas (I - VI)

Environmental Area		Subject Area	
PHYSICAL	I	Site Natural Attributes Infrastructure Housing/Built Environment	A B C D
DEMOGRAPHIC	II	Population Distribution Population Dynamics Population Projections	A B C
SOCIAL	III	Family & Household Education Language & Culture Social Indicators	A B C D
ECONOMIC	IV	Employment & Income Wages & Prices Trade & Industry Health Insurance	A B C D
POLITICAL	V	Administration Legislation	A B
HAZARDS	VI	Typhoon & Flood Earthquake Fire Pollution Transport Military Other	A B C D E F G

#### APPENDIX III.

EXAMPLE MEMORANDUM OF AGREEMENT FOR COOPERATION	
IN DATA AND INFORMATION SHARING BETWEEN THE	
GUAM HEALTH PLANNING AND DEVELOPMENT AGENCY	
The state of the s	
The following statement of understanding sets forth as	nd
defines the agreement for coordinating activities between	veen
the Guam Health Planning and Development Agency, here:	inafter
referred to as the "Agency" and the	
hereinafter referred to as the "".	

The Agreement has been consummated in order that the intent of Federal expectations and/or requirements as set forth in P.L. 93-641 and P.L. 96-79 and their enabling regulations may be realized in conjunction with requirements pertinent to

The Agreement is based upon the following:

I

The parties to this agreement acknowledge that: The Agencyas a designated State Agency pursuant to the provisions of P.L. 93-641 and P.L. 14-150 (Guam) is responsible for the health planning and health resources development in Guam. The Agency's primary mission is the development of a comprehensive health plan and medical facilities plan for the Territory.

In consideration of these responsibilities, it is mutually agreed that:

affirm that a working The Agency and relationship between the parties will contribute to a more effective and comprehensive health planning process in Guam.

<sup>\*</sup> This draft is a slightly modified version of a preliminary version employed by the Guam Health Planning and Development Agency.

### MUTUAL AGREEMENT

The	Agency	agrees:
-----	--------	---------

Age	ncy agrees:
1.	To provide technical assistance in the areas of planning, plan implementation, data management and related support assistance as requested in writing to the Agency consistent with the Agency's and government budgetary, administrative, and work program requirements, regulations and policies.
2.	will be informed of the information products to be generated from's data. The information products expected will be indicated as part of an Attachment to this Agreement.
3.	will have review and comment privileges for all information products to be produced by the Agency.
4.	All program and budget data collected by the Agency will be used for one or more of the following purposes: (a) plan development, (b) plan implementation, (c) issue and policy analysis, (d) certificate-of-need review, (e) community and public information or education, and (f) federal or local program/plan review.
5.	The Agency has established appropriate policies and procedures to safeguard sensitive and confidential data which it may receive from, and will secur prior approval of before releasing or commenting on such data in raw or processed form.
6.	The use of "donated data" in the form of documents produced by as part of its normal reporting activities to official agencies will not be subject to review and prior approval for release by

7. New data or new uses of data as identified in any revised information product list Attachment will be subject to negotiation and amendment to the standing Cooperative Agreement.

The	agrees:

- To appoint a staff member of its organization to serve as liaison officer for the purpose of coordinating and carrying out the intent of the Agreement.
- 2. To provide the Agency with health data, information products and related program and budgeting information including descriptive and narrative information on services, manpower, equipment, finances, and utilization as agreed upon.
- 3. To provide the Agency with health and related data and information on a timely basis as requested and agreed upon, according to an established and mutually acceptable schedule for transfer of data and information, to and from the Agency.
- 4. To identify all projects and programs which require Agency review and submit such a listing annually to the Agency.

THE ADMINISTRATOR OF THE GUAM HEALTH PLANNING AND DEVELOPMENT AGENCY AND THE ADMINISTRATOR OF

ADOPT THIS AGREEMENT WHICH WILL BE IN EFFECT, UPON INITIALING BY BOTH PARTIES, FOR ONE (1) YEAR AND WILL BE EVALUATED AND RE-NEGOTIATED FOR ANY FUTURE PERIOD OF TIME.

This Agreement in no way precludes future or additional agreements which may be made between the two parties.

#### APPENDIX IV.

#### FRAMEWORK FOR GHPDA POLICY ON CONFIDENTIALITY AND PRIVACY PROTECTION

- All data collected and stored by GHPDA will, to the maximum extent possible be maintained in "stripped", confidential form, i.e., all individual identifiers (such as name, address, and social security number or driver's license) will be removed.
- 2. Where unavoidable, data that is collected by GHPDA which does contain individual identifiers will be maintained under strict standards of security and file protection. No persons will have legal access to such data other than data source agency personnel in charge of releasing such data to GHPDA and GHPDA personnel (H.I.S. staff) specified by Coperative Agreement to handle the data.
- 3. No confidential data will be copied or transmitted for other than data processing purposes which are limited to those types of processing that are consented to by data donor agency and GHPDA per Cooperative Agreement pursuant to information product generation.
- 4. No information product generated from confidential data will identify or enable identification of individuals by name or by distinct characteristics; cross-tabulations of data which enable the identification of individual persons are prohibited.
- 5. Data which is encoded by electronic means for use and manipulation by computer facilities and software are subject to special stipulations covering processing of confidential data.



Below three separate kinds of supplementary personnel are identified and characterized in brief: namely, (1) computer programmer, (2) survey interviewers and (3) various statistical and planning consultants.

- (1) Computer Programmer: It is envisaged that for the immediate future, separate computer facilities and programming staff will not be acquired by an H.I.S. organization or its parent agency (GHPDA). However, since the H.I.S. draws upon a large and vital amount of computer-based data, the organization will necessarily require the assistance of a computer programmer. This assistance includes acquiring copies of all health-related computer-based data of use to the Guam H.I.S.; processing the data using computer facilities and software to generate desired outputs; and documenting all computer-related H.I.S. activities. The assistance should be secured and maintained by contract with a single computer programmer with thorough knowledge of Guam computer facilities, statistical and data management software, and computational procedures. At the present time, a cooperative agreement/contract is in effect with the Bureau of Planning to secure the part-time services of the Bureau's computer programmer. This arrangement has proven satisfactory for the past two years and should be maintained.
- (2) Survey Interviewers: Occasionally the H.I.S. staff may require consultation with individuals skilled in survey design and analysis. Such consultation may help to establish the limitations of particular (survey-based) data sets and the interpretations which can be made of them. The H.I.S. may also be called upon to assist in survey work itself or to help combine survey data with other sources. It may also undertake its own survey effort or append a questionnaire to an existing survey effort (such as the quarterly Bureau of Labor Statistics labor force survey). In all such cases, the advice of trained survey workers and interviewers will be helpful to H.I.S. staff. Such personnel can be found in the Bureau of Labor Statistics, the Department of Commerce, and at the University of Guam.
- (3) Additional Consultants: Briefly mentioned here are several kinds of resource persons who may provide valuable insights into certain aspects of data or their collection, analysis or interpretation.

Such persons include Epidemiologists and Vital Statistics
Specialists; Economists and Financial or Budget Analysts;
Statisticians; and Health Planner. Guam is fortunate in having
locally employed individuals skilled in these areas, either in
government agencies or in the University of Guam. It is also
possible for H.I.S. staff, through the auspices of GHPDA, to seek
assistance from the Western Consortium or Western Center for Health
Planning based in San Francisco, or from consultant groups with
requisite knowledge of the Pacific island and its developmental
and health care context.

#### SECTION H. GUAM H.I.S. MANAGEMENT: A SUMMARY VIEW

#### 1. The Central Role of the Data Manager

This Report now draws to a close by considering the nature and priority of various activities which are central to the operation of the Guam H.I.S. and which are the responsibility of the H.I.S. Data Manager to undertake. While the previous section has identified the necessary staffing requirements and the series of specific tasks to be associated with the H.I.S., discussion here focuses on identifying how such tasks can meet the data processing requirements as detailed in the first half of this Report. Thus, it is important to identify the key role played by the Data Manager in perpetuating the H.I.S. as a productive and effective organizational component of a health planning function in the Territory. To this end, attention is drawn to four responsibilities of which the Data Manager should be constantly aware in undertaking any assigned task and generally in seeking to make the Guam H.I.S. a viable entity.

It cannot be stressed too much that the operation of the Guam H.I.S., at least in its infancy, will be closely associated with the activities and performance of the Data Manager. This person alone will be engaged in contanst interaction with the data staff of numerous agencies in the Territory, and through such contacts will forge the collective impression of the value and utility of the health information system enterprise. It is important that the Manager be visible, communicative, and cooperative in all interactions with these agencies. It is also important that the Manager not assume that any other individual or agency is in a position to render assistance or support on a continuing basis; in other words, the Manager must be willing to assume a great deal of independence and individual initiative for the initial development of the system. To this end, it is advised that the Data Manager be aware at all times of the nature of his or her responsibilities in a broad philosophical sense. These responsibilities are discussed below.

#### 2. Key Responsibilities in Management

The previous Section of thisReport has identified six tasks which should be undertaken by a Data Manager role in order to fulfill the H.I.S. function of "information system management". Those six tasks include:

(1) data donor agency contacts and consultations, (2) cooperative agreements creation and maintenance, (3) staff training and supervision, (4) H.I.S. advisory group participation, (5) H.I.S. reporting, documenting and inter-agency relations, and (6) H.I.S. planning, budgeting, scheduling, and implementing.

In examining the basis for assigning these six tasks to the Data Manager, and in providing a rationale for the Data Manager to administer the H.I.S. as an organizational entity, what stand out are four basic responsibilities which go with this staff position. These responsibilities are the essence of management, insofar as a health information system are concerned. They may well in fact appear so obviously a part of a manager's role as to require no special mention. However, at the risk of overstatement, it is worth identifying each of these responsibilities, if only to emphasize the strategic means by which a Guam H.I.S. can be - in fact must be - promoted in the governmental and administrative milieu on Guam. The key responsibilities which stand out include: (a) assessment, (b) planning and scheduling, (c) coordination, and (d) communication. Each responsibility is briefly clarified below.

### a) Assessment:

TheH.I.S. clearly is not at the present time a vital or central organizational component of health care delivery or health care planning; otherwise, this organizational function would long since have been established. The health care sector on Guam is in a state of transition at present. It can be characterized broadly as a multi-functional, public-private system which has a less than ideal amount of organization and coordination. Apart from straightforward questions concerning why the present leadership or responsible administrators have not been able to

select or impose a developmental path, the question of why individual branches or components of the system have not been able to plan or organize their services better must be raised. And while partial answers may lie in identifying weak administrative skills or organizational conflicts or inadequate policies and regulations, it is quite clear that no agency or branch has been able to formulate a clear-cut, comprehensive assessment of problems, resources, opportunities and desired strategies. What is apparent that the agencies and branches are much too involved in daily operations and routine service or administrative tasks and do not have sufficient staff expertise to devote appropriate time and resources to this assessment function. This situation holds equally for all Public ealth branches as well as for the Guam Memorial Hospital and its various services. In addition, no other governmental agency is in a position to identify and document th problems and options related to the entire system of health crae delivery for Guam.

By foresight or by default, the Guam Health Planning and Development Agency is in a unique position to sponsor a health information system which can provide the entire Territory with not only a comprehensive, organized collection of health and health-related data, but also the capability to analyze, evaluate and document problems and alternatives. The assessment function is therefore critical to the proper reception of the Guam H.I.S. as a new activity. And this assessment function must be the responsibility of the manager of the H.I.S. who alone will respond to requests for particular studies or evaluations, or will initiate such studies as a positive and constructive step towards assisting Guam's health agencies to plan and coordinate their services better.

### b) Planning and Scheduling:

Assuming that the H.I.S. will become actively involved in collecting health and health-related data for Guam and will apply this data to selected analyses and evaluations (assessments) of various health problems and health care activities in the Territory, it is essential that the H.I.S. manager carry out all data processing activities in an orderly manner. The usefulness of data is obviously time-dependent, and the value of health care information for planning and evaluation purposes is clearly

limited to the rather narrow time-frame within which the need for such information is identified and its application is determined to have a bearing on decisions or actions to be taken. Given the broad variety of actors and agencies participating in health care delivery on Guam, including the health planning agency itself, it is essential that all activities of the H.I.S. be thoroughly planned, sequenced, and scheduled for periods as long as a year in advance. It is just as clear that the Data Manager is the only staff person who can assume responsibility for this planning/scheduling function. Such a staff person must also bear in mind the conditional nature of all such planning and scheduling and be prepared and willing to reorder priorities and re-schedule various activities and tasks in order to meet new demands. The plan and the schedule that are assembled by the Data Manager must be specific and be available as a concrete document at all times for review by all interested agencies. There should be no hidden agenda and no activities or tasks confined to memory or simply assumed to be the purview of a particular individual. The H.I.S., if it is to gain credibility as an organization, must be able to document its own activities as well as or better than its ability to document any other part of the health care system.

### c) Coordination:

Public agencies in any government are not generally known for their ability to coordinate activities with each other. But an information system for health planning and analysis must seek to coordinate its activities with other agencies within both public and private sectors for its very survival. The GUam H.I.S. is not a management information system. Such systems are usually confined to one organizational domain and serve the single administration of that domain. The Guam H.I.S. will answer to and seek data from a multiplicity of agencies and organizations; it will in fact serev the entire health care system on Guam. In such a capacity, the H.I.S. manager must spend a considerable amount of time consulting with various agency heads - as well as agency data staff - understanding the often changing agency activities, determining what data is desirable and feasible to acquire and what information can be efficiently generated for joint use, and, overall, assessing how agency administrators and officials can best be served and motivated to contribute to the mission of the health information system.

Coordination is more than simply a matter of joint identification of needs and resources and scheduling of activities. It is also, and more importantly, an approach to management which necessitates a frequency and openness of communications; solicitation of opinions and recommendations; willingness to revise plans, to accept different points of view and even less-than-optimal recommendations on actions to be taken, to assume the role of initiator, prodder and promoter of all joint activities. This responsibility for coordination inherent in the nature of the management function of the Guam H.I.S. in fact demands a special kind of person to fill the role of Data Manager, and may well have to be accorded the status of a separate job qualification in order to ensure the proper staffing of the information system activity.

#### d) Communication:

Much of what has been said about the manager's responsibility to coordinate diverse activities and actors applies equally well to consideration of the need for strong communication skills in order to support the H.I.S. All formal communications to and from the H.I.S. must be channelled through the Data Manager, yet this stipulation cannot preclude the manager from employing more diverse and informal means to convey the messages from the H.I.S. Again, the managerial responsibility for effective communication at the same time pojnts up a critical skill which the manager must have initially or must acquire rather quickly. There must be absolutely no reticence in speaking with or writing or responding to actors and agencies ranging from individual line staff in Public Health and individual physicians in private or independent clinics to directors of public agencies or legislators or the Governor, or key figures or Region IX officials in the federal government. Appropriate and often overlapping use of informal and formal communications, reminders and memoranda, letters and reports, telephone conversations, lunchtime meetings, official appointments and conferences must all e thought of as available means of conveying various messages. These messages may include specific data requests, requests for monetary or other assistance, notifications of meetings, decisions, options, and findings, and reports or delivery of information by request or voluntarily provided as a means of indicating what is and available or valuable product of the H.I.S. effort.