

**Health Data Needs of the Pacific Insular
Areas, Puerto Rico, and the U.S. Virgin
Islands**

**National Committee on Vital and Health
Statistics**

Subcommittee on Populations

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Health Data Needs of the Pacific Insular Areas, Puerto Rico, and the U.S. Virgin Islands: A Report from the National Committee on Vital and Health Statistics

Executive Summary

Background

The National Committee on Vital and Health Statistics' (NCVHS) Subcommittee on Populations' charge is to focus both on (a) population-based data concerning the U.S. population generally, as well as on (b) data about specific vulnerable groups within the population which are disadvantaged by virtue of their special health needs, economic status, race and ethnicity, disability, age, or area of residence.

A priority in its 1998 work plan was the assessment of the health data needs in the Pacific insular areas, Puerto Rico, and the Virgin Islands.. Beyond the 50 States, U.S. territories and other political jurisdictions receive federal funding for selected health care services and the U.S. government has varying degrees of responsibility for the health and well-being of populations living in these areas. The Subcommittee had concerns about the availability and utility of data on public health, chronic illness, and disability in these areas, recognizing the underdeveloped health information systems and the general lack of inclusion of these areas in national health surveys. While substantial diversity exists between Puerto Rico, the Virgin Islands, and the Pacific insular areas in terms of many factors not the least of which are the various political relationships to the U.S., the Subcommittee nevertheless wanted to use this opportunity to include all of these areas in its assessment.

First and foremost, any examination of life on the Pacific insular areas, the Virgin Islands and Puerto Rico must take into account the unique characteristics of the islands. While all these areas vary substantially from the mainland U.S, there is also considerable variation among the islands themselves. As already noted, one source of variation is the differing political relationships these areas have with the U.S. The Pacific insular areas are spread over a huge area, roughly the size of the continental U.S., and are distributed across several time zones and the international date line. Their economies are generally quite dependent on the U.S. The populations, while totaling only about 500,000, are growing rapidly. The people are sometimes crowded into urban centers and tend to be relatively young and with low incomes. In addition, the cultures and languages vary among the areas, and even within certain of the political entities. Health concerns are often unique to a particular area or culture and data collection efforts must be tailored to reflect this.

The U.S. Virgin Islands and Puerto Rico are U.S. territories with locally-elected governments. The six Pacific island jurisdictions are either U.S. territories or independent nations in free association with the U.S. according to terms of a Compact of Free Association. Guam and American Samoa are territories of the U.S. The Commonwealth of the Northern Mariana

Islands is a commonwealth in political union with the U.S. Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands are sometimes referred to as “Flag Territories.” The Republic of Palau, the Republic of the Marshall Islands, and the Federated States of Micronesia are termed “Freely Associated States. They are sovereign nations covered by Compacts of Free Association which are agreements designed to mutually benefit these nations and the U.S. For example, the U.S. retains its rights to put military personnel and military bases if necessary in the freely associated states and in return the states are covered under the protective umbrella of the U.S. and are eligible for certain grants. In this report, the term “insular areas” is used to refer both to the flag territories and the freely-associated states.

This report is based on information collected during a hearing held on July 14th and 15th of 1998. At that meeting, federal representatives first presented brief summaries of their agency’s activities in the morning of the first day. Representatives from the islands then summarized their data needs in the afternoon and in part of the second day. The second day ended with a round table discussion. Representatives from the Pacific insular areas, Puerto Rico and the Virgin Islands addressed the Subcommittee reporting on their health information infrastructure and some of the problems faced. Although there is wide diversity among these areas, all representatives agreed on the importance of high quality health information for informing decision making. Their health data systems, while essentially facing the same classes of problems, are in differing stages of development. Those testifying before the Subcommittee identified several major needs or problems:

- With the possible exception of Puerto Rico, senior level officials and the population at large need to better understand the importance of collecting health data and data sharing needs to be encouraged.
- Health system planning needs to be strengthened in most areas.
- Data quality should be improved, both through development of new data systems and strengthening and integrating of existing systems.
- Lack of trained technical personnel make improvements in data collection and analysis difficult—especially the lack of statistical and analytic skills.
- The Pacific Insular areas need local capacity for training in epidemiology, computer science, bio-statistics, health planning and related fields.
- Hardware and software are outdated, and in some instances unreliable.
- Currently available funding, especially from Federal sources, tends to be categorical and promotes the development of single use data systems rather than to support overall infrastructure development.

- Population data, as well as health data systems, must be strengthened before adequate incidence rates can be development in many areas.

• There were certain consistent findings leading to principles along which recommendations were developed which broadly apply to all of the areas. First and foremost all stakeholders, HHS, the island governments, the health systems, and the people of the islands need data relating to the consequences of inadequate public health and medical interventions to target areas for improvement. Currently there is an overall primary need across all jurisdictions for strengthening existing data collection and analysis capacity as a means of improving public health. Within this overall theme, several specific needs emerged from the hearing:

- There is a common need for promoting capacity-building, including local workforce and training, rather than relying on bringing in outside assistance to address problems. HHS must recognize that developing an information infrastructure and strengthening the health data capacity are long-term projects, and to achieve these goals there must be long-term plans in place, consistency, and above all perseverance in carrying out the plans.
- The approach used by Healthy People 2010, which encourages States and communities to set locally appropriate public health goals and collect the data to monitor their progress toward goals could be encouraged for adoption on the islands. This process allows for local “buy-in” both to the improvement of the health of the population but also to the collection and analysis of data that are directly relevant to the local area.
- Although it is not a problem unique to Puerto Rico, the Virgin Islands, or the Pacific insular areas, the current categorical system of block grant funding hampers the development of developing integrated health data systems in these areas.
- There is also a need for a more inclusive approach on the part of Federal Departments to address the data needs of Puerto Rico, the Virgin Islands, and especially the Pacific insular areas. Rather than ruling these areas out of planned activities because of their distance from the mainland, Federal agencies should be asked to address in their work plans how they intend to integrate these areas into their health data initiatives.

Based on these considerations, the NCVHS created its recommendations in four areas: health data infrastructure, local data processes similar to the Healthy People 2010 approach, an expanded or more flexible approach allowing for increased federal funds to be used for the development and maintenance of a health data infrastructure, and a voice at the HHS policy table for representatives of Puerto Rico, the Virgin Islands, and the Pacific Insular areas. Within these four broad areas, it is recognized that the needs of Puerto Rico, the Virgin Islands, and the Pacific insular areas differ because of the different stages development of health information systems. However, to a greater or lesser extent, all apply. Specific action steps taken by HHS must account for the diversity of the islands in terms of their needs and stages of development.

Recommendations

Recommendation 1: HHS should assist Puerto Rico, the Virgin Islands, and the Pacific insular areas in developing improved health information infrastructures which will support the collection and use of quality health data. The information infrastructures must include both the tools and trained professionals to collect and compile data, as well as the tools, hardware, software, and trained professionals needed to analyze the data and produce information useful to policy makers at the local level.

Recommendation 2: NCHS should consult with the Puerto Rico Department of Health to learn the status of the recommendations made as a result of a site visit by NCHS and health data experts and determine if there are specific action steps that HHS could now take to insure implementation of the recommendations.

Recommendation 3: NCHS should continue to expand its vital statistics program into the islands of American Samoa, the Commonwealth of the Northern Marianas, and Guam. Higher payment for vital certificates should be explored as a means of improving accuracy and reliability of vital statistics. In addition NCHS should encourage the development of local vital statistics systems in all of the Pacific insular areas by investigating new, cost-effective training modalities with packaged modules focusing on specific topics. The application of new technologies as used in long distance learning to the training curriculum of the Applied Statistics Training Institute should be studied for use in the Pacific insular areas as well as for Puerto Rico and the Virgin Islands.

Recommendation 4: HHS should encourage SAMHSA to continue its plans for developing local infrastructure for substance abuse research and prevention modeled after the National Institute on Drug Abuse's Community Epidemiology Work Group (CEWG). As part of this effort, SAMHSA is facilitating the development of local forums on each of the six Pacific insular areas. These local forums would provide ongoing community-level surveillance of alcohol and drug abuse and the public health and social consequences of abuse, as well as the mental health of the population. SAMHSA would provide training in data collection, including data collection through ethnography and other methods appropriate for the varying geographic and cultural contexts of these areas.

Recommendation 5: Given both the associations between drug and alcohol abuse and many communicable diseases and cost-savings which should be accomplished by an integrated approach to prevention and treatment, HHS should support and encourage the long-term plans of SAMHSA and CDC to integrate data collection and training activities on the islands.

Recommendation 6: Through the Healthy People 2010 process, HHS should continue and expand assistance to the Pacific insular areas, Puerto Rico, and the Virgin Islands in order that they may become full participants in the process. This assistance can take the form of helping to formulate local public health goals and objectives, acquiring the baseline data necessary in order to measure progress, and in strengthening the local data infrastructure to support the monitoring progress.

Recommendation 7: Whenever the data are available, Healthy People 2010 reporting should include information from Puerto Rico, the Virgin Islands, and the Pacific insular areas in a manner similar to that for mainland U.S. populations.

Recommendation 8: HHS should encourage efforts like those of SAMHSA and joint CDC/HRSA initiatives which allow portions of certain block grant funds to be used for developing information infrastructure. Additional efforts are needed to permit more flexible use of HHS categorical funds for health data-related infrastructure development.

Recommendation 9: HHS and the Census Bureau should reach an agreement on official population figures for the islands to use for funding purposes and health statistics.

Recommendation 10: HHS should promote the local development of programs and surveys comparable to national ones as appropriate and encourage Census to routinely include Puerto Rico, the Virgin Islands, and the Pacific insular areas in as many of its statistical programs as feasible, especially the Current Population Survey, or other mechanisms which could be used to produce accurate and timely intra-Censal population estimates.

Recommendation 11: HHS should support the development of standard health data reporting requirements for these islands, especially since three of the Pacific insular areas are sovereign nations (Palau, the Federated States of Micronesia, and the Marshall Islands) with reporting requirements to groups other than the U.S. government (for example the World Health Organization).

Recommendation 12: HHS should invite either representatives from the islands, or those with jurisdiction over the islands to participate in the formulation for data collections when such collections might be feasibly be conducted in Puerto Rico, the Virgin Islands, and the Pacific Insular areas.

Recommendation 13: HHS should require agency plans for new health initiatives to include provisions for extending the proposed activities and associated data collections to Puerto Rico, the Virgin Islands, and the Pacific insular areas or to demonstrate that this is not feasible.

Recommendation 14: HHS should act through the Data Council to identify a single point of accountability and contact relating to health statistics, health information systems, and data needs for the Pacific insular areas, Puerto Rico, and the Virgin Islands.

Recommendation 15: As another step toward improved health information systems and healthier populations, HHS should work with other Departments, particularly the Department of Interior (DOI) and the Department of Commerce, to encourage the development of a health data systems in the islands. As an example, HHS should urge the DOI to continue providing support for the Census Bureau training program and support for periodic censuses and surveys. HHS should also at the Department level, support and encourage the DOI's efforts to export the IHS' Resource and Patient Management System to the Pacific insular areas. The system is now in use in the Commonwealth of the Northern Marianas and DOI plans to support its implementation in American Samoa in the near future.

Finally, the Committee recognizes that implementing many of its recommendations will require a commitment of additional resources. We have suggested some mechanisms for spending HHS grant funds more efficiently, including more flexible use of block grant and categorical funding streams. Nevertheless, the scale of need, especially for infrastructure development, is such that additional HHS resources will be required to implement these recommendations. Without these resources, the Pacific insular areas, Puerto Rico, and the U.S. Virgin Islands will continue to face significant barriers to addressing critical public health needs. Given the existing federal responsibility, we encourage HHS to take proactive and effective action to improve the availability and utility of data on public health, chronic illness, and disability in these areas.

Health Data Needs of the Pacific Insular Areas, Puerto Rico, and the U.S. Virgin Islands: A Report from the National Committee on Vital and Health Statistics

I. Background

The National Committee on Vital and Health Statistics is the Department's statutory public advisory body on health data, statistics and national health information policy. The Committee's Charter may be found in Appendix I.

The NCVHS has a Subcommittee on Population Issues. Appendix II contains a list of the members and staff. The Subcommittee focuses both on (a) population-based data concerning the U.S. population generally, as well as on (b) data about specific vulnerable groups within the population which are disadvantaged by virtue of their special health needs, economic status, race and ethnicity, disability, age, or area of residence.

As part of its 1998 work plan, the Subcommittee made the assessment of the health data needs in the Pacific insular areas, Puerto Rico, and the Virgin Islands a priority. Beyond the 50 States, U.S. territories and other political jurisdictions receive federal funding for selected health care services and the U.S. government has varying degrees of responsibility for the health and well-being of populations living in these areas. The Subcommittee had concerns about the availability and utility of data on public health, chronic illness, and disability in these areas recognizing the underdeveloped health information systems and the general lack of inclusion of these areas in national health surveys. This report was prepared with the recognition that substantial diversity exists between Puerto Rico, the Virgin Islands, and the Pacific insular areas in terms of many factors not the least of which are the various political relationships to the U.S. The Subcommittee nevertheless wanted to use this opportunity to include all of the areas in its assessment.

Information Gathering

The Subcommittee convened a public hearing to consider testimony from representatives from American Samoa, the Commonwealth of the Northern Mariana Islands, the Federated States of Micronesia, Guam, the Republic of the Marshall Islands, the Republic of Palau, Puerto Rico, and the U.S. Virgin Islands. The meeting was held on July 14-15, 1998, in Washington, D.C., and was open to the public. The representatives from the islands were asked to discuss issues relating to health statistics, health information systems, data needs and their governmental capacity to manage the health of their population.

Federal agencies were also invited to participate by giving brief presentations regarding their programs and data activities relating to the Pacific insular areas, Puerto Rico and the Virgin Islands. Federal agencies participating included the Centers for Disease Control and Prevention, the Health Services and Resources Administration, the Substance Abuse and Mental Health Services Administration, and the Health Care Financing Administration. Representatives from HHS Regional Offices for Regions II and IX, the Department of Energy, and the Department of Interior also participated. A representative from the Census Bureau was present. The federal

agencies were asked about their role in supporting data infrastructure development and/or data collection and analytical activities in the insular areas.

The study director from the Institute on Medicine which had conducted an inquiry into health care needs in the Pacific insular areas also attended. The panel issued a report¹ which focused charting a course for health care services in the Pacific insular areas over the coming years. This report describes some data needs associated with both public health and the delivery of health care services.

The Subcommittee examined the relations between these islands and the Federal government with regard to the current status of health data collection, analysis, and utilization. The Subcommittee's assessment included the adequacy of the available health data and statistics, as well as the health information systems for assessing population health needs and health service requirements; examining the results of Federal public health spending; and documenting *Healthy People* objectives. With a goal of developing recommendations for improving health information systems in the Pacific insular areas, Puerto Rico, and the Virgin Islands, the Subcommittee's examination included identifying impediments to improving health data collection and use; learning about any special considerations involving privacy and confidentiality; and identifying the most critical areas where health data gathering capabilities are undeveloped but essential.

The findings and recommendations contained in this report are based on information collected during the July 1998 hearing. Since that time the NCVHS has been pleased to learn of some significant new and ongoing initiatives which have components designed to improve the health data area infrastructure in the islands. Because these occurred subsequent to the July 1998 hearing however, these initiatives are not covered in this report.

II. Background on the Insular Areas

Any attempt to examine aspects of contemporary living in the Pacific insular areas, the Virgin Islands and Puerto Rico must take into account the unique characteristics of the islands. While all these areas vary substantially from the mainland U.S., there is also considerable variation among the islands themselves. One source of variation is the differing

"I think that you have to look at us at different levels. I don't want to sound harsh or bragging or anything, but we are at different steps to our goal. We are all looking to get to the same goal, but we are in different stages. I think that each territory or possession has its own worries and hard times on priorities. Basically we have the same problems, but some are in a starting stage, some are in a middle stage, some are a little forward in their work."

Ruth Zamora, Puerto Rico

¹Pacific Partnerships for Health: Charting a Course for the 21st Century. Committee on Health Care Services in the U.S.-Associated Pacific Basin, Division of Health Care Services and Board on International Health. Feasley, J.C. and Lawrence, R.S., eds. National Academy Press, Washington, DC, 1998.

political relationships these areas have with the U.S. The Department of Interior (DOI) has the lead responsibility for maintaining the political relationships with the Pacific insular areas and the U.S. Virgin Islands.

The mission of the Department of Interior's Office of Insular Affairs is to build mutually beneficial partnerships between insular areas and federal and other sources of assistance and to provide financial and technical assistance to help the insular governments attain locally determined economic, social and political goals. The office also facilitates the development and implementation of federal policies as they affect the insular areas.

The Pacific insular areas are spread over a huge area, roughly the size of the continental U.S., across several time zones and the international date line. Their economies are generally quite dependent on the U.S. The populations, while totaling only about 500,000, are growing rapidly. The people are sometimes crowded into urban centers and tend to be relatively young and with low incomes. In addition, the cultures and languages vary among the areas, and even within certain of the political entities. Health concerns are often unique to a particular area or culture and data collection efforts must be tailored to reflect this.

"We have added another item to the birth certificate which is the chewing of the betel nut. In the islands it is popular to chew betel nut. It is like a nut that you chew with lime juice and certain mint leaves and you get the ups. You chew it and you get heated up and it is like a stimulant.....we have added this item to study the possible association between chewing the betel nut and low birth weight or high risk babies"

Magdalena Sablan, Commonwealth of the Northern Marianas

The U.S. Virgin Islands and Puerto Rico are U.S. territories with locally-elected governments. The six Pacific island jurisdictions are either U.S. territories or independent nations in free association with the U.S. according to terms of a Compact of Free Association. Guam and American Samoa are territories of the U.S. The Commonwealth of the Northern Mariana Islands is a commonwealth in political union with the U.S. Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands are sometimes referred to as "Flag Territories." The Republic of Palau, the Republic of the Marshall Islands, and the Federated States of Micronesia are termed "Freely Associated States. They are sovereign nations covered by Compacts of Free Association which are agreements designed to mutually benefit these nations and the U.S. For example, the U.S. retains its rights to put military personnel and military bases if necessary in the freely associated states and in return the states are covered under the protective umbrella of the U.S. and are eligible for certain grants. Each of the three freely associated states requested that U.S. public health service programs be made available to them. These programs include grants for mental health and substance abuse programs, maternal and child health, community health centers, several categorical grants from the Centers for Disease Control and Prevention, and Title X Family Planning Grants. However, the freely associated states are not eligible for either Medicare or Medicaid.

In this report, the term “insular areas” is used to refer both to the flag territories and the freely-associated states in the Pacific. The DOI has lead responsibility for Federal program coordination, disbursement and monitoring responsibilities for U.S. funds annually provided these island nations under the terms of the Compacts of Free Association. The funds are transferred with few restrictions or reporting requirements. The political relationship between the individual areas and the U.S. is described below. Table I. summarizes the political status of each area vis a vis the U.S. and also presents some information on geography and population size.

Territories and Commonwealths

As mentioned earlier, even though there are large differences in political status, culture, the sophistication of health information systems and many other factors, the Subcommittee chose to base this study and report on the U.S. Virgin Islands, Puerto Rico, and six Pacific insular areas. Each of the areas is described briefly below and in Table I. Figures 1 and 2 are maps showing the locations of Puerto Rico, the Virgin Islands, and the Pacific insular areas.

Puerto Rico is a self-governing commonwealth in association with the United States. Puerto Rico has authority over its internal affairs. The U.S. controls such matters as: interstate trade, foreign relations and commerce, and other areas generally controlled by the federal government in the U.S. Puerto Rican institutions control internal affairs unless U.S. law is involved. Puerto Rico elects a non-voting delegate to Congress. The major differences between Puerto Rico and the 50 States are its local taxation system and exemption from Internal Revenue Code, the ineligibility of Puerto Ricans residing on the island to vote in presidential elections, and its lack of participation in the distribution of some revenues reserved for the States. Beyond those differences, the Puerto Rican people generally possess all the rights and obligations of other U.S. citizens. While Puerto Rico does not lack for hospitals and clinics, a large portion of the island’s population has historically lacked health insurance. This has prompted a health care reform movement with an aim to guarantee health care to all citizens through a managed care model.

The U.S. Virgin Islands (USVI) is a United States territory with a locally-elected government. Residents born in the USVI are citizens of the United States and they elect a Governor, unicameral (15-member) Legislature, and delegate to Congress. The USVI is an organized territory because Federal legislation - an organic act - has established the institutions of local government. It is an unincorporated territory because not all the provisions of the U.S. Constitution apply. The territorial court system has jurisdiction for all local legal issues. The Virgin Islands Department of Health operates the clinics on the islands. Two new hospitals were opened in 1982.

American Samoa is termed an unincorporated and unorganized territory of the United States. It is "unincorporated" because not all provisions of the U.S. Constitution apply. It is "unorganized" because Congress has not provided the territory with legislation that would provide for the organization of the government and its relationship to the Federal Government. Congress has delegated the authority over American Samoa to the Secretary of the Interior, who in turn

authorized the territory to draft the constitution under which it operates. American Samoa elects a non-voting delegate to Congress. American Samoans are nationals of the United States and may become naturalized U.S. citizens. American Samoa is the only U.S. territory south of the

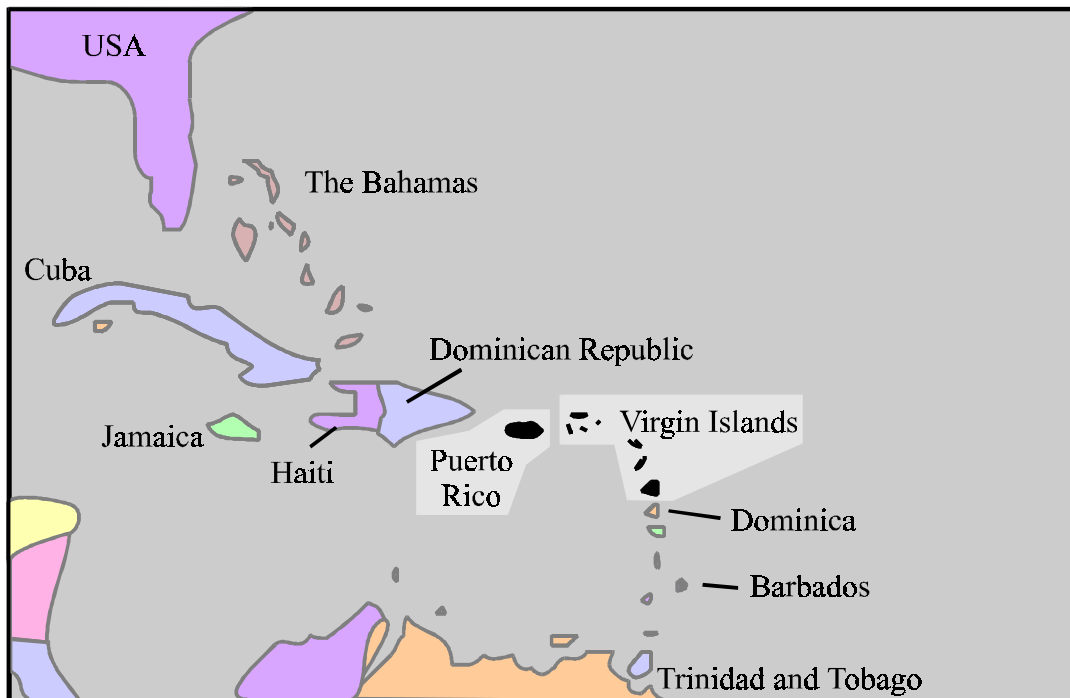


Figure 1

Map of the Carribbean highlighting Puerto Rico and the Virgin Islands (Note- Map does not distinguish between U.S. and British Virgin Islands)

equator and the only one of the Pacific insular areas on the U.S. side of the international date line. The LBJ Medical Center provides dental, general medical, and emergency care services to the residents of American Samoa. Persons requiring extensive special health care are transferred to Hawaii or New Zealand.

The Commonwealth of the Northern

Mariana Islands (CNMI) is a self-governing Commonwealth in union with the United States. The people of the CNMI chose to join the United States in a 1975 act of self-determination and were granted U.S. citizenship in 1986. Pursuant to a locally-adopted constitution, they elect a Governor, bicameral legislature, and Washington Representative. The Department

of Public Health is the sole provider of comprehensive health services in the CNMI. There are several small, private medical and dental clinics on Saipan, none on Rota or Tinian. Rota and Tinian have health centers and each of the inhabited outer islands has one dispensary. A dispensary has been opened in the heavily populated southern village of San Antonio on Saipan; a full-time nurse provides public health services (immunization, prenatal, referral services, etc.) The Commonwealth Health Center is located on Saipan and is the principal health care facility in the CNMI. The hospital is a 64-bed inpatient, full service facility, as well as a 10-bed Psychiatric Unit and a 5-unit Haematolysis service center.

Guam is a United States territory with a locally-elected government. The people of Guam elect a Governor, who serves a four-year term, 21 senators who serve two-year terms in a unicameral legislature, and a Delegate to Congress, who also serves a two-year term. The people of Guam became U.S. citizens in 1950 when the Congress enacted the Guam Organic Act, which established institutions of local government and made Guam an organized territory. Guam is an unincorporated territory because not all provisions of the Constitution apply to the island. The Guam Memorial Hospital, with 147 beds, is government-owned and is the major health facility in Guam and Micronesia. The U.S. Naval Hospital serves military personnel and dependents as well as veterans. Guam's Department of Public Health operates

The Commonwealth of the Northern Mariana Islands had an estimated population of 59,913 in 1995. This represented a nearly 40 percent increase over the 1990 population.

A Report on the State of the Islands, U.S. Department of Interior

The health care delivery systems of the different jurisdictions in the (Pacific) region reflect the challenges and strengths unique to the islands. The health status of the islanders naturally varies within and among the jurisdictions. In general, however, almost all health indicators for islanders are worse than those for mainland Americans. This is most notably so in the freely associated states. The systems must deal with health conditions typical of those of both developing countries (e.g., malnutrition, tuberculosis, dengue fever, and cholera) and developed countries (e.g., diabetes, heart disease, and cancer.)

“Pacific Partnerships for Health: Charting a New Course.” Institute of Medicine

about a dozen medical and dental clinics. Guam also has an inpatient/outpatient mental health facility run by the Department of Mental Health and Substance Abuse. About 140 physicians and 30 dentists practice in Guam. Guam faces the problem of building up the civilian economic sector to offset the impact of military downsizing.

Freely Associated States

Palau is a sovereign state associated with the U.S. through the Compact of Free Association. Palau has a constitutional government, modeled on the United States presidential form, with three coequal branches - executive, legislative and judicial. Palau has a federal system with a national government and sixteen state governments, each of which has a constitution, governmental structure and elected officials. The terms of the Compact between Palau and the U.S. run until 2009. Two private medical clinics and a new public hospital provide general medical and dental care.

The Federated States of Micronesia (FSM) is a sovereign State within the international community. The U.S. accepted the responsibility for defense and security as delegated under the FSM Constitution, and a Compact of Free Association which, was signed in 1982. It has been a member of the United Nations since 1991. The FSM Constitution, like that of the US, provides for three separate branches of government at the national level - Executive, Legislative and Judicial. It contains a Declaration of Rights similar to the US Bill of Rights, specifying basic standards of human rights consistent with international norms. The basic Compact is in place indefinitely, however for both FSM and the Marshall Islands (below) certain provisions of the Compact expire on October 21, 2001. By October 21, 1999, the U.S. Government and the FSM Government must begin discussions regarding those provisions of the Compact which expire. The period of discussion will extend until no later than October 21, 2003. Each of the four FSM states has a state-hospital; however, their levels of staff expertise and resources vary significantly.

The Marshall Islands and the U.S. Government signed the Compact of Free Association, which went into effect in 1986, providing the means for the Marshall Islands to gain international recognition as a sovereign state. The Compact recognizes that the Marshall Islands is a sovereign nation that can conduct its own foreign policy. In 1991, the Marshall Islands joined the United Nations and it maintains diplomatic relations with fifty-eight other nations. As with FSM above, renewal of the Compact of Free Association

between the U.S. and the Marshall Islands is now being discussed. Majuro, the capital, has a government hospital. A major Community Health Center, the only one on the Marshall Islands, is located at Ebeye in the Kwajalein Atoll. Each outer island community has a health assistant

I can tell you now that if the Compact is not renewed, it will have a dramatic effect on the Marshall Islands in particular. A large portion of our revenue comes from the Compact. That is just a basis in addition to the federal grants. It will mean everything. It will mean the world, basically. We will be seriously affected.

Jonathan Santos, Marshall Islands

connected by marine high frequency radio to the main center in Majuro. Preventive health care has become the main priority of the health ministry.

III. Federal Activities Relating to Health Data

Within HHS, the **Regional Offices** serve as a bridge between policy makers in Washington and the islands. Region II's responsibilities cover the U.S. Virgin Islands and Puerto Rico, while Region IX is responsible for the Pacific insular areas. Within the organizational structure of the Region IX is the Office of Pacific Health and Human Services (OPHHS) which deals directly with the islands. Of the Pacific insular areas, only Guam, American Samoa, and the Commonwealth of the Northern Marianas are eligible for major HHS health programs like Medicare and Medicaid. While the major HHS entitlement program in which the freely associated States participate is Head Start, they are also eligible for most public health programs.

Blood banking in the Pacific insular areas is virtually non-existent except in Guam. When transfusions are needed, the community responds by donating blood. Testing for viruses, including HIV, if done at all is done after the fact.

Joseph Iser, HHS, Region IX

Through the OPHHS, Region IX provides and develops technical assistance to the Pacific insular areas. They also maintain an awareness of health and human services problems in these areas and work with the HHS operating divisions, the Department as a whole, and other Departments to find resources to solve these problems. Even for the OPHHS, travel costs to the Pacific insular areas are substantial and effectively prohibit the Office from carrying out many activities in which it would otherwise engage. Emerging teleconferencing and long-distance learning technologies potentially can reduce the need for travel, but currently the resources to use the technology are either not in place or not working as well as desired.

"Head Start is an anomaly out of the Administration for Children and Families, because it has separate Congressional legislation that allows programs to be based in the freely associated States. Otherwise, none of the other major HHS entitlement programs including Medicare and Medicaid and other ACF or Administration on Aging programs are eligible to be established in the freely associated States."

Joseph Iser, HHS, Region IX

Other health groups, such as the World Health Organization (WHO) also operate with significant influence in the Pacific and try to improve the health status of the population. While certainly not without benefits, these programs may have reporting requirements substantially different from those of HHS programs. This contributes to the fragmentation and compartmentalization of health information systems in the islands. One organization, the Secretariat of the Pacific Community is working to harmonize health data requirements in the region.

The role of the **Centers for Disease Control and Prevention (CDC)** in the Pacific insular areas, Puerto Rico, and the Virgin Islands with respect to health data activities is largely organized around surveillance issues with the exception of the National Vital Statistics System administered by the National Center for Health Statistics (NCHS). CDC considers such surveillance to be the corner stone of public health practice. Categorical funding provides some support for health information systems focused on certain diseases, but the bulk of the surveillance work that CDC does is dependent on working relationships with States and national associations.

“We have access to the statistics compiled in the Virgin Islands and Puerto Rico which have been very helpful. We have found however that sometimes trying to mesh CDC statistics and the statistics coming from the jurisdictions doesn’t always work and makes comparisons difficult.”

Robert Davidson, HHS, Region II

With regard to disease surveillance among the Pacific insular areas, Puerto Rico, and the Virgin Islands, a significant CDC contribution to surveillance comes in the areas of technical assistance in the form of on-site training. However, since this is very expensive to do in the Pacific, efforts in training and strengthening the public health infrastructure has been limited. The most heavily invested areas have been immunization, tuberculosis, HIV, and sexually transmitted diseases, because these are categorically funded areas. When disease outbreaks occur in the islands and there is a need for an investigation, CDC staff will usually travel to the affected area as the infrastructure locally is often limited in capacity. Again training efforts aimed at strengthening the infrastructure are constrained by travel expenses, and hampered by personnel turnover in the islands and challenges relating to obtaining needed computer hardware and other supplies. One CDC initiative, with HRSA as a partner, may provide a new way for the island areas to strengthen their health information systems. This initiative is referred to as “investment analysis” and would allow recipients of categorical grants to divert portions of categorical funds and direct them in a flexible fashion for developing or strengthening information infrastructure. In the past, Puerto Rico, the Virgin Islands, and some of the Pacific insular areas have conducted behavioral risk factor surveys with support from CDC. Table II lists by island CDC programs which have a health data component.

At the **National Center for Health Statistics**, the health data focus on the islands is almost entirely on vital statistics. Guam, Puerto Rico, and the Virgin Islands have historically furnished NCHS with records of vital events. Arrangements are now underway with American Samoa and the Commonwealth of the Northern Marianas to join the national system. The need for training of vital registrars in the Pacific insular areas is significant and hampered by the cost of travel. NCHS has no arrangements with the freely associated States of Palau, the Marshall Islands, and the Federated States of Micronesia covering the provision of vital records to the national system. In 1997, Puerto Rico invited NCHS along with the National Association for Public Health Statistics and Information Systems to undertake an evaluation of the Commonwealth’s vital and

health statistics systems. That effort led to a brief report² of findings and recommendations. Problems cited include inadequate staffing levels, high turnover rate among staff, insufficient numbers of personal computers, timeliness of reporting, and inadequate sharing of funding from other agencies in the Commonwealth who utilize health data. Table III lists by island the involvement with NCHS.

At the **Health Resources and Services Administration (HRSA)** health data involvement with Puerto Rico, the Virgin Islands, and the Pacific insular areas is largely related to grant reporting requirements. HRSA funds States and communities through grants focusing on different aspects of health services. Grants going to the islands are basically one of three kinds: Maternal and Child Health Title V Block Grants, Community Health Center Grants, and Title II Ryan White HIV/AIDS Grants. Each of the islands covered in this report has at least one of these grants. Each of these grants has its own reporting system, and the quality of data coming into HRSA in the reports varies substantially. Recently HRSA has been redesigning the reporting requirements to move more into performance measurement and needs assessment. This effort would allow HRSA to work with its grantees to develop a set of core national measures and then some other measures that the grantees, States, communities, or the islands, could choose from to reflect their own programmatic interests and activities. HRSA health data activities in each of the Pacific insular areas, Puerto Rico, and the Virgin Islands are listed in Table IV.

At the **Substance Abuse and Mental Health Services Administration (SAMHSA)**, health data systems with Puerto Rico, the Virgin Islands, and the Pacific insular areas, also revolve primarily around grants. SAMHSA administers a number of grants, the largest being the Substance Abuse Prevention and Treatment (SAPT) Block Grant, and the Center for Mental Health Services (CMHS) Block Grant. Each of the islands covered by this report receives a grant under these two programs and may receive additional funding as well. Associated with the SAPT Block Grant is a program called Substance Abuse Needs Assessment Program. This is a mechanism for assisting States and other areas to gather data to direct SAPT Block Grant funds to areas of greatest need. In the Pacific insular areas, this program has also been used to develop the basic infrastructure for collecting the data. SAMHSA finds that Puerto Rico, the Virgin Islands, and the Pacific Insular areas, like many rural areas in the U.S., have difficulties meeting federal reporting requirements. SAMHSA has provided technical assistance in the Virgin Islands to increase the collaboration of the Single State Agency for substance abuse and the Department of Health Office of HIV/AIDS/TB to improve their required block grant reporting. As part of SAMHSA's effort to develop a meaningful health data infrastructure, the Agency is interested in collecting data not only on alcohol and drug abuse and mental health but also their public health and social consequences. SAMHSA is exploring approaches to gather information and adapting these methods to the varying geographic and cultural needs of Puerto Rico, the Virgin Islands, and the Pacific Insular areas. It is trying when possible to help develop community work groups and investing in locally-based training efforts. To this end, SAMHSA is working on implementing a plan for a Pacific Islands' Collaborating Initiative for Substance Abuse and Mental Health

² Technical Assessment of Health Statistics and Vital Registration in Puerto Rico, NCHS, 1997

Systems Development project. They are coordinating this activity with the HHS Region IX office, the Pacific Islands Health Officers Association (PIHOA) and also the HHS Office of Minority Health. They have also contracted with a consultant who provides technical assistance to Puerto Rico and the Virgin Islands in data collection, analysis, and interpretation. A list of SAMHSA activities relating to data activities in the islands may be found in Table V.

The **Health Care Financing Administration (HCFA)** collects Medicare claims data and Medicaid reporting data. These data are generally available from Puerto Rico and the Virgin Islands, but not from the Pacific insular areas. Of the Pacific insular areas, only Guam, American Samoa, and the Commonwealth of the Northern Marianas are eligible to participate in Medicare and Medicaid. Because the total population of these islands is relatively tiny compared to the number of overall participants in these two huge health care programs, little attention has been given to completeness or quality of data submitted to HCFA from the Pacific insular areas. In fact, for Medicare there are only about 760,000 or a total of 0.2 percent participants from Puerto Rico, the Virgin Islands, and the eligible Pacific insular areas out of 38,000,000 participants nationally. However, HCFA is working on several ways to improve the utility of Medicare claims reporting data in general and is developing tool-based approaches to help areas do their own data collection and analyses. Some of these tools are available free on the Internet. HCFA health data related activities in the islands are listed in Table VI.

HHS department-wide Asian American and Pacific Islander (AAPI) Initiative³ To identify and address the disparities in health status and access to health and human services for AAPI communities, HHS launched a department-wide Asian American and Pacific Islander (AAPI) Initiative in June, 1997. The AAPI Initiative includes an Action Agenda that has been developed to ensure that HHS is responsive to the health, mental health, and social service needs of AAPIs and improves their quality of life. HHS recognizes the challenges presented by the great diversity of AAPI communities and is taking steps to address the key issues, including disproportionate rates of morbidity and mortality among some populations and lack of access to culturally and linguistically appropriate services.

The **U.S. Department of Energy (DOE)** provides medical care to a small group of Marshall Islands residents and a comparison group because of exposure of the Islands residents to U.S. nuclear weapons testing in the 1950s. The DOE collects data on this group and issues a report every five years. The program is now in transition from having medical care provided by a biannual medical mission to ongoing community-based primary care to be provided by the Pacific Health Research Institute. In addition to treating radiation related illnesses and caring for other conditions, this program intends for the first time to build the public health infrastructure. Enhancing data collection capacities for the Marshall Islands as a whole will be part of this effort, working in partnership with other organizations. This activity is summarized in Table VII.

³The initiative focuses largely on AAPIs living in the 50 States.

The Department of Commerce through the Census Bureau provides technical assistance to the Virgin Islands and the Pacific insular islands through grants and workshops in cooperation with the Department of Interior (see below). It also conducts the decennial censuses on Puerto Rico, the U.S. Virgin Islands, American Samoa, the Commonwealth of the Northern Marianas, and Guam. In the past Palau was included in U.S. censuses but it will not be in the future. In the U.S. Virgin Islands and American Samoa, the Commonwealth of the Northern Marianas and Guam, the censuses are conducted as joint projects with the local governments. In Puerto Rico the Census Bureau conducts the census. The Bureau also periodically conducts or assists the islands in conducting intra-censal surveys, collecting data on the labor force, household income, and expenditures. Census data of course are often critical as denominator data for health studies. There is some question of the accuracy of intra-censal estimates for the islands and for the Pacific insular areas in particular. Census activities are listed in Table VIII.

The Department of Interior's Office of Insular Affairs annually produces a report entitled "State of the Islands." Most of the data come from secondary sources. While the report typically contains only a limited amount of health information, the descriptive text provides an excellent introduction to the politics, geography, population, commerce, culture, infrastructure and environment of the Pacific insular areas and the Virgin Islands and is very valuable for providing a local context. The DOI has a technical assistance program which totals approximately \$6 million divided among the four territories and three freely associated states. This is used for a variety of programs, emphasizing government efficiency including computerization, training, economic development, health programs, anti-drug programs, and statistics. Statistical funding has been used primarily for a reimbursable agreement with the Census Bureau. That amount has been increasing as DOI has been trying to emphasize the actual technical assistance and training rather than data collection itself in the territories, although it continues to fund three or four surveys and similar activities a year in the territories.

In concluding this summary of federal activities relating to health data in the island areas, it should be noted that as mentioned earlier, the **Institute of Medicine** (IOM) completed a study on the health care delivery system of the Pacific insular areas. The study was sponsored by the HRSA. The study panelists were commissioned by HRSA to perform several tasks, which basically involved collecting all readily available information on the status of health service programs in the area, analyzing the information, and developing a strategic plan to address inadequacies and problem areas.

Although the IOM study did not focus on health data, the panel found that the quality of health data collections varies considerably among the Pacific insular areas. The report noted that there are multiple problems surrounding health data including difficulties

Father Francis Hezel, a Jesuit priest working in the Federated States of Micronesia, has estimated that on the Island of Chuuk, roughly 55 to 60 percent of deaths were not reported. His estimate was calculated based on examining death certificates and comparing his findings to people's recollection of deaths on the island.

Jill Feasley, formerly of the Institute of Medicine

in collecting the data, particularly when births and deaths occur outside hospitals, and data collection burdens are excessive relative to resources available. There is a lack of standardization of data requirements among groups requesting data, and there may be problems associated with computerization and automation because of insufficiently trained personnel, lack of appropriate hardware and software as well as unreliable power supplies.

In the past it has been sometimes perceived that there has often been little local utility for the data the federal government requires and in some cases this has had an impact on validity of data collected and reported. At the same time, some federal programs, such as HRSA's MCH program are beginning to tighten up reporting requirements, often along the lines of Healthy People goals and objectives.

One recommendation of the IOM study that is directly relevant to the health data was a call for the establishment of a regional based independent oversight group to provide technical assistance on issues like health data and to monitor the quality of data reported. Another recommendation involved the suggestion that each jurisdiction develop a health improvement bench marking process as a way to increase community involvement. Finally, the study report called for education and training of the local health care and public health work forces and establishing the local infrastructure to continuously provide this education and training.

I would specifically highlight for your Subcommittee's consideration, our panel's recommendation that if there is special training that is done to improve health data collection and analysis, that it be done as much as possible using educational resources that are available on the islands.

- Jill Feasley, formerly of the Institute of Medicine

IV. Data Issues and Needs in the Pacific Insular Areas, Puerto Rico and the Virgin Islands

At the July 1998 meeting, federal representatives presented summaries of their agency's activities in the morning of the first day. Representatives from the islands summarized their data needs in the afternoon and in part of the second day. The second day ended with a round table discussion. Representatives from the Pacific insular areas, Puerto Rico and the Virgin Islands addressed the Subcommittee reporting on their health information infrastructure and the problems faced. Although there is wide diversity among these areas, the representatives all agreed on the importance of high quality health information for informing decision making. Their health data systems, while facing the same classes of problems, are in differing stages of development. Puerto Rico, for example, faces problems

"I have been so worried about HIPAA. We are under health care reform, but we still have the Medicaid data base and we serve Medicare patients, so we have to comply with HIPAA. Every time we have a chance, I talk about HIPAA in every meeting I go. People stare at me and say, what is this lady talking about."

Ruth Zamora, Puerto Rico

similar to those faced by some states, such as, continued reliance on mainframe computing, difficulty in competing in the marketplace for highly skilled technical human resources, and complying with the administrative simplification provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

Many insular areas lack a basic

computing infrastructure and markets for highly skilled technical human resources. Some problems did not affect all areas. The Pacific insular areas face problems collecting data over widely scattered geographic areas without a consistent framework, mutually agreed upon format, or standard variables, while these problems affected Puerto Rico and the Virgin Islands to a lesser extent.

Although this concern is not unique to the areas studied in this report, another issue involves overcoming a perception that sometimes even the collection of critical data pointing to a public health problem often does not lead to action. An example of this is the known low rates of childhood immunization in the FSM, especially on the island of Chuuk. While rates are suspected to be in the neighborhood of 40 to 50 percent, little action has been taken to improve the rates, either by the U.S. government or locally. When data are collected and a problem is identified but no action is taken, the incentive to collect additional data or to strengthen a data collection infrastructure is greatly diminished. Those testifying before the Subcommittee identified several major needs or problems:

- With the possible exception of Puerto Rico, senior level officials and the population at large need to better understand the importance of collecting health data and data sharing needs to be encouraged.
- Health system planning needs to be strengthened in most areas.
- Data quality should be improved, both through development of new data systems and strengthening and integrating of existing systems.
- Lack of trained technical personnel make improvements in data collection difficult---especially the lack of statistical and analytic skills.
- The Pacific Insular areas need local capacity for training in epidemiology, computer science,

“When it comes to data sharing, each part of the health information system wants to do their own thing. Getting health data is like how to approach a dog to release a bone.”

Fale Uele, American Samoa

“In Palau we gather a lot of data. But in order to make use of these data, we need a planner to sort out the data, use the data, and hopefully be able to direct the data into the right places, whether it be for legislative purposes, to enact laws and regulations for the health industry, or for other purposes.”

Nick Ngwal, Republic of Palau

bio-statistics, health planning and related fields.

- Hardware and software are outdated, and in some instances unreliable.
- Currently available funding, especially from Federal sources, tends to be categorical and promotes the development of single use data systems rather than support overall infrastructure development.
- Population data, as well as health data systems, must be strengthened before adequate incidence rates can be development in many areas.

The following sections provide a synopsis of data system requirements identified by the representative from each insular area.

Commonwealth of Puerto Rico: A wide range of health information is collected including registries and vital statistics. However, there is a need to strengthen existing systems, for example, through providing reliable municipality estimates, improving timeliness of data, integrating different systems, eliminating redundant data collection as people go through the health care system and expanded data collection in the areas of addiction and alcohol abuse. Failure to include Puerto Rico in the sampling frames of most stateside surveys, especially Census programs like the Current Population Survey, has short-changed the Commonwealth in receiving Federal program funds—even through its residents are U.S. Citizens. As an example Puerto Rico received less money for the Child Health Insurance Program than it would have if it were treated as a State with funding based on data from the CPS.

“Puerto Rico Medicaid payments are capped at \$167 million. That is not even 10 percent of what we would receive if we were being treated as a State.”

Yvonne Benner, Puerto Rico

A major problem for Puerto is attracting experienced human resources to manage data systems, prepare statistical analyses and reports and respond to outside requests for data in a timely manner. While universities in Puerto Rico are providing the necessary training, the government is not competitive with the private sector in hiring these highly skilled resources. The most advanced computer technology is also not available. Many systems are still mainframe based. Training in the use of advanced statistical software packages is also needed.

“What resources do we need on Puerto Rico? We need human resources. We need to retrain personnel. We need to hire new personnel. That sounds familiar to everybody.”

Ruth Zamora, Puerto Rico

Virgin Islands: Currently, health information is not systematically used in developing health policy and no overarching health plan has been developed since the 1980s. Indeed the need for better health information to inform policy making is not recognized within the health department, or more broadly by the general population—who are not receptive to questionnaires and telephone surveys. First and foremost, the Virgin Islands need assistance in developing a culture supportive of health data collection and analysis as core functions of the health department. Between two thirds and three quarters of current data collections today are supported by Federal funds. Existing data are frequently incomplete, manually stored, redundant and there is limited standardization across data sets. For example, vital statistics are incomplete and consistent data on service utilization and immigration is lacking. Incidence and prevalence rates cannot be generated for many chronic diseases—mortality data are still used as proxy for morbidity data. Trained staff and computing resources are also unavailable—staff have limited training in designing and administering surveys, analyzing data and preparing reports.

“At a more fundamental level , I believe a change or paradigm shift is needed, just in the way we think about data and the importance of data, the importance of quality data. Just having data isn’t enough. We need quality data.”

Noreen Michael, The U.S. Virgin Islands

American Samoa: It is difficult to get access to needed health information. The health information system is very fragmented, and there is limited awareness of data maintained by others. The most frequent problems are insufficient cooperation, inadequate communication, insufficient training, and duplicative or unnecessary data collection. At the same time, there has not been a health survey since 1995. Consequently data have not been used to inform action.

Guam: Information is provided to legislators who approve the health department’s budget. Guam has not yet introduced managed care, but is looking into it. Most data collection is based on Federal program requirements. Guam collects vital statistics and maintains cancer and diabetes registries. Other disease specific data are also collected. Health information systems are varied and fragmented. Information is difficult to obtain in a timely manner. Integration of data systems would support improved service planning. Because Congress caps the allocation of federal funds to Guam at a certain amount, rather than calculated from a population-based format as is routinely done for States, Guam receives fewer dollars for federal programs such as Medicaid and TANF than it would if it were a State.

“I think integration of the information systems that exist would definitely help Guam, especially in terms of analyzing the information that is available and planning for services as a whole community as opposed to departments in isolation providing specific services to the people that they do serve.”

PeterJohn Camacho, Guam

Commonwealth of the Northern Marianas (CNMI) A health planning and statistics office exists that consists of the Director and two staff persons. They are in the process of implementing new software systems and are instituting U.S. standard forms for vital statistics. CNMI had characteristics similar to Guam and faces challenges similar to those described in other areas such as turf battles and inadequate computing equipment and technical staff. Fragmentation of health information systems is a problem. CNMI conducted a Census in 1995 and has undertaken many special purpose surveys, head start, dental, breast feeding, but nothing equivalent to the National Health Interview Survey.

The Republic of Palau: System-based problems exist similar to those in other Pacific insular areas. Health planning is one of the critical areas where help is needed along with a networked computer system and technical training. Other needs are epidemiologic capabilities and technical assistance. Much of the data now gathered are rarely used other than to satisfy Federal program reporting requirements. There is a lack of staff for data analysis. It is very difficult to integrate data from differing systems.

The Federated States of Micronesia (FSM): Health information systems in FSM are being reformed. The current situation is one in which there is little coordination among agencies while at the same time increasing demands for data raise the level of confusion among health care providers and lead to even less coordination of services. Small infusions of Federal funds, around \$50,000, would go a long way toward supporting health information infrastructure development. Medical and vital statistics do not currently receive such support. FSM is moving toward standardization in terms of data entry, outputs and definitions of terms/diseases and assigning responsibility for continued support and maintenance of health data components. All morbidities, births and deaths occurring in one of FSM's hospitals are reported, however, reporting rates are lower in outlying areas. Overall, about 81% of births and 50% of deaths are reported. FSM is also experiencing staffing shortages and needs training, for example, on the use of ICD9 and ICD10.

The Marshall Islands: There is a need for updated information to inform planning. For example, the last official census was in 1988 and health planning since that time has based on forecasts. Health data needs should be evaluated in order to ensure that scarce funds are allocated to the highest priority uses. A massive downsizing of the government's budget is underway. The newly designed Health Management Information System, developed by Boston University with some help from Queensland Institute of Technology, should provide continued strengthening of health data. Vital statistics obtained from the outer island are under reported. This system, which is mostly paper based, is being computerized. Standardization and completeness of data need improvement. The Marshall Islands are experiencing the same manpower shortages and needs for technical assistance as other areas.

V. Subcommittee's Review and Recommendations

In reviewing the testimony, and bringing its findings to the full NCVHS, the Subcommittee noted that there are more than the ordinary sorts of complexities involved in crafting a set of proposals to promote and strengthen health data collection in Puerto Rico, the Virgin Islands, and the Pacific insular areas. Currently there is marked diversity in the sophistication of the data collection systems on the islands; geographically the island groupings are dispersed over huge areas, as well as the

Pacific insular areas being huge distances from the continental U.S.; and the islands political relationships to the U.S. vary greatly. Much as the cultures of the islands are markedly different, the public health needs are diverse as well. There are some truly basic problems such as the lack of reliable electrical power in some areas, as well as the disproportionate risk of damage to the physical infrastructure from hurricanes or other severe storms. Still there are certain uniform principles along which recommendations may be developed which would broadly apply to all of the areas. First and foremost all stakeholders, HHS, the island governments, the health systems, and the people of the islands need data relating to the consequences of inadequate public health and medical interventions to target areas for improvement. Currently there is an overall, and substantive need across all jurisdictions for strengthening existing data collection and analysis capacity as a means of improving public health. Within this overall theme, several specific needs emerged from the hearing:

- There is a common, major need for promoting capacity-building, including local workforce and training, rather than relying on bringing in outside assistance to address problems. HHS must recognize that developing an information infrastructure and strengthening the health data capacity are long-term projects, and to achieve these goals there must be long-term plans in place, consistency, and above all perseverance in carrying out the plans.
- The approach used by Healthy People 2010, which encourages States and communities to set locally appropriate public health goals and collect the data to monitor their progress toward goals could be encouraged for adoption on the islands. This process allows for local “buy-in” both to the improvement of the health of the population but also to the collection and analysis of data that are directly relevant to the local area.
- Although it is not a problem unique to Puerto Rico, the Virgin Islands, or the Pacific insular areas, the current categorical system of block grant funding hampers the development of integrated health data systems in these areas.

“There are electrical brown outs and failures throughout the jurisdictions, but in particular in places such as Chuuk, the most populous island of the FSM.....Up to date telecommunications systems are accessible on the main islands but not necessarily on the outer islands, where there may not even be electricity.”

Joseph Iser, HHS, Region IX

- There is also a need for a more inclusive approach on the part of Federal Departments to addressing the data needs of Puerto Rico, the Virgin Islands, and especially the Pacific insular areas. Rather than ruling these areas out of planned activities because of their distance from the mainland, Federal agencies should be asked to address in their work plans how they intend to integrate these areas into their health data initiatives.

Based on these considerations, the NCVHS created recommendations in four areas: health data infrastructure, local data processes similar to the Healthy People 2010 approach, an expanded or more flexible approach allowing for increased federal funds to be used for the development and maintenance of a health data infrastructure, and a voice at the HHS policy table for representatives of Puerto Rico, the Virgin Islands, and the Pacific Insular areas. Within these four broad areas, it is recognized that the needs of Puerto Rico, the Virgin Islands, and the Pacific insular areas differ because of the different stages development of health information systems. However, to a greater or lesser extent, all apply. Specific action steps taken by HHS must account for the diversity of the islands in terms of their needs and stages of development.

Toward an improved public health information infrastructure.

Recommendation 1: HHS should assist Puerto Rico, the Virgin Islands, and the Pacific insular areas in developing improved health information infrastructures which will support the collection and use of quality health data. The information infrastructure must include both the tools and trained professionals to collect and compile data, as well as the tools, hardware, software, and trained professionals needed to analyze the data and produce information useful to policy makers at the local level.

Infrastructure development can be accomplished by a variety of means with education being a primary method. There is a need to establish a cadre of trained health data professionals, especially in the Pacific insular areas and to insure that this expertise remains in the islands and to facilitate training of other professionals. Each of the islands have at least a community college. Puerto Rico, of course, has several colleges and universities, some with medical schools. These local facilities should be brought into the training process. Training is needed in many areas, including but not limited to, vital statistics, medical coding, quality control, use of standard statistical analytical packages including those available at no charge over the Internet, and use of data for health planning. Since the initial costs of training can be high for the remote islands, options should be explored for long distance learning. Additionally, updated computer hardware and software is needed for all of the islands. As mentioned earlier in this report, in April, 1997 an NCHS led team of national and State experts visited Puerto Rico to evaluate the Commonwealth's vital and health statistics programs. The team made some specific recommendations around five categories: staff issues, technical improvements, production and output enhancements, Department of Health data policy, and Department of Health general policy.

Recommendation 2: NCHS should consult with the Puerto Rico Department of Health to learn the status of the recommendations made as a result of the site visit by NCHS and

health data experts and determine if there are specific action steps that HHS could now take to insure implementation of the recommendations.

Recommendation 3: NCHS should continue to expand its vital statistics program into the islands of American Samoa, the Commonwealth of the Northern Marianas, and Guam. Higher payment for vital certificates should be explored as a means of improving accuracy and reliability of vital statistics. In addition NCHS should encourage the development of local vital statistics systems in all of the Pacific insular areas by investigating new, cost-effective training modalities with packaged modules focusing on specific topics. The application of new technologies as used in long distance learning to the training curriculum of the Applied Statistics Training Institute should be studied for use in the Pacific insular areas as well as for Puerto Rico and the Virgin Islands.

Although much has been accomplished to improve both health information systems and the health of the people of the islands with very limited resources, more could be done if there were a wider appreciation for the value of high quality data for effecting positive change. Educating political and other leaders about the utility of information both as a means to make policy decisions and as a tool to secure funding from various sources is very important. To this end it is important to demonstrate that even the limited data available now can be used to improve the lives of the people of the islands. For example, in some of the Pacific insular areas, data raised concerns about low immunization rates, a high incidence of diabetes, substance abuse problems, and other public health issues. To establish a culture which is willing to invest resources in improving its health information systems, showing that data can lead to action steps would be very important.

“I may be wrong, but I don't think money is the problem. I think sometimes when we put the money in front of us, it doesn't solve the problem. If you look at it, we already have resources that we can -- what we need to do is, we need to integrate and utilize the resources better. The point I am trying to say here is, the more we have money, it still doesn't solve it. I think the commitment of the people and the policy directions is the best in the overall health.”

*Amato Elymore, Federated States of
Micronesia*

Recommendation 4: HHS should encourage SAMHSA to continue its plans for developing local infrastructure for substance abuse research and prevention modeled after the National Institute on Drug Abuse's Community Epidemiology Work Group (CEWG). As part of this effort, SAMHSA is facilitating the development of local forums on each of the six Pacific insular areas. These local forums would provide ongoing community-level surveillance of alcohol and drug abuse and the public health and social consequences of abuse, as well as the mental health of the population. SAMHSA would provide training in data collection, including data collection through ethnography and other methods appropriate for the varying geographic and cultural contexts of these areas.

Recommendation 5: Given the associations between drug and alcohol abuse and many communicable diseases and cost-savings which should be accomplished by an integrated approach to prevention and treatment, HHS should support and encourage the long-term plans of SAMHSA and CDC to integrate data collection and training activities on the islands.

The Healthy People 2010 approach

Healthy People 2010 is the national prevention agenda. It is a process by which the most significant preventable threats to health are identified. It promotes public and private sector efforts to address those threats. Healthy People 2010 is based upon the concept that providing the needed information and knowledge on improving health can be done in a format that enables diverse groups to combine their efforts and work as a team to improve health. It can serve as a road map to better health for all that can be used at many different levels: states and communities, professional organizations, groups whose concern is a particular threat to health, or a particular population group. Each participating entity can focus on their unique circumstances, culture, burden of disease, and need. Public health problems, such as low childhood immunization rates, or population groups at risk because of poor diet or lack of exercise, can be identified and action plans developed to lessen the severity of the problems. Healthy People is based on scientific principles and is used for decision making and for action at the local level. There are presently Healthy People coordinators in most of the islands included in this report although the degree of participation in the project varies. Guam has had considerable involvement. There remains much potential for the participation of the other islands in the Healthy People process.

Recommendation 6: Through the Healthy People 2010 process, HHS should continue and expand assistance to the Pacific insular areas, Puerto Rico, and the Virgin Islands in order that they may become full participants in the process. This assistance can take the form of helping to formulate local public health goals and objectives, acquiring the baseline data necessary in order to measure progress, and in strengthening the local data infrastructure to support the monitoring progress.

Recommendation 7: Whenever the data are available, Healthy People 2010 reporting should include information from Puerto Rico, the Virgin Islands, and the Pacific insular areas in a manner similar to that for mainland U.S. populations.

More flexibility with categorical and block grant funds.

While great differences exist between the islands, all are eligible to apply for block grants authorized under the Public Health Service Act. The level of funding these areas receive, in addition to being relatively small, is often capped below the level they would receive were the grants distributed by population-based formulae. The funding levels and the programmatic or legislative restrictions on how the money is to be used make it difficult for the islands to develop and maintain an adequate, up-to-date, data infrastructure.

Recommendation 8 HHS should encourage efforts like those of SAMHSA and joint CDC/HRSA initiatives which allow portions of certain block grant funds to be used for developing information infrastructure. Additional efforts are needed to permit more flexible use of HHS categorical funds for health data-related infrastructure development and maintenance.

A related important issue is Census coverage. HHS block grant formulae and other funding streams often rely on Census data to allocate funds. Currently, some of the islands are effectively “short-changed” in receipt of Department funds because lack of the appropriate Census data. Capped dollar amounts are allocated by Congress rather than amounts based on population data as is done for the 50 States. Representatives at the July meeting from the islands felt that the availability and use of CPS data could strengthen their case for receiving a fair share of programmatic funding. Census data are also of extreme importance as denominators for health statistics such as mortality and morbidity rates.

Recommendation 9: HHS and the Census Bureau should reach an agreement on official population figures for the islands to use for funding purposes and health statistics.

Recommendation 10: HHS should promote the local development of programs and surveys comparable to national ones as appropriate and encourage Census to routinely include Puerto Rico, the Virgin Islands, and the Pacific insular areas in as many of its statistical programs as feasible, especially the Current Population Survey, or other mechanisms which could be used to produce accurate and timely intra-Censal population estimates.

Recommendation 11: HHS should support the development of standard health data reporting requirements for these islands especially since three of the Pacific insular areas are sovereign nations (Palau, the Federated States of Micronesia, and the Marshall Islands) with reporting requirements to groups other than the U.S. government (for example the World Health Organization).

A voice at the HHS data policy table

The implementation of recommendations in this report as well as other activities to improve the availability and utility of data in the insular areas will require their full and active participation. Yet there is no current mechanism within HHS to facilitate such participation. An inclusive approach is needed on the part of federal departments to address the data needs of Puerto Rico, the U.S. Virgin Islands, and the Pacific insular areas.

Recommendation 12: HHS should invite either representatives from the islands, or those with jurisdiction over the islands to participate in the formulation for data collections when such collections might be feasibly be conducted in Puerto Rico, the Virgin Islands, and the Pacific Insular areas.

Recommendation 13: HHS should require agency plans for new health initiatives to include provisions for extending the proposed activities and associated data collections to Puerto Rico, the Virgin Islands, and the Pacific insular areas or to demonstrate that this is not feasible.

Recommendation 14: HHS should act through the Data Council to identify a single point of accountability and contact relating to health statistics, health information systems, and data needs for the Pacific insular areas, Puerto Rico, and the Virgin Islands.

Beyond HHS

Recommendation 15: As another step toward improved health information systems and healthier populations, HHS should work with other Departments, particularly the Department of Interior (DOI) and the Department of Commerce, to encourage the development of a health data systems in the islands. As an example, HHS should urge the DOI to continue providing support for the Census Bureau training program and support for periodic censuses and surveys. HHS should also at the Department level, support and encourage the DOI's efforts to export the IHS' Resource and Patient Management System to the Pacific insular areas. The system is now in use in the Commonwealth of the Northern Marianas and DOI plans to support its implementation in American Samoa in the near future. In addition, HHS should increase collaborative efforts

Ensuring potable water supplies, adequate sanitation, and reliable electricity throughout the (Pacific) jurisdictions must be a clear priority for both the agencies of the U.S. Federal government providing the aid and the communities striving to create healthy islands.

"Pacific Partnerships for Health: Charting a New Course." Institute of Medicine

with groups such as the World Health Organization and the Secretariat of the Pacific Community to devise region-wide strategies for addressing health data needs.

Finally, the Committee recognizes that implementing many of its recommendations will require a commitment of additional resources. We have suggested some mechanisms for spending HHS grant funds more efficiently, including more flexible use of block grant and categorical funding streams. Nevertheless, the scale of need, especially for infrastructure development, is such that additional HHS resources will be required to implement these recommendations. Without these resources, the Pacific insular areas, Puerto Rico, and the U.S. Virgin Islands will continue to face significant barriers to addressing critical public health needs. Given the existing federal responsibility, we encourage HHS to take proactive and effective action to improve the availability and utility of data on public health, chronic illness, and disability in these areas.

Table I. Description of the relation of the Pacific insular areas; Puerto Rico, and the Virgin Islands to the U.S⁴. with Population⁵ and Geographic Information

Island(s)	Relation to the U.S.
American Samoa	Unincorporated ⁶ and unorganized ⁷ territory of the U.S. Interior Department authorized the territory to draft the constitution under which the local government operates. U.S. nationals. (Seven islands, 76 square miles, 1995 population estimated to be 58,000)
Commonwealth of the Northern Mariana Islands	Self-governing Commonwealth of the U.S. Citizenship granted in 1986. (Fourteen islands, 183.5 square miles , 1995 population estimated to be 59,913)
Federated States of Micronesia	Sovereign state, freely associated trusteeship of the U.S. (Six hundred and seven small islands grouped into four states with a land total of 270 square miles and an approximate population of 100,000)
Guam	Unincorporated U.S. territory. U.S. citizens since 1950. (One island, 212 square miles, 1995 population estimated to be 156302.)
Republic of the Marshall Islands	Sovereign state, freely associated with the U.S. (Five islands and 29 atolls with a total land area of about 70 square miles. Estimated population of 56,000.

⁴ One way of sorting these relationships out is to remember that the three freely associated States are independent to the point where they have their own ambassadors to the U.S. as well as their own representatives to the U.N.

⁵ Population estimates are from the Dept. of Interior's Office of Insular Affairs' May, 1998 Fact Sheets on the U.S. Insular Areas and Freely Associated States for all but Puerto Rico which are from an October 1998 release on the population of Puerto Rico .

⁶ Unincorporated means that not all provisions of the U.S. Constitution may apply.

⁷ Unorganized means that Congress has not provided an organic act which would provide for the organization of government and its relationship to the U.S. government. (An organic act of Congress is used to confer powers of government upon a territory.)

Republic of Palau	Sovereign state associated with the U.S. (Three hundred mile long archipelago made up of more than 200 islands, total land area of 196 square miles, with an estimated 1995 population of 17,285.
Puerto Rico	Commonwealth associated with the U.S. Residents are U.S. citizens. (One island, total land area of 3,460 square miles, estimated 1997 population of 3,827,038
U.S. Virgin Islands	Organized but unincorporated U.S. territory, residents born in the USVI are U.S. citizens. (Three major islands with many small cays and out islands, total land area 136 square miles, estimated 1995 population of about 106,800.)

Table II. Major Health Data Activities of the Centers for Disease Control and Prevention in the Pacific Insular Areas, Puerto Rico, and the Virgin Islands.

Island(s)	CDC Major Health Data Activities
American Samoa	Breast and cervical cancer early detection activities; diabetes control programs; HIV/AIDS, and tuberculosis (TB) surveillance; sexually transmitted disease control activities (STD) ⁸ ; general notifiable disease surveillance*; clinical assessment software application (CASA) ⁹ ; perinatal hepatitis B prevention management system
Commonwealth of the Northern Mariana Islands	Behavioral risk factor surveillance; breast and cervical cancer early detection activities; diabetes control programs; HIV/AIDS surveillance*; TB surveillance; sexually transmitted disease control activities; general notifiable disease surveillance*; clinical assessment software application (CASA); perinatal hepatitis B prevention management system
Federated States of Micronesia	HIV/AIDS and TB surveillance; sexually transmitted disease control activities; clinical assessment software application (CASA); perinatal hepatitis B prevention management system; diabetes control
Guam	Behavioral risk factor surveillance; diabetes control programs; HIV/AIDS surveillance*; TB surveillance; sexually transmitted disease control activities; general notifiable disease surveillance*; immunization registry; clinical assessment software application (CASA); perinatal hepatitis B prevention management system
Republic of the Marshall Islands	Diabetes control programs; HIV/AIDS surveillance*; TB surveillance; sexually transmitted disease control activities; clinical assessment software application (CASA); perinatal hepatitis B prevention management system

⁸STD control activities naturally include surveillance, health promotion, partner notification, outreach activities, health education.

⁹ Clinical assessment software application (CASA) allows a clinic to assess its age-appropriate immunization coverage levels.

Republic of Palau	Breast and cervical cancer early detection activities; diabetes control programs; diabetes control programs; HIV/AIDS surveillance*; TB surveillance; sexually transmitted disease control activities; cancer registries; immunization registry; clinical assessment software application (CASA); perinatal hepatitis B prevention management system
Puerto Rico	Behavioral risk factor surveillance; breast and cervical cancer early detection activities; dengue surveillance and program activities; diabetes control programs; HIV seroprevalence studies; HIV testing of blood donors; cancer registries; HIV/AIDS and TB surveillance; general notifiable disease surveillance*; immunization registry; clinical assessment software application (CASA); perinatal hepatitis B prevention management system; vaccine management system (VACMAN)
U.S. Virgin Islands	Behavioral risk factor surveillance; breast and cervical cancer early detection activities; diabetes control programs; cancer registries; HIV/AIDS, TB surveillance; general notifiable disease surveillance; immunization registry; clinical assessment software application (CASA); perinatal hepatitis B prevention management system; vaccine management system (VACMAN)

Note * = Technical support only, no funding

Table III. Major Health Data Activities of the National Center for Health Statistics, CDC, in the Pacific Insular Areas, Puerto Rico, and the Virgin Islands.

Island(s)	NCHS CDC Major Health Data Activities (Vital Records System)
American Samoa	Developing relationship now. Expect to receive vital records from 1997 data year onward.
Commonwealth of the Northern Mariana Islands	Developing relationship now. Expect to receive vital records from 1997 data year onward.
Federated States of Micronesia	None
Guam	Historically has furnished NCHS with data on vital events
Republic of the Marshall Islands	None
Republic of Palau	None
Puerto Rico	Historically has furnished NCHS with data on vital events
U.S. Virgin Islands	Historically has furnished NCHS with data on vital events

Table IV. Major Health Data Activities of the Health Resources and Services Administration in the Pacific Insular Areas, Puerto Rico, and the Virgin Islands.

Island(s)	HRSA Major Health Data Activities ¹⁰¹¹
American Samoa	Maternal and Child Health Title V Block Grant and associated reporting requirements, State System Development Initiative
Commonwealth of the Northern Mariana Islands	Maternal and Child Health Title V Block Grant and associated reporting requirements, State System Development Initiative
Federated States of Micronesia	Maternal and Child Health Title V Block Grant, Community Health Center Grant and associated reporting requirements, State System Development Initiative
Guam	Maternal and Child Health Title V Block Grant, Community Health Center Grant, Title II Ryan White HIV/AIDS Grant and associated reporting requirements, State System Development Initiative
Republic of the Marshall Islands	Maternal and Child Health Title V Block Grant, Community Health Center Grant and associated reporting requirements, State System Development Initiative
Republic of Palau	Maternal and Child Health Title V Block Grant, Community Health Center Grant and associated reporting requirements, State System Development Initiative
Puerto Rico	Maternal and Child Health Title V Block Grant, Community Health Center Grants, Title II Ryan White HIV/AIDS Grant and associated reporting requirements, State System Development Initiative
U.S. Virgin Islands	Maternal and Child Health Title V Block Grant, Community Health Center Grants, Title II Ryan White HIV/AIDS Grant and associated reporting requirements, State System Development Initiative

¹⁰ HRSA grants have program reporting requirements. In some cases a portion of the grant is allocated for administrative purposes which can include information systems activities.

¹¹ Above and beyond reporting requirements, HRSA provided the funds for the 1998 Institute of Medicine report “Pacific Partnerships for Health.”

Table V. Major Health Data Activities of the Substance Abuse and Mental Health Services Administration in the Pacific Insular Areas, Puerto Rico, and the Virgin Islands.

Island(s)	SAMHSA Major Health Data Activities ¹²
American Samoa	Substance Abuse Prevention and Treatment (SAPT) Block Grant, Center for Mental Health Services (CMHS) Block Grant, Protection and Advocacy (P&A) Program, Pathways to Transitions from Homelessness (PATH) Program, Mental Health Statistics Improvement Program (MHSIP) technical assistance, Substance Abuse Needs Assessment ¹³
Commonwealth of the Northern Mariana Islands	Substance Abuse Prevention and Treatment (SAPT) Block Grant, Center for Mental Health Services (CMHS) Block Grant, Protection and Advocacy (P&A) Program, Pathways to Transitions from Homelessness (PATH) Program, Mental Health Statistics Improvement Program (MHSIP) technical assistance, Substance Abuse Needs Assessment ¹⁴
Federated States of Micronesia	SAPT Block Grant, CMHS Block Grant, Substance Abuse Needs Assessment
Guam	Substance Abuse Prevention and Treatment (SAPT) Block Grant, Center for Mental Health Services (CMHS) Block Grant, Protection and Advocacy (P&A) Program, Pathways to Transitions from Homelessness (PATH) Program, Mental Health Statistics Improvement Program (MHSIP) technical assistance, Substance Abuse Needs Assessment ¹⁵
Republic of the Marshall Islands	SAPT Block Grant, CMHS Block Grant, Substance Abuse Needs Assessment

¹²SAMHSA also has the Pacific Islands Collaborating Initiative for Substance Abuse and Mental Health Development for the Pacific insular areas which has been developed and is being implemented.

¹³The Substance Abuse Needs Assessment Program is a mechanism for assisting States and other areas to gather data needed to direct SAPT block grant funds to areas of greatest need. In the Pacific insular areas, this program as also been used to develop the basic infrastructure for collecting data.

¹⁴The Substance Abuse Needs Assessment Program is a mechanism for assisting States and other areas to gather data needed to direct SAPT block grant funds to areas of greatest need. In the Pacific insular areas, this program as also been used to develop the basic infrastructure for collecting data.

¹⁵The Substance Abuse Needs Assessment Program is a mechanism for assisting States and other areas to gather data needed to direct SAPT block grant funds to areas of greatest need. In the Pacific insular areas, this program as also been used to develop the basic infrastructure for collecting data.

Republic of Palau	SAPT Block Grant, CMHS Block Grant, Substance Abuse Needs Assessment
Puerto Rico	Substance Abuse Prevention and Treatment (SAPT) Block Grant, Center for Mental Health Services (CMHS) Block Grant, Protection and Advocacy (P&A) Program, Pathways to Transitions from Homelessness (PATH) Program, Mental Health Statistics Improvement Program (MHSIP) technical assistance, Substance Abuse Needs Assessment ¹⁶
U.S. Virgin Islands	Substance Abuse Prevention and Treatment (SAPT) Block Grant, Center for Mental Health Services (CMHS) Block Grant, Protection and Advocacy (P&A) Program, Pathways to Transitions from Homelessness (PATH) Program, Mental Health Statistics Improvement Program (MHSIP) technical assistance, Substance Abuse Needs Assessment ¹⁷

¹⁶The Substance Abuse Needs Assessment Program is a mechanism for assisting States and other areas to gather data needed to direct SAPT block grant funds to areas of greatest need. In the Pacific insular areas, this program as also been used to develop the basic infrastructure for collecting data.

¹⁷The Substance Abuse Needs Assessment Program is a mechanism for assisting States and other areas to gather data needed to direct SAPT block grant funds to areas of greatest need. In the Pacific insular areas, this program as also been used to develop the basic infrastructure for collecting data.

Table VI. Major Health Data Activities of the Health Care Financing Administration in the Pacific Insular Areas, Puerto Rico, and the Virgin Islands.

Island(s)	HCFA - Major Health Data Activities¹⁸
American Samoa	None
Commonwealth of the Northern Mariana Islands	None
Federated States of Micronesia	None
Guam	None
Republic of the Marshall Islands	None
Republic of Palau	None
Puerto Rico	Medicare and Medicaid reporting, Current Medicare Beneficiary Survey (although very small numbers)
U.S. Virgin Islands	Medicare and Medicaid reporting

¹⁸At the July 14-15 meeting, HCFA reported that virtually no Medicaid data are reported from Guam, American Samoa, or the Commonwealth of the Northern Marianas. Medicare data are reported but are suspected to be of questionable quality.

Table VII. Major Health Data Activities of the U.S. Department of Energy in the Pacific Insular Areas, Puerto Rico, and the Virgin Islands.

Island(s)	Department of Energy - Major Health Data Activities
American Samoa	None
Commonwealth of the Northern Mariana Islands	None
Federated States of Micronesia	None
Guam	None
Republic of the Marshall Islands	Responsible for care of population exposed to radioactive fallout during nuclear testing in the 1950s. Patients and controls total about 250. Basically a case study.
Republic of Palau	None
Puerto Rico	None
U.S. Virgin Islands	None

Table VIII. Major Health Data Activities of the U.S. Department of Commerce's Census Bureau in Cooperation with the Department of Interior's Office of Insular Affairs in the Pacific Insular Areas, Puerto Rico, and the Virgin Islands.

Island(s)	Census Bureau and Office of Insular Affairs - Major Health Data Activities
American Samoa	Technical Assistance ¹⁹ , Decennial Censuses, Censuses of Agriculture
Commonwealth of the Northern Mariana Islands	Technical Assistance, Decennial Censuses, Agricultural and Economic Censuses
Federated States of Micronesia	Technical Assistance
Guam	Technical Assistance, Decennial Censuses, Agricultural and Economic Censuses
Republic of the Marshall Islands	Technical Assistance
Republic of Palau	Technical Assistance, Included in 1990 Decennial Census
Puerto Rico	Regular Census activities including Decennial Censuses, Economic and Agricultural Censuses
U.S. Virgin Islands	Technical Assistance, Decennial Censuses, Economic and Agricultural Censuses

¹⁹Six million dollars divided between all but Puerto Rico for which the Dept. of Interior does not have a like responsibility. Focuses on technical assistance and training rather than actual data collection.

List of Participants

NCVHS Subcommittee Members

Lisa Iezzoni, M.D., Chair
 Hortensia Amaro, Ph.D.
 Richard Harding, M.D.
 Vincent Mor, Ph.D.
 David Takeuchi, Ph.D.
 M. Elizabeth Ward, M.N.

Subcommittee Staff

Carolyn Rimes, HCFA
 David Brown, SAMHSA
 Olivia Carter-Pokras, Ph.D., OMH
 Aaron Handler, IHS
 Dale Hitchcock, OSASPE
 Michael Millman, Ph.D., HRSA
 Beatrice Rouse, Ph.D., SAMHSA

Guest Speakers

PeterJohn Camacho, M.P.H., Guam Department of Public Health and Social Services
 Robert Davidson, U.S. Department of Health and Human Services, Region II
 Amato Elymore, Federated States of Micronesia
 Jill Feasley, formerly with the Institute on Medicine (IOM)
 Mary Anne Freedman, National Center for Health Statistics (NCHS)
 Joseph Iser, Ph.D., U.S. Department of Health and Human Services, Region IX
 Denise Koo, M.D., Centers for Disease Control and Prevention (CDC)
 Robert Mayes, Health Care Financing Administration (HCFA)
 Noreen Michael, Ph.D., Virgin Islands Department of Health
 Richard Miller, U.S. Department of Interior
 Michael Millman, Ph.D., Health Resources and Services Administration (HRSA)
 Michael Montopoli, M.D., U.S. Department of Energy
 Nick Ngwal, Ministry of Health, Republic of Palau
 Beatrice Rouse, Ph.D., Substance Abuse and Mental Health Services Administration
 (SAMHSA)
 Magdalena Sablan, Northern Mariana Islands Department of Health
 Jonathan Santos, Marshall Islands Ministry of Health and Environment
 Fale Uele, American Samoa Government
 Ruth Zamora, M.S., Puerto Rico Department of Health

Others

Marjorie Greenberg, Executive Secretary, NCVHS
James Scanlon, Office of the Assistant Secretary for Planning and Evaluation (OASPE)
Lynnette Araki, NCHS
Barbara Hetzler, NCHS
George Gay, NCHS
Fred Seitz, Ph.D., NCHS
Regina Lee, Office of Minority Health (OMH)
Jessie Washington, OCR/OS
Betty Lee Hawks, OMH
Ana Velilla Arce, OMH
Sonia Munoz, SAMHSA
Sheila Pack Merriweather, M.P.H., OMH
Shulamit Lewin, EMSC National Resource Center
Leandris Liburd, CDC
Joe Martinez, Agency for Health Care Policy and Research (AHCPR)
David Brey, Congressman Romero-Barcelo's Office
Dong Suh, Asian and Pacific Islander American Health Forum
Louis Salinas, CDC
Amelia Arria, Johns Hopkins University
Bruce Grant, SAMHSA
Joan Turek, OASPE
Donna Christian-Green, Member of Congress, U.S. Virgin Islands
Stephanie Ventura, NCHS
Rebecca Sauer, U.S. Bureau of the Census
Yvonne Benner, Congressman Romero-Barcelo's Office
Deborah Duran, Ph.D., SAMHSA
Roylinne Wada, U.S. Department of the Interior
Brenda Brown, OCR/OS
Miryam Granthon, Office of Disease Prevention and Health Promotion

CHARTER**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS****PURPOSE**

Collection, analysis and dissemination of health and health-related information is a crucial aspect of the responsibilities of the Department of Health and Human Services. The Department also plays a national leadership role in health data standards and health information privacy policy, and is charged with the responsibility for implementation of the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act of 1996. In addition, the Department engages in cooperative efforts with other countries and the international community to foster health data standards, comparability and cross-national research.

The National Committee on Vital and Health Statistics is the Department's statutory public advisory body on health data, statistics and national health information policy. This Committee shall serve as a national forum on health data and information systems. It is intended to serve as a forum for the collaboration of interested parties to accelerate the evolution of public and private health information systems toward more uniform, shared data standards, operating within a framework protecting privacy and security. The Committee shall encourage the evolution of a shared, public/private national health information infrastructure that will promote the availability of valid, credible, timely and comparable health data. With sensitivity to policy considerations and priorities, the Committee will provide scientific-technical advice and guidance regarding the design and operation of health statistics and information systems and services and on coordination of health data requirements. The Committee also shall assist and advise the Department in the implementation of the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act, and shall inform decision making about data policy by HHS, states, local governments and the private sector.

AUTHORITY

42 U.S.C. 242k(k), Section 306(k) of the Public Health Service Act, as amended. The Committee is governed by provisions of Public Law 92-463, as amended, (5 U.S.C. App. 2), which sets forth standards for the formation and use of advisory committees.

FUNCTION

It shall be the function of the Committee to assist and advise the Secretary through the Department of Health and Human Services Data Council, on health data, statistics, privacy, national health information policy, and the Department's strategy to best address those issues.

Specifically, the Committee shall advise the Department in the following matters:

(A) Monitor the nation's health data needs and current approaches to meeting those needs; identify emerging health data issues, including methodologies and technologies of information systems, databases, and networking that could improve the ability to meet those needs.

(B) Identify strategies and opportunities to achieve long-term consensus on common health data standards that will promote (i) the availability of valid, credible, and timely health information, and (ii) multiple uses of data collected once; recommend actions the federal government can take to promote such a consensus.

(C) Make recommendations regarding health terminology, definitions, classifications, and guidelines.

(D) Study and identify privacy, security, and access measures to protect individually identifiable health information in an environment of electronic networking and multiple uses of data.

(E) Identify strategies and opportunities for evolution from single-purpose, narrowly focused, categorical health data collection strategies to more multi-purpose, integrated, shared data collection strategies.

(F) Identify statistical, information system and network design issues bearing on health and health services data which are of national or international interest; identify strategies and opportunities to facilitate interoperability and networking.

(G) Advise the Department on health data collection needs and strategies; review and monitor the Department's data and information systems to identify needs, opportunities, and problems; consider the likely effects of emerging health information technologies on the Department's data and systems, and impact of the Department's information policies and systems on the development of emerging technologies.

(H) Stimulate the study of health data and information systems issues by other organizations and agencies, whenever possible.

(I) Review and comment on findings and proposals developed by other organizations and agencies with respect to health data and information systems and make recommendations for their adoption or implementation.

(J) Assist and advise the Secretary in complying with the requirements imposed under Part C of Title XI of the Social Security Act;

(K) Study the issues related to the adoption of uniform data standards for patient medical record information and the electronic interchange of such information, and report to the Secretary not later than August 21 2000 recommendations and legislative proposals for such standards and electronic exchange;

(L) Advise the Secretary and the Congress on the status of the implementation of Part C of Title XI of the Social Security Act;

(M) Submit to the Congress and make public, not later than one year after the enactment of the Health Insurance Portability and Accountability Act, and annually thereafter, a report regarding the implementation of Part C of Title XI of the Social Security Act. Such report shall address the following subjects, to the extent that the Committee determines appropriate:

- The extent to which persons required to comply with Part C of the Act are cooperating in implementing the standards adopted under such part;
- The extent to which such entities are meeting the security standards adopted under such part and the types of penalties assessed for noncompliance with such standards.
- Whether the federal and State Governments are receiving information of sufficient quality to meet their responsibilities under such part.
- Any problems that exist with respect to implementation of such part.
- The extent to which timetables under such part are being met.

(N) Assist and advise the Secretary in the development of such reports as the Secretary or Congress may require.

In these matters, the Committee shall consult with all components of the Department, other federal entities, and non-federal organizations, as appropriate.

STRUCTURE

The Committee shall consist of 18 members, including the Chair. The members of the Committee shall be appointed from among persons who have distinguished themselves in the fields of health statistics, electronic interchange of health care information, privacy and security of electronic information, population-based public health, purchasing or financing health care services, integrated computerized health information systems, health services research, consumer interests in health information, health data standards, epidemiology, and the provision of health services. Members of the Committee shall be appointed for terms of

up to four years. The Secretary shall appoint one of the members to serve a two year, renewable term as the Chair.

Of the members of the Committee, one shall be appointed by the Speaker of the House of Representatives after consultation with the minority leader of the House of Representatives; one shall be appointed by the President pro tempore of the Senate after consultation with the minority leader of the Senate, and 16 shall be appointed by the Secretary.

Membership terms of more than two years are contingent upon the renewal of the Committee by appropriate action prior to its termination. Any member appointed to fill a vacancy occurring prior to the expiration of the term for which his or her predecessor was appointed shall be appointed only for the remainder of such term. Members may serve after the expiration of their terms until successors have been appointed.

Standing and ad hoc subcommittees, composed solely of members of the parent Committee, may be established to address specific issues and to provide the Committee with background study and proposals for consideration and action. The Chair shall appoint members from the parent Committee to the subcommittees and designate a Chair for each subcommittee. The subcommittees shall make their recommendations to the parent Committee. Timely notification of the subcommittees, including charges and membership, shall be made in writing to the Department Committee Management Officer by the Executive Secretary of the Committee. The HHS Data Council, through the Assistant Secretary for Planning and Evaluation, shall oversee and coordinate the overall management and staffing of the Committee. Professional, scientific, and technical staff support shall be provided by all agencies of the Department. The National Center for Health Statistics shall provide executive secretariat and logistical support services to the Committee.

MEETINGS

Meetings shall be held not less than annually at the call of the Chair, with the advance approval of a Government official, who shall also approve the agenda. A Government official shall be present at all meetings.

Meetings of the subcommittees shall be held at the call of the Chair, with the advance approval of a Government official, who shall also approve the agenda. A Government official shall be present at all subcommittee meetings. All subcommittees shall report their findings to the Committee. Meetings shall be open to the public except as determined otherwise by the Secretary; notice of all meetings shall be given to the public. Meetings shall be conducted, and records of the proceedings kept, as required by the applicable laws and departmental regulations.

COMPENSATION

Members who are not full-time Federal employees shall be paid at a rate not to exceed the daily equivalent of the rate in effect for an Executive Level IV of the Executive Schedule for each day they are engaged in the performance of their duties as members of the Committee. All members, while so serving away from their homes or regular places of business, may be allowed travel expenses, including per diem in lieu of subsistence, in the same manner as such expenses are authorized by Section 5703, Title 5, U.S. Code, for employees serving intermittently.

ANNUAL COST ESTIMATE

Estimated annual cost for operating the Committee, including compensation and travel expenses for members but excluding staff support, is \$363,768. Estimated annual person-years of staff support required is 4.0, at an estimated annual cost of \$268,897.

REPORTS

In the event a portion of a meeting is closed to the public, a report shall be prepared which shall contain, as a minimum, a list of members and their business addresses, the Committee's functions, dates and places of meetings, and a summary of Committee activities and recommendations made during the fiscal year. A copy of the report shall be provided to the Department Committee Management Officer.

TERMINATION DATE

Unless renewed by appropriate action prior to its expiration, the charter for the National Committee on Vital and Health Statistics will expire on January 16, 2000.

APPROVED:

/s/

Date

Secretary

Appendix II

**National Committee for Vital and Health Statistics
Membership of the Subcommittee on Populations**

SUBCOMMITTEE

Lisa I. Iezzoni, M.D., M.S., Chair
Kathryn L. Coltin, M.P.H.
Daniel Friedman, Ph.D.
Vincent Mor, Ph.D.
Paul Newacheck, Dr.P.H.
Barbara Starfield, M.D., M.P.H.
M. Elizabeth Ward, M.N.

STAFF

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Aaron O. Handler, B.A.
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Dale C. Hitchcock
Rose Maria Li, M.B.A., Ph.D.
Deborah R. Maiese, M.P.A.
Ronald W. Manderscheid, Ph.D.
Michael L. Millman, Ph.D., M.P.H.
Susan G. Queen, Ph.D.