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# Exploring the Future of Indian Health Information Systems

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*Final Report*



# **The Data Policy Roundtable**

## **Exploring the Future of Indian Health Information Systems**



U.S. Department of Health and Human Services  
Indian Health Service  
Office of Public Health  
Division of Community and Environmental Health  
Program Statistics Team

**February 1998**



# Acknowledgments

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# Preface

We are in an era that is changing rapidly in many respects. Budgets for most Federal programs are being cut, major developments are taking place in the health care arena, responsibility for health care delivery is being transferred from the Indian Health Service to Tribes and Urban associations, and technological advances are continuing at a rapid pace. Building for the future is critical. We are going to see more changes down the road in the year 2000 and that is not too far away. It is important to lay a foundation today for that future, keeping in mind that our main emphasis, our priority, is to deliver the highest quality health care services to Indian people nationwide.

Within the Federal Government, the Indian Health Service has been at the forefront in development and use of data systems for health care statistics. We have had a long history in the development of information systems that have been a mainstay not only for the clinical management of health care per se, but also for the advocacy of health care programs. These systems have been of great importance to the administration and Congress for policy analysis and development. Use of the data from these systems has been critical to where we are today and where we will be in the future with regard to funding and also the associations we have with other Federal and State agencies and institutions

such as universities, colleges, and professional organizations. In developing strategies to take advantage of the changes taking place and to ensure a smooth transition from an IHS-managed information system to an Indian Health Information System sponsored and supported by the Tribes (both those who chose to contract/compact and those who did not), Urban associations, and IHS, this roundtable faces not only challenges, but opportunities. There are opportunities for development of an enhanced system, which means enhancement of all aspects of the Indian health care delivery system. There are opportunities for growth, for building an unprecedented coalition, and for bringing others into the health care arena for Indian people.

As Director of the Indian Health Service, and in keeping with our trust responsibility to the sovereign Indian nations, I pledge my support in implementing your recommendations.

Michael H. Trujillo, M.D., M.P.H., M.S.  
Assistant Surgeon General  
*Director, Indian Health Service*



# **Executive Summary**





## *Executive Summary*

### **Purpose**

*The Data Policy Roundtable—The Future of Indian Health Information Systems* was convened to explore options and develop strategies for future Indian Health Service/Tribal/Urban (I/T/U) program information systems. The concerns and needs of both Tribes who chose to contract/compact and those who did not were considered. Initial questions to be addressed by the participants were:

- What are the advantages and disadvantages of the current I/T/U information system structure?
- What steps can be taken with respect to the I/T/U information system structure to improve Tribal/Urban participation in the system and to improve I/T/U data quality?
- What are the changing internal and external environmental conditions that will require changes in the I/T/U information system structure?
- Which new information system technologies will assist in the evolution of the I/T/U information system structure and which are feasible to implement within I/T/U budget constraints?

The focus was on developing strategies to create a new Indian Health information system, one that was not an Indian Health Service system but rather a system designed and supported by the Tribal and Urban health care delivery organizations and the Indian Health Service.

### **Background**

Decisionmakers and policymakers at the local, State, and Federal levels need accurate, timely, understandable information and statistics to develop programs and formulate strategies to improve the health status of Indian people and reduce health risks. Data assists in patient management; budget formulation, presentation, and justification; program planning and evaluation; and resource management. Information from data is used to determine health education, protection, treatment, and preventive services needs, to determine the level of access to health care services, and to assess the status of a community's health. It provides information to present outcomes and support accountability in use of funds. Data answers the need for the Indian Health Service to provide its mandated reports to Congress. It enables presentation of reports such as the annual *Trends in Indian Health* and *Regional Differences in Indian Health* and special reports such as *Indian Health Focus: Women*, *Indian Health Focus: Youth*, and *Indian Health Focus: Elderly*.

Currently, the Indian Health Service (IHS) collects data on the health care services provided by IHS and Tribal direct and contract programs. The software used by IHS facilities and most Tribal facilities is the Resource and Patient Management System (RPMS). Patient-specific data is collected through the Patient Care Component (PCC) for each inpatient discharge, ambulatory medical visit, and





## *Executive Summary*

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dental visit. Other parts of RPMS provide for data collection on community health service programs, including health education, community health representatives, environmental health (safe drinking water/sanitary facilities), diet and nutrition, public health nursing, mental health and social services, and substance abuse.

Each local facility that utilizes the PCC system has a facility-level database containing the detailed PCC data collected at that site. A subset of this detailed PCC data is transmitted to the IHS central database to meet the needs of IHS headquarters in planning, budgeting, and advocating for improvements in Indian health care.

Although the RPMS/PCC has provided for a centralized database of aggregate data for many years, there are gaps in the current system. There is a need for improved:

- Hardware and software maintenance;
- Training and technical assistance in use of the system;
- Response time to users' needs and requests;
- Reporting capabilities, at the local, area, and national levels;
- Software for accounting, billing, and non-IHS reporting requirements;
- Integrated I/T/U communications network; and
- Financial support to maintain and update the system.

### **A Changing Environment**

The roundtable participants carefully looked at many aspects of the future of Indian health care data information systems in light of the changing environment. They noted that there is both challenge and opportunity in the trend towards shifting of functions, funds, and responsibilities from the Federal level to the local level. They were cognizant of the many changes taking place in the organization and funding of the health care industry itself. And they welcomed the continuing rapid development of communication and information technologies. They agreed that the successes and problems of the past were in the past. The question was: Where do we go from here?

### **Issues and Highlights**

The participants represented a broad range of concerns and needs. They were clear and forthright in expressing these concerns. They identified problems, issues, and solutions. They generously shared information and reports about the often extensive work their groups have done to assess their needs and study the options available to them to improve their systems to meet those needs. The group benefited from the candid expression of viewpoints coming from representatives of Tribes and Urban groups, members of national and regional Tribal Health Boards, medical professionals, staff from various Indian Health Service (IHS) divisions, industry experts, and interested observers.







## Executive Summary

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Early on in the roundtable deliberations, the following points emerged:

- The overall purpose of an Indian Health Information System is to provide needed information to the Indian Health Service and Tribes and Urban associations to assist them in their mission of providing a high level of quality health care to Indian people. The Indian health care system is the focus; the information system is a tool.
- There continues to be a need for an aggregate database for program planning, budgeting, and advocacy at the local, regional, and national levels.
- Both clinical information to better care for patients and communities and administrative information for program management are needed.
- Tribes and Urban associations are unique in size, in their local needs, in their financial resources, and in the extent of their technological expertise.
- Provisions must be made for all I/T/U partners to contribute to and have access to an aggregate database regardless of what hardware or software they use.
- There is a need to support the current RPMS system that the majority of groups still use.
- A changing environment internally and externally means strategies are necessary to establish an Indian Health Care Information System. It can no longer be an IHS information system. If it is to exist, it needs to become an I/T/U system with all parties having a stake in the system.

### Recommendations

As the roundtable discussion of issues, concerns, and options progressed it became clear that in the future an Indian Health Information System would be driven increasingly by the needs of and ultimately directed by Tribes (both those who chose to contract/compact and those who did not) and Urbans. Even so, although the Indian Health Service would be playing a lesser role as more Tribes take over the program, it would continue to fulfill its Federal trust responsibility as an active partner and as an advocate for presenting the health care status and needs of the Indian people to Congress. Together, the participants summed up their deliberations with the following 10 recommendations:

<p><b>1. Establish an Indian Health Service, Tribal, Urban Program (I/T/U) Data Consortium.</b></p>
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This is the key recommendation of the roundtable participants since most of the other recommendations would fall under the purview of the I/T/U Data Consortium. This would be a consortium between contracting/compacting Tribes, non-contracting/compacting Tribal-IHS partnerships, and Urbans. The Tribes and Urban groups would be the main players at the table, with IHS serving as a partner. The consortium would be responsible for providing recommendations to the Director of the Indian Health Service on data and information issues affecting its members.





## Executive Summary

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Initial concerns of the consortium would be:

- Development of a uniform data set;
- Determination of a means for aggregating data for use nationally and locally;
- Adoption of data content and transmission standards;
- Establishing priorities for data and information activities, such as which software development activities should be pursued and in what order; and
- Estimating required resources for information system activities and determining means for obtaining the resources.

The I/T/U Data Consortium would interface with the Department of Health and Human Services Data Policy Council. However, its main focus would be dealing with I/T/U data and information issues.

### **2. Develop a uniform data set.**

An I/T/U group, possibly a subgroup of the I/T/U Data Consortium, would identify a subset of data that needs to be aggregated for national and local planning and advocacy purposes. The data would represent only essential, non-burdensome data to be used by those groups who choose to participate.

### **3. Determine a means for aggregating the data.**

The participants clarified that aggregate data does not necessarily have to be in a centralized database, as long as it is easily accessible in a user-friendly format for planning, budgeting, and advocacy of the Indian health care delivery system on the local, regional, and national levels. It might be obtained directly from local databases via Web sites or a central and/or regional repositories might be operated by IHS, an I/T/U group, or a private sector

contractor. Security of the data was an important issue to ensure the privacy and confidentiality of individuals.

### **4. Determine how best to account for non-participating I/T/U entities in the presentation of national aggregate data.**

The participants hoped that the partners could design and promote an Indian Health Information System that invited widespread participation. Although there are not historical precedents for such collaboration among the Tribes and between Tribes and Urban programs, it was considered an opportunity to engage more groups in this initiative by clearly demonstrating that the benefits to them would outweigh their concerns. It was suggested that a study might be conducted to determine and evaluate the quality and completeness of the data collected and how representative it is of the whole I/T/U system. In addition, when presenting information derived from aggregate data, a qualifying statement should be included regarding the fact that the data represents only that of the participants, not all I/T/U people.

### **5. Adopt, along with the data set, data content and transmission standards to ensure that aggregate data are comparable and can be transmitted between systems, independent of hardware and software configurations.**

The roundtable recommended that existing Federal/industry standards be used whenever possible. It was also suggested that the group inquire into the work being done by the Veterans Administration and the Department of Defense and possibly partner with them in developing standard interfaces.





## Executive Summary

**6. Develop a means for maintaining and upgrading the Resource and Patient Management System (RPMS) and, in particular, the Patient Care Component (PCC), to meet the needs of the I/T/U participants who choose to continue to use it.**

The RPMS is the clinical information infrastructure for the IHS-operated and most of the Tribal-operated health care facilities. In spite of its need for upgrades, it appears to be the most highly integrated patient information system available. It was recognized that due to downsizing and lack of residual funds, IHS's ability to continue supporting and operating RPMS is coming to an end. The need to transfer this function from IHS to an I/T/U consortium was a major factor in calling for this roundtable. Some RPMS users have been struggling to upgrade the system themselves to meet their needs with the result that the system is becoming fragmented, resources are being expended to "reinvent the wheel," and there is unnecessary and costly duplication of effort across the country. The roundtable participants suggested that RPMS users form regional consortiums and collaborate in their efforts to address their needs. The consortiums would enable the participants to share information and resources. They could develop their own upgrades or they could jointly contract with the private sector for the necessary enhancements. The consortiums also might serve as testing "labs" for interfaces and other developments.

**7. Make greater use of current and new information and communication technologies to improve the Indian health program.**

It was recommended that an Intranet be established as an effective I/T/U communications network. It was strongly felt that all Tribes and Urban associations must have e-mail and Internet capabilities. An I/T/U testing lab would be useful to test out new technologies for the group as a whole. Geographic mapping, data warehousing, Graphic User Interfaces, and other tools can be used to make databases more user friendly and more accessible.

Initial and ongoing training and technical assistance is needed, both for the computer shy and the computer literate. Most systems have capabilities and databases have information that are never accessed because users don't know how to do this. Training can produce cost benefits for almost any system. Technical assistance is also needed to ensure the most cost-effective building and expansion of systems.

**8. Establish a clearinghouse to share information models related to specific health problems and conditions.**

Possibly under the purview of the I/T/U Data Consortium, the clearinghouse would enable the sharing of data models to address specific health problems such as diabetes management; prenatal and postnatal care for babies of teen mothers; reduction in unintentional injuries; or alcohol and substance abuse in young adults.





## *Executive Summary*

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### **9. Develop an I/T/U finance committee or commission to address funding issues.**

The responsibilities of the finance committee or commission would include determining the level of resources needed to carry out the consortium's and I/T/U's information systems activities, establishing financial priorities and strategies, and developing funding sources.

Possible funding sources suggested by the roundtable participants included provision of equitable shares from partners/decisionmakers; convincing Congress of cost benefits of additional funding; formation of for-profit ventures; sharing development and/or user costs with other Federal agencies; establishing financial relationships with State agencies, foundations, and the private sector; using program income; and serving as pilot sites for testing information systems. Providing training programs, supplying technical assistance, and marketing results of development efforts were examples given of possible fundraising activities.

### **10. Establish an environment that fosters an equal partnership among the Tribes, Urbans, and IHS.**

All partners should see themselves as equal players at the table. Such a partnership has never before been demonstrated. This will be the number one challenge for the consortium.

The characteristics and needs of each of the Tribes and Urban groups are so widely diverse, that it will take intelligence, ingenuity, patience, and diplomacy to ensure that all see this as an association that has something of value in it for them equal to the cooperation, efforts, and resources being asked of them.

## **Conclusion**

The members of the roundtable recognized that there is an urgency in responding to these recommendations because the environment has changed, is changing, and will continue to change ever more rapidly. The many groups that make up the Indian Health Care Delivery System need to move quickly if they are to successfully accomplish their mission of providing the highest level of quality health care to Indian people.

## **Organization of Report**

This report is presented in four parts. Part 1 describes the purpose for the roundtable; Part 2 describes the background which prompted the need for the roundtable; Part 3 presents issues and highlights of the discussion; and Part 4 provides the 10 recommendations of the roundtable participants. Appendix A is a list of the participants and observers; Appendix B is a copy of the agenda; Appendix C is a brief history of the Indian Health Service's Federal trust responsibility, and Appendix D is a list of materials submitted by the participants.





# Purpose





## *Purpose*

The roundtable was convened to explore options and develop strategies for future Indian Health Service/Tribal/Urban (I/T/U) program information systems. The concerns and needs of both Tribes who chose to contract/compact and those who did not were considered. Many elements of change—the downsizing of the Indian Health Service (IHS), the movement of program administration and funds from IHS to the Tribes, new developments in the health care industry, changes in outside requirements at both the State and Federal levels, and the continuing rapid growth of new technologies—called for a representative group to consider the future of the I/T/U information system and recommend feasible strategies to ensure that the data needed for planning, budgeting, and advocacy will be readily available at both the local and Federal levels. Initial questions to be addressed by the participants included:

- What are the advantages and disadvantages of the current I/T/U information system structure?
- What steps can be taken with respect to the I/T/U information system structure to improve Tribal/Urban participation in the system and to improve I/T/U data quality?

- What are the changing internal and external environmental conditions that will require changes in the I/T/U information system structure?
- Which new information system technologies will assist in the evolution of the I/T/U information system structure and which are feasible to implement within I/T/U budget constraints?

The focus was on developing strategies to create a new Indian Health information system, one that was not an Indian Health Service system but rather a system designed and supported by the Tribal and Urban health care delivery organizations and the Indian Health Service.

Roundtable participants represented Tribal and Urban programs; national and regional Tribal Health Boards; Indian Health Service statistical, epidemiological, and information systems divisions; the nursing and clinical professions; and industry experts in new technologies.





# Background





## Background

### Benefits of Good Data

Decisionmakers and policymakers at the local, State, and Federal levels need accurate, timely, understandable information and statistics to develop programs and formulate strategies to improve the health status of Indian people and reduce health risks. Data assists in patient management; budget formulation, presentation, and justification; program planning and evaluation; and resource management. Information from data is used to determine health education, protection, treatment, and preventive services needs, to determine the level of access to health care services, and to assess the status of a community's health. It provides information to measure outcomes and support accountability in the use of funds. Data answers the need for the Indian Health Service to provide its mandated reports to Congress. It enables presentation of reports such as the annual *Trends in Indian Health* and *Regional Differences in Indian Health* and special reports such as *Indian Health Focus: Women*, *Indian Health Focus: Youth*, and *Indian Health Focus: Elderly*.

Data is useful if it provides beneficial information. Clinical program data describes health services by type, provider, recipient, quality, quantity, and outcome. It is a tool for achieving better care for patients and communities. For example, data can tell you the number and ages of clients served by a health station, the illnesses that most frequently result in hospital stays, the rise or fall in prevalence

of illnesses involving substance abuse, and the increase or decrease in injuries caused by domestic violence. Data helps a community determine what its main health problems are, for example, breast cancer, diabetes, obesity, alcohol/drug abuse, domestic violence, home accidents, depression, or teen pregnancy.

Clinical data permits the evaluation of program outcomes based on risk/protective factors and changes in health status. Such data can provide information on areas where health education is needed in the community in general or among targeted groups in the community. Data allows for comparison of similar facilities, programs, and systems. It can identify priority needs and enable a facility to secure funding for those needs.

A state-of-the-art accounting system enables management to make effective use of resources and to develop budgets to implement programs that address identified health problems. Patient and cost data provide the information needed for development, presentation, and justification of budget requests for appropriations. State Medicaid programs are rapidly purchasing managed care programs for their beneficiaries. This has significant implications for Indians and Indian health facilities. In negotiating with managed care systems, management must know the cost of specific services to ensure that the reimbursement offered is adequate.







## *Background*

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A state-of-the-art management information system facilitates analysis of administrative, demographic, epidemiologic, and service data for planning, administration, and evaluation of a health care delivery system. It provides the information needed to plan and implement needed prevention, intervention, and treatment programs.

Today's need for accountability in the spending of funds and for program outcomes makes data even more important than ever. Data provides the information needed to meet Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and other agency's accreditation standards. As of January 1, 1996, all IHS and Tribally operated hospitals and eligible IHS-operated health centers were accredited.

The systematic collection, analysis, and dissemination of information on health status, health needs, and health problems is necessary to assess the outcomes of programs. Good data will measure whether or not the 61 health objectives for Indians set by Congress under P.L. 102-573, Indian Health Care Amendments of 1992, and the additional 5 Indian-specific health objectives set by Healthy People 2000: National Health Promotion and Disease Prevention Objectives will be met by the year 2000.

### **Overview of Current Indian Health Information System**

In the 1970's, the Indian Health Information System was headquarters oriented, collecting information needed for headquarters activities. In the 1980's, the system became patient oriented with the development of the Resource and Patient Management System (RPMS) and its Patient Care Component (PCC). The information gathered was primarily for use at the local level, with a subset of information being available for the Indian Health Service (IHS). In the future, the system must be increasingly Tribal/Urban oriented with IHS serving in a facilitator and national advocacy role. Besides patient information not currently being collected, there is a strong need for financial data and interfacing with the systems of other parties, as well as a need to collect data to meet the information requirements of management and groups other than the providers.

Currently, IHS collects data on the health care services provided by IHS and Tribal direct and contract programs. The software used by IHS facilities and most Tribal facilities is the Resource and Patient Management System. Patient-specific data is collected through the Patient Care Component for each inpatient discharge, ambulatory medical visit, and dental visit. Other parts of RPMS provide for data collection on community health service programs, including health education, community health representatives, environmental health (safe drinking water/sanitary facilities), diet and nutrition, public health nursing, mental health and social services, and substance abuse. PCC's clinical components are instrumental in providing better care for patients and communities.





## Background

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Each local facility that utilizes the PCC system has a facility-level database containing the detailed PCC data collected at that site. A subset of this detailed PCC data is transmitted to the IHS central database to meet the needs of IHS headquarters in planning, budgeting, and advocating for improvements in Indian health care. This PCC data is the source of most of IHS's Government Performance and Results Act (GPRA) measures since they reflect prevention activities and morbidity and do not have the time lags associated with data from non-IHS sources. However, many of IHS's proposed measures rely on detailed PCC data not currently transmitted to the IHS central database or not currently coded at some facilities or not part of PCC. IHS uses sampling routines and local surveys to capture such data.

The IHS program information systems collect data only for persons accessing the IHS-sponsored health care system. Since this data is not population based, true prevalence and incidence rates for an entire Tribe or community cannot be calculated, only approximated. IHS would like to use the population-based results of national health surveys, such as the National Health Interview Survey conducted annually by the National Center for Health Statistics (NCHS). Unfortunately, these surveys are not designed to properly sample American Indians and Alaska Natives and thus produce statistically reliable results for Indians. Plans are underway to correct this situation and to at least ensure inclusion of Indians in the IHS service population (i.e., on or near reservations) and those in Urban Project areas.

Although the RPMS/PCC has provided for a centralized database of aggregate data for many years, there are gaps in the current system.

There is a need for improved:

- Hardware and software maintenance;
- Training and technical assistance in use of the system;
- Response time to users' needs and requests;
- Reporting capabilities, at the local, area, and national levels;
- Software for accounting, billing, and non-IHS reporting requirements;
- Communications, such as an integrated I/T/U communications network; and
- Financial support to maintain and update the system.

Besides its own information system, the Indian Health Service uses non-IHS sources to manage its program and assess the health status of the nation's American Indians and Alaska Natives. The two principal outside data sources are the Bureau of the Census and the Centers for Disease Control and Prevention (CDC), in particular, the National Center for Health Statistics (NCHS).

In addition to these two main sources, data is available from other agencies. The Health Care Financing Administration provides Medicare and Medicaid data; it also requires data from local facilities for payment and from IHS for negotiating rates. CDC provides surveillance data; the Women, Infants, and Children Program in the U.S. Department of Agriculture provides data on nutritional health of mothers, babies, and children; some national health surveys address Indians and other special populations. State records, police departments, schools, health facilities, and third-party payers also supply information. Tribes conduct special data collections including health risk appraisal surveys and focus groups.





## *Issues and Highlights*

The roundtable was formed with the understanding that the past is past, a clean slate is needed, and the Indian Health Service/Tribes/and Urbans (I/T/U) must decide on where they want to be in the future with regard to sharing health care information.

### **Basic Issues and Concerns**

Early on in the roundtable deliberations, the following points emerged:

- The overall purpose of an Indian Health Information System is to provide needed information to the Indian Health Service, Tribes, and Urban associations and to assist them in their mission of providing a high level of quality health care to Indian people. The Indian health care system is the focus; the information system is a tool.
- There continues to be a need for an aggregate database for program planning, budgeting, and advocacy at the local, regional, and national levels.
- Both clinical information for patient and public health management and cost information for program management are needed.
- Tribes and Urban associations are unique in size, in their local needs, in their financial resources, and in the extent of their technological expertise.
- Provisions must be made for all I/T/U partners to contribute to and have access to an aggregate database regardless of what hardware or software they use.
- There is a need to support the current RPMS system that the majority of groups still use.
- A changing environment internally (downsizing of IHS, Tribes and Urbans taking over programs and funds) and externally (changes in welfare regulations, Medicare/Medicaid reform, transfer of functions and funds from the Federal Government to the States, managed care, accountability, new technology) means strategies are necessary to establish an Indian Health Care Information System. It can no longer be an IHS information system. If it is to exist, it needs to become an I/T/U system with all parties having a stake in the system.

#### *Need for Aggregate Data*

In 1995 the Director of IHS charged the Baseline Measures Workgroup (BMW) to develop a series of mutually determined baseline measures that could be used by Self-Governance Tribes for reporting to Congress. These baseline measures were to serve as a tool to monitor performance of health care programs. While firmly supporting the legal right of Tribes to negotiate reporting requirements on an individual basis and to participate in a national database or not, BMW strongly recommended that it was in the mutual self-interest of all "to preserve a recognition of an AI/AN specific health care agenda at the national level" and "to maintain a unified data system that is useful to advocate effectively for AI/AN people" on both a local and national basis.





## *Issues and Highlights*

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In discussing what aggregate data is needed, it became evident that each Tribe's (including those that rely on IHS for health care services) or Urban's health care program has group-specific needs that vary widely from program to program. The resources and technological expertise of each group is unique. This makes it very difficult to come up with a collective list of data needs.

### *Need for Clinical and Cost Information*

Clinical information is of the utmost importance for patient management, for meeting accountability requirements, for planning health care programs, and for providing outcome measurements to the Health Plan Employer Data Information System (HEDIS), Joint Commission on Accreditation of Healthcare Organizations (JCAHO), and other such groups. Financial information is critical for billing, cost accounting, negotiating rates, applying for grants and other funding, and financial management of programs. Roundtable representatives stated firmly that regardless of how excellent a health care program is, it cannot exist today without a steady revenue stream to support it.

Tribes who have conducted market surveys, non-IHS users such as the Presbyterian Hospital in Albuquerque, and many clinical persons consider RPMS/PCC the most highly integrated patient information system available today. It is the infrastructure used by the majority of the Tribes. A major advantage in these times of limited funds and increasing costs is the fact that RPMS is in the public domain. On the other hand, it does not have all the financial and management information software components needed by the Tribes and Urban associations, and so it is less competitive with the excellent off-the-shelf but stand-alone commercial packages in these areas. However, there are no

current information systems packages that meet all needs for health care organizations.

Participants emphasized that integration of clinical and financial packages is a key issue in order to avoid double entering of data and in order to quickly and easily produce the reports needed by management.

### *Uniqueness of Tribal/Urban Characteristics*

Early in the discussions, it became obvious that the groups the participants represented varied greatly in their needs and their capability to meet those needs. Some Tribal Nations had both the financial and personnel resources to set up their own information systems and act independently in meeting their local needs. Other groups were dependent on the RPMS, but were frustrated by some of its deficiencies. There was strong concern for the smaller Tribes and those who did not have the funding or expertise to set up their own systems or to interface with other systems.

Groups nationwide are at widely different points in development and use of their health information systems. Some have state-of-the-art systems to meet many of their local or regional clinical and management needs; at the other end of the spectrum are those who have not entered the communications technology age at all. In between are those struggling to put together systems with what they have and what they can obtain to meet the diverse needs and stages of development of their members. No group found a system that met all projected needs.





## *Issues and Highlights*

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### *Training and Technical Assistance*

The need for improved training and technical assistance was repeatedly mentioned. Initial and ongoing training in the use of the information systems and readily available technical assistance at each stage of development is crucial. This is a huge unmet need for all components and levels of an I/T/U system. There is a tremendous loss in productivity and cost benefits when staff cannot properly use their existing software and hardware and take full advantage of its features.

For some people, there is still a general fear of computers. Managers of information systems need to know a lot, but users just need to be comfortable with the system and be able to use it.

### *Summary of Issues*

Based on a discussion of such issues, the original agenda was modified to specifically address the following questions:

- How will data policy be set for the I/T/U to ensure that I/T/U needs are met for strategic planning, coordination and sharing of efforts, establishing development priorities, resolving problems, and so forth?
- Is there a need for a uniform data set, and if so, how should it be developed?
- How should aggregate data be obtained and made available to the I/T/U for national planning, budgeting, and advocacy purposes?
- How should non-participating T/U entities be accounted for in the aggregate data?
- Are uniform hardware, software, and data content and transmission standards required? If so, how should they be developed or obtained?
- How and by whom should the RPMS/PCC system be maintained and upgraded to meet I/T/U needs for those who choose to use it?
- How should programs that use non-RPMS hardware and software be tied into the information network?
- How will new technologies benefit the future system(s)?
- Where will the resources come from to support an Indian health care information system?
- What are the roles of the Tribes (both those who chose to contract/compact and those who did not), Urbans, and IHS in the evolving systems?





## Issues and Highlights

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### Highlights of the Roundtable Discussion

The roundtable participants' discussion is summarized below. The issues and concerns presented with each of the questions were the basis for the group's recommendations.

**1. How will data policy be set for the I/T/U in terms of ensuring that I/T/U needs are met for strategic planning, coordination and sharing of efforts, establishing development priorities, resolving problems, and so forth?**

- The major challenge is how to manage this transition time. How can the IHS/Tribes/ Urbans work together to support a common set of information—where and how to site such a system, develop it, support it, and interface it with other systems?
- How does data fit into overall policy regarding advocating for resources? How does it help keep dollars flowing into each organization's programs in order to provide high quality health care services?
- It has been IHS headquarters' experience that Congress wants detailed data and detailed measures to support and justify budget requests, as well as pertinent case studies. IHS is asked: How many services did you provide last year? With dwindling dollars, what's happening to services? What are the problems you are encountering? How are you handling these problems? What are the outcomes of your solutions? What are the leading causes of inpatient discharges? What are you doing? How are you doing it? What do you plan to do? What regional differences are there? They want information on process, outcome, and intervention measures.
- An I/T/U consortium or council would provide collective bargaining power and empower local groups in their advocacy for resources to meet their needs.
- There is a need to define what data is needed at each level, beginning at the local level.
- A lot of data has direct utilitarian usage. We need to see data as "alive" not as a set of numbers but as valuable information capable of helping decisionmakers deal with health care delivery issues. In fact, data is not necessarily numbers; it can be descriptive in nature, for instance, how something is done.
- The IHS/Tribes/Urbans may want comparative information to compare their outcomes, patient discharges, and so forth with other programs in their region or nationally. Does it appear that someone else's program is working better? Does someone else have a similar problem? How have they approached it?
- Data needs are growing because of requirements from many sources. Outcome data is needed for transmission to State agencies, for instance for Medicaid, in order to recover costs. Data is needed to participate in HMO's in order to get paid as a provider.
- One problem is that groups define outcome differently. They don't all interpret Centers for Disease Control requirements the same, or even immunization data. Who is going to define what is meant? Who is going to agree with these definitions? When is it truly necessary to agree on a common definition and when can it be left to local decisionmakers?





## *Background*

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### **New Thinking for a Changing Environment**

The Indian Health Service and Tribes are moving into a new information system environment. This is being generated by:

- Tribal takeover of Indian health care programs under Title I contracts and Title III compacts and the Tribal option on whether or not to report the same program data to the IHS central database as IHS providers report;
- Removal of Tribal shares from support of the current IHS-based information system;
- Reorganization and downsizing of IHS;
- New reporting requirements prescribed by other Federal and State agencies and other members of the health care industry;
- Changing information technologies.

The Indian Health Service, Tribes, and Urban groups are in the process of establishing a new relationship that gives more responsibility to Tribes and Urbans opting to take over their health care program. The three entities are now partners in an Indian Health Service/Tribal/Urban (I/T/U) health care delivery system. Since Tribes have the option of assuming operation of their health care program, those that opt not to are represented through the IHS entity.

In this new environment, Tribes can negotiate what program data they will provide to IHS and how they will provide the data. Urban groups also have no requirement to provide such data to the IHS central database. However, all three still need program data to conduct program planning, budget resources, and advocate for the Indian health program and

public/private funding at the local, regional, and national levels.

A major challenge is how to manage this transition time. How can the IHS/Tribes/Urbans work together to support a common set of information—where and how to site such a system, how develop it, how support it, how interface it with other systems?

IHS has encouraged the Tribes to use RPMS software and the majority are doing so, very often because of their own funding constraints; however, the upgrading of the current system has become a somewhat controversial item. Due to the reorganization and downsizing of IHS headquarters, personnel resources are now limited. More work is being done by private contractors, but as Tribal shares are being removed, there is less and less funding for such contracts. As this trend continues, IHS will not be able to continue to do much of what it now does.

Some Tribes have been spending funds on their own RPMS upgrades, depending on outside consultants. This frequently results in non-standardized solutions between their software and IHS-maintained RPMS software and in fragmentation of the system.

As Tribes are assuming their new responsibilities, there is a growing tendency to acquire new hardware and software and develop their own systems based on local needs. Integrating the parts of these systems is often difficult. Title I regulations regarding data reporting and the recommendations from the Baseline Measures Workgroup have brought up questions about the development of a uniform program data set and interfacing requirements.





## *Background*

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Along with a downward trend in Federal resources, more responsibility for program management is being transferred to the State and local levels by the health and welfare reforms taking place. There is an increased emphasis on performance measures, on outcomes and accountability. Technology continues to change rapidly and to offer new possibilities for I/T/U communication and sharing of information. All of these changes call for interfacing with a variety of systems.

In the past when IHS was the primary provider of Indian health care, there was an understood strategy based on IHS-developed and operated program information systems. This strategy no longer fits the current and changing environment. Meanwhile, data is becoming critical in a performance-oriented health care industry and the I/T/U must jointly develop program data policies and strategies to guide and assist them in the challenging times ahead. The purpose of the August 12-14, 1997, roundtable was to address this need.







# **Issues & Highlights**





## *Issues and Highlights*

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- Look at various models. The Indian Health Design Team has recommended a national data advisory committee be formed similar to the Department of Health and Human Services (HHS) Data Policy Council. The HHS Council is composed of members from the operational divisions and agencies.
- It would be better for such a group to be charged with setting up standards, rather than policy, for instance how will data be packaged to be transmitted to a central or regional repository? Setting policy sounds like mandating decisions rather than offering assistance and guidance.
- “Marketing” the consortium idea is crucial. It would need to promote such concepts and advantages as advocacy needs, availability of technical assistance, and advantage of joint contracting.
- Who should be on the data policy committee or consortium? A set group needs to meet periodically.
- Initially, it will probably be a self-elected group of those who are interested.
- Travel costs are a problem for membership in a national council or consortium. Perhaps the group could meet less often and at alternate sites.
- An RPMS consortium could be a subgroup of the data consortium. There may be other subgroups, such as one to examine financial resources or one to determine what information will be reported.
- A joint group is needed to provide guidance in development of systems for economies of scale and to avoid duplication of effort.
- The consortium could be a clearinghouse for ideas and information. A subgroup could test new technologies in a “working lab” for benefit of the members.
- The consortium will need staff support. All groups involved need to contribute to this. The staff unit could be modeled after the HHS, i.e., the HHS Data Policy Council is staffed to some degree by an HHS data policy office.

**2. Is there a need for a uniform data set, and, if so, how should it be developed?**

- A uniform data set is needed to produce a national aggregate collection of information. Such a data set would be a subset of locally collected data and would be independent of hardware or software.
- Development of a uniform data set is called for in the regulations that implement Title I. IHS and the Tribes are required to jointly develop such a data set to serve as a target for negotiations over program data reporting requirements.
- For Urban groups, who have no requirement to report data to the IHS central database, a uniform data set would enable them to voluntarily contribute data needed for the aggregate.
- The current Core Data Set is too burdensome; it needs to be streamlined. Tribes question what data is really needed, even at the local level.
- It is best to develop a uniform data set similar to that for HEDIS (Health Plan Employer Data Information System), not start from scratch.





## Issues and Highlights

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- A key question is what data is needed—locally, regionally, nationally? What reports are needed at each level?
- We also need to take into account the data requirements recommended by the Baseline Measures Workgroup.
- Development of a uniform data set will encourage vendors to produce software packages and systems that can be integrated nationally regardless of the vendor.
- With a uniform data set and standard interfaces that can go out to various vendors, local, regional, and national groups can extract needed data and compile reports.
- Short- and long-term reporting requirements need to be looked at to determine if all the data needed is being collected.
- The Baseline Measures Workgroup (BMW) highly recommended 10 baseline measures that the group believed to be important for national planning and advocacy on issues of specific importance to American Indian and Alaska Native communities. These include age-specific overweight and obesity prevalence rates; tobacco use; group-specific alcohol and drug dependence; family violence; deficiencies in sanitation of drinking water and waste disposal; hospital discharges and ambulatory clinic visits for injury; screenings for cancer of the uterine cervix, breast cancer, and colo-rectal cancer; age-specific immunization rates; incidence and prevalence of diabetes mellitus; and respect for and inclusion of community values or spiritual healing at health care facilities.

- BMW also recommended collection of Tribal-specific data on teen pregnancy rates, prenatal care rates, and homicide, suicide, and motor vehicle crash fatality rates that are now estimated from national vital statistics.
- A set of data requirements is essential before a group can consider selecting a system.

*Note: The roundtable group determined that the question regarding how would those not using RPMS hardware and software be tied into the information network would be resolved by the development of a uniform data set and transmission standards.*

### **3. How should aggregate data be obtained and made available to the I/T/U for national planning, budgeting, and advocacy purposes?**

- Aggregate data has uses at all levels—facility, regional, national.
- Aggregate data is valuable in all aspects of managing and supporting the health care delivery system, not just for advocating for funds.
- Aggregate data does not necessarily mean a central database. There is more than one way to acquire aggregate data.
- Again, a key question is what data is needed—locally, regionally, nationally? What information is needed? What reports need to be produced?
- A combination of individual and summary data is needed. There is a concern about protection of privacy of patient information. Security requirements for access to information need to be determined.





## Issues and Highlights

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- Several subsets of data are needed — national, State, HMO's, etc.
- The need for aggregate data is a separate issue from the need to maintain RPMS hardware and software.
- Both RPMS and non-RPMS users must be considered when talking about aggregate data. What is needed now are alternatives to IHS management/funding of these items.
- Central or regional repositories are options. These could be operated by a Tribal or Urban organization or private sector contractor.
- A regional or national aggregate database need not be dependent on one particular system.
- It is essential to work to get all groups on the Internet, to communicate by E-mail and share information inexpensively. A group could store data on their own system but make an appropriate subset available by Internet.
- There needs to be more intergroup communication to share ideas and the work being done to accomplish transition, in order not to reinvent the wheel. The Web can cost-effectively make existing information and data available to more people.
- IHS or the consortium might set up an Intranet specifically for the Tribes (including those who rely on IHS for health care services), Urbans, and Indian Health Service. This would facilitate intergroup communication and would maintain the access security needed.
- Managers and clinicians need to be able to go to a PC, type in questions, and get answers without extensive knowledge of what's in the database and without being a technology expert.

- Aggregate data should provide for looking at various programs, relationships, and issues.
- It is important to clarify that aggregate data only applies to participating groups, not to all Indian people. It can only be as complete as is the participation.


#### **4. How should non-participating I/T/U's be accounted for in the aggregate data?**

- The key is to design a system people will want to participate in.
- It is important to clearly identify the benefits of partnership in an Indian Health Information System and then actively "sell" the system.
- Urban groups are not part of the current system. Before collecting and contributing data to a central repository, they would want to know what is wanted from them and what is in it for them.
- Again, it is important to clarify that aggregate data only applies to participating groups, not to all Indian people.

#### **5. Are transmission standards and uniform hardware, software, and data content required? If so, how should they be obtained or developed?**

- Uniform hardware and software are not needed. What is needed are uniform transmission standards and a uniform data set.
- For any information system, programming may be required so that data is transmitted in a standardized and thus usable format.





## Issues and Highlights

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- Transmission standards and a uniform data set would allow aggregation of data while allowing for maximum flexibility in designing systems to meet individual program and local or regional needs.
  - There needs to be standards to best ensure the integrity of entered data.
  - Currently there is no standard interface between vendors. There are as many standards as there are vendors. The Veterans Administration (VA) and the Department of Defense (DoD) are working together to design a standard interface. Since these entities are such big purchasers, vendors would be forced to comply with this interface. The I/T/U could cooperate with the VA and DoD in this development.
  - Congress has charged the Secretary of Health and Human Services to set up standards for data definitions, data transmissions, and so forth, related to health care billing and payment transactions.
  - DoD is looking for a means for MUMPS to talk to other databases comfortably.
- 6. How should the RPMS/PCC system be maintained and upgraded to meet the needs of those I/T/U partners who choose to continue to use it, and who should do the maintenance and upgrading?**
- RPMS is complex and not as user-friendly as other programs; consequently, users are not able to fully benefit from what the database has to offer. Training and technical assistance need to be continued, but improved and made more accessible for old and new users. There is a deep learning curve involved in using RPMS, especially for smaller Tribes.
  - RPMS needs to be repackaged to be more user-friendly, easier to learn, and to better meet local needs. Then it needs to be marketed to I/T/U groups and maintained.
  - There needs to be improved integration of clinical and financial data to eliminate double entry of information and to meet the needs of providers, management, State and Federal agencies, and private sector groups. There is some question as to whether such integration is possible within the RPMS framework.
  - RPMS users need bridges to off-the-shelf management and financial packages.
  - Although off-the-shelf patient care programs are not as complete and precise as RPMS, they can integrate the financial and clinical data. Perhaps the level of sophistication of RPMS is not needed and should be modified.
  - Due to limited Federal resources, some users of RPMS have turned to private contractors to assist them with needed upgrades. This is expensive for them, and there is the likelihood that these groups are wasting precious funds “reinventing the wheel.”
- Majority of groups represented at the roundtable currently use RPMS.
  - RPMS addresses needs of patient management very well; it needs improved financial management and some program management capability, especially cost and resource allocation data.





## *Issues and Highlights*

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- Some Tribes have performed an analysis on the cost of staying with the RPMS system and the cost of migrating out of it. Some groups feel that migration will provide the best cost benefit; for others, staying in may be best for now.
- Many RPMS-users cannot afford to purchase other packages or pay for software support; they must stick with what they currently have, whether they feel it is satisfactory or not.
- As Tribes spend money on consultants and other systems, the current system is becoming fragmented. There is a need to take action before it becomes more fragmented.
- Some users of RPMS want a commitment from IHS to maintain the system and be responsive to their needs or they may have to move away from the system.
- IHS has a firm commitment to RPMS, but not the needed resources to maintain it for all the I/T/U system. What IHS staff used to do, private sector contractors now do. For IHS to continue to maintain RPMS for all, Tribal financial input or other outside funding is necessary; there are not residual funds for IHS to continue to support the system without this user input.
- All RPMS users are affected when Tribes take part or all of their shares from the IHS budget. Currently, half of all federally recognized Tribes administer their own health care programs; approximately one-third of the IHS budget funds are directly administered by these Tribes. By the year 2000, it is estimated that more than 50 percent of the IHS budget may be administered by the Tribes.
- There is concern for those Tribes who can't afford to migrate from RPMS. If larger Tribes take their Tribal shares, what will happen to the smaller Tribes who can't afford to migrate?
- Focus needs to shift from a federally operated system to an I/T/U operated system.
- RPMS can mirror the current transition in patient care from IHS management of programs to Tribal management of programs. The patient care programs did not disappear when this happened. The same movement from IHS to I/T/U control can be true of the RPMS system with cooperation and support from the entire I/T/U spectrum.
- An RPMS consortium to maintain and support RPMS could be a totally separate consortium or a subgroup of the data consortium. Through a RPMS consortium member Tribes could take over the training, support, and development of functions now provided by IHS.

### **7. How can new technologies fit into future information systems?**

- New technologies are part of the changing environment. They can also be part of the needed solutions.
- New technologies — data warehousing, Graphic User Interfaces (GUI's), geographic mapping — have a great deal to offer to make computers more user friendly and more useful to decisionmakers.
- Again, meeting the need for aggregate data does not have to mean creating a central database; with current and future technology, regional and national needs may be met by extracting data from local databases as required.





## *Issues and Highlights*

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- The most immediate thing is to get all groups on the Internet and communicating by e-mail in order to share information inexpensively.
- More Tribes and Urbans can participate in the consortium and its discussions if these are conducted via electronic media.
- Groups, whether participants in an aggregate system or not, can store data information on their own systems and make part of it available by Internet.
- Many Tribes do not have the financial resources or technical expertise to set up their own information systems. For some groups, having access to someone else's system via a modem is a viable solution.
- Training and technical assistance are crucial.
- New technologies may help offset reduced funds.
- President Clinton recommended in his initial health care reform proposal that central repositories be the responsibility of a consortium of public/private sector groups or private vendors.
- A Business Plan is needed to address what it costs to develop, maintain, and support a data system. Groups must recover every bit of revenue they can and control costs every way they can.
- For Tribes and Urbans to support a central system or a central consortium, they need to be shown the results of doing so. How will such a system benefit their people?
- The consortium can apply for other Federal funds, whereas IHS cannot as easily go to another Federal agency for dollars.
- The consortium could recover costs by contracting to develop software; Tribes and Urban groups could recover costs by developing software, charging user fees, and conducting training programs.
- The consortium could be nonprofit or for-profit, with shareholders being Tribes, Urban associations, even individuals. Since Congress is interested in the business aspects of health care, a for-profit group might be more attractive to them.
- Tribes and Urbans can receive funds as pilot sites for testing software.
- Tribes could work regionally to pool resources.
- The RPMS could be kept in the Federal realm with contractor support paid for by participants or it could move to the private sector or a consortium could contract for support.

**8. Where will the resources come from to support an Indian Health Information System?**

- Funding is needed beyond what is currently available in Federal appropriations.
- Funding needs to come from other sources than the Federal Government. The T/U need to go to foundations, universities, and medical centers and form partnerships with the public and private sectors. There is strict competition for such funding. Tribes and Urbans may not want to share their sources and resources.
- The Veterans Administration is using other sources to help fund their development efforts.





## *Issues and Highlights*

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- Retaining RPMS in IHS has the important consideration of retaining it in the public domain.
- Support, training, and technical assistance are crucial. There needs to be sufficient funding for all three.
- Questions asked by other funding sources tend to change. Data must be able to answer the questions being asked now and prepared to answer future questions.

### **9. What are the roles for each of the partners in the evolving system?**

- It must be acknowledged that the Tribes (both those who chose to contract/compact and those who did not), Urbans, and IHS are all partners in an Indian Health Information System.
  - Tribes, Urbans, and IHS do have a vested interest in working together.
  - Tribes, Urbans, and IHS are separate units but all are working toward the common goal of providing high quality health care to Indian people. All have some common data needs to meet this goal.
  - For Tribes and Urbans to work well together will be a challenge. There are few, if any, historical precedents and many historical barriers. This will take a lot of leadership.
  - In assuming responsibility for program operation, Tribes and Urbans must also assume responsibility to present needs to Congress and justify the need for funds by showing how well the dollars are being used and why more dollars are needed.
- An I/T/U consortium could help decide what data needs to be collected to present funding needs and justification to Congress.
- Each group's needs and capabilities are unique. It is very difficult to come up with something for everyone. Some Tribes who can afford it believe it is more cost-effective to migrate off the RPMS system. They need to know just what information IHS or a central repository would need and would then plan to provide it.
  - Urbans are like a small Tribe. They are limited as to what they can do, what they can contribute.
  - Most Urban groups are not part of the current system. Before collecting and contributing data to a central repository, they would want to know what is in it for them.
  - Urbans are not currently collecting data on outcomes and other components that IHS and Tribes collect.
  - A crucial part of this is that Tribes and Urbans have a sense of ownership, a recognition that they are and need to be stakeholders in a consortium or central repository.
  - The payback to each group from a central system needs to be clear.
  - Marketing the consortium idea is crucial. It will be necessary to promote such benefits as advocacy needs, availability of technical assistance, and the advantages of joint contracting.







# **Recommendations**





## Recommendations

The roundtable participants carefully looked at many aspects of the future of Indian health care data information systems in light of the changing environment. They noted that there is both challenge and opportunity in the trend towards shifting of functions, funds, and responsibilities from the Federal level to the local level. They were cognizant of the many changes taking place in the organization and funding of the health care industry itself. And they welcomed the continuing rapid development of communication and information technologies. They agreed that the successes and problems of the past were in the past. The question was: Where do we go from here?

The participants represented a broad range of concerns and needs. They were clear and forthright in expressing these concerns. They identified problems, issues, and solutions. They generously shared information and reports about the often extensive work their groups have done to assess their needs and study the options available to them to improve their systems to meet those needs. The group benefited from the candid expression of viewpoints coming from representatives of Tribes and Urban groups, members of national and regional Tribal Health Boards, medical professionals, staff from various Indian Health Service (IHS) divisions, industry experts, and interested observers. It was clear that in the future an Indian Health Information System would be increasingly driven by the needs and under the province of the Tribes and Urbans. Even so, although the Indian Health Service would be playing a lesser role, it would continue to fulfill its Federal trust responsibility as an active partner and as an advocate for presenting

the health care status and needs of the Indian people to Congress. Together, the participants summed up their deliberations with the following 10 recommendations:

**1. Establish an Indian Health Service, Tribal, Urban Program (I/T/U) Data Consortium.**

This is the key recommendation of the roundtable participants since most of the other recommendations would fall under the purview of the I/T/U Data Consortium. This would be a consortium between contracting/compacting Tribes, non-contracting/compacting Tribal-IHS partnerships, and Urbans. The consortium would be responsible for providing recommendations to the Director of the Indian Health Service on data and information issues affecting its members.

Initial concerns of the consortium would be:

- Development of a uniform data set;
  - Determination of a means for aggregating data for use nationally and locally;
  - Adoption of data content and transmission standards;
  - Establishing priorities for data and information activities, such as which software development activities should be pursued and in what order;
- and
- Estimating required resources for information system activities and determining means for obtaining the resources.





## Recommendations

Determining the proper membership of the I/T/U Data Consortium is crucial to its success. All groups (contracting/compacting Tribes, non-contracting/compacting Tribes, Urbans, and IHS) and their needs would need to be represented at the table. The IHS Director could request nominations from each group, request that a nationally representative, all inclusive Indian group set up the consortium, or appoint members in consultation with IHS, Tribal (all modes of service), and Urban leaders.

It was recommended that the consortium hold periodic meetings, perhaps alternating sites. Between meetings and in order to reduce travel costs and encourage wider participation, it was recommended that the membership communicate via the Internet, either through an I/T/U Data Consortium Homepage or Bulletin Board, as well as by e-mail, or possibly on an I/T/U Intranet.

The I/T/U Data Consortium would interface with the Department of Health and Human Services Data Policy Council. However, its main focus would be dealing with I/T/U data and information issues.

### **2. Develop a uniform data set.**

An I/T/U group, possibly a subgroup of the I/T/U Data Consortium, would identify a subset of data that needs to be aggregated for national and local planning and advocacy purposes. The data would represent only essential, non-burdensome data to be used by those groups who choose to participate. Adoption of the uniform data set is intended to facilitate use of aggregate data by all partners in the Indian Health Information System.

### **3. Determine a means for aggregating the data.**

The participants clarified that aggregate data does not necessarily have to be in a centralized database, but that it is important that it be easily accessible in a user-friendly format for planning, budgeting, and advocacy of the Indian health care delivery system on the local, regional, and national levels.

Suggestions for aggregating the data defined in the uniform data set included a central and/or regional repositories or directly from local databases via Web sites. Security of the data was an important issue to ensure the privacy and confidentiality of individuals. Repositories might be operated by IHS, an I/T/U group, or a private sector contractor.

### **4. Determine how best to account for non-participating I/T/U entities in the presentation of national aggregate data.**

It was the hope of the participants that the partners could design and promote an Indian Health Information System that invited widespread participation. Although there are not historical precedents for such collaboration among the Tribes and between Tribes and Urban programs, it was considered an opportunity to engage more groups in this initiative by clearly demonstrating that the benefits to them would outweigh their concerns.

It was suggested that a study might be conducted to determine and evaluate the quality and completeness of the data collected and how representative it is of the whole I/T/U system. In addition, when presenting information derived from aggregate data, a qualifying statement should be included regarding the fact that the data represents only that of the participants, not all I/T/U people.





## Recommendations

**5. Adopt, along with the data set, data content and transmission standards to ensure that aggregate data are comparable and can be transmitted between systems, independent of hardware and software configurations.**

The roundtable recommended that existing Federal/industry standards be used whenever possible. It was also suggested that the group inquire into the work being done by the Veterans Administration and the Department of Defense and possibly partner with them in developing standard interfaces.

**6. Develop a means for maintaining and upgrading the Resource and Patient Management System (RPMS) and, in particular, the Patient Care Component (PCC), to meet the needs of the I/T/U participants who choose to continue to use it.**

The RPMS is the clinical information infrastructure for the IHS-operated and most of the Tribal-operated health care facilities. In spite of its need for upgrades, it appears to be the most highly integrated patient information system available. However, the current environment requires an increasing emphasis on financial management of revenue, costs, and resources in order for programs to continue to operate, fulfill accountability requirements, contract for managed care and other health care programs, and seek funding from other than the Federal resources that are no longer adequate. Off-the-shelf management and financial packages are available but need to be interfaced with RPMS. It was recognized that due to downsizing and lack of residual funds, IHS's ability to continue supporting and operating RPMS is coming to an end. The need to transfer this function from IHS to the I/T/U was a major factor in calling for this roundtable.

Some RPMS users have been struggling to upgrade the system themselves to meet their needs with the result that the system is becoming fragmented, resources are being expended to "reinvent the wheel," and there is unnecessary and costly duplication of effort across the country. The roundtable participants suggested that RPMS users form regional consortiums and collaborate in their efforts to address their needs. The consortium would enable the participants to share information and resources; they could develop their own upgrades or they could jointly contract with the private sector for the necessary enhancements. The consortiums also might serve as testing "labs" for interfaces and other developments.

**7. Make greater use of current and new information and communication technologies to improve the Indian health program.**

It was apparent that an effective I/T/U communications network is needed in order to collaborate with one another and share information. This might be accomplished through the Internet; however, it was recommended that an Intranet be established that would ensure the security and confidentiality needed in the health care field and be more cost-effective. It was strongly felt that all Tribes and Urban associations must have e-mail and Internet capabilities and the training needed to use these effectively. An I/T/U testing lab would be useful to test out new technologies for the group as a whole. More effective use can be made of geographic mapping and data warehousing to present information to managers. Graphic User Interfaces and other tools can be used to make databases more user friendly and more accessible.





## Recommendations

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A need for initial and ongoing training and technical assistance was emphasized over and over again. There are still many computer shy persons who need to be helped to feel comfortable sitting down at a PC and experiencing it as a useful tool. Most systems have capabilities that are never used by the majority of even the computer literate. Databases have information that no one accesses because they don't know it's there or they don't know how to extract it in a useful form. Training can produce cost benefits for almost any system. Technical assistance is also needed to ensure the most cost-effective building and expansion of systems.

**8. Establish a clearinghouse to share information models related to specific health problems and conditions.**

This clearinghouse could also come under the purview of the I/T/U Data Consortium. It would enable the sharing of data models to address specific health problems such as diabetes management; prenatal and postnatal care for babies of teen mothers; reduction in unintentional injuries; or alcohol and substance abuse in young adults.

**9. Develop an I/T/U finance committee or commission to address funding issues.**

The finance committee or commission would probably be a subgroup of or at least report to the I/T/U Data Consortium. Its responsibilities would include determining the level of resources needed to carry out the consortium's and I/T/U's information systems activities, establishing financial priorities and strategies, and developing funding sources.

Possible funding sources suggested by the roundtable participants included provision of equitable shares from partners/decisionmakers; convincing Congress of cost benefits of additional funding; formation of for-profit ventures; sharing development and/or user costs with other Federal agencies; establishing financial relationships with State agencies, foundations, and the private sector; using program income; and serving as pilot sites for testing information systems. Providing training programs, supplying technical assistance, and marketing results of development efforts were examples given of possible fundraising activities.

**10. Establish an environment that fosters an equal partnership among the Tribes, Urbans, and IHS.**

All partners should see themselves as equal players at the table. Such a partnership has never before been demonstrated. This will be the number one challenge for the consortium.

The characteristics and needs of each of the Tribes (including those who rely on IHS for health care services) and Urban groups are so widely diverse, that it will take intelligence, ingenuity, patience, and diplomacy to ensure that all see this as an association that has something of value in it for them equal to the cooperation, efforts, and resources being asked of them.

Finally, there must also be a clear recognition by all parties that the Indian Health Service has a firm, inviolable commitment to its trust responsibility to provide the highest possible level of quality health care to all Indian people, whether they are members of urban or rural communities, whether they belong to the smallest or the largest Tribe.



## *Recommendations*

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### **Conclusion**

The members of the roundtable recognized that there is an urgency in responding to these recommendations because the environment has changed, is changing, and will continue to change ever more rapidly. The many groups that make up the Indian Health Care Delivery System need to move quickly if they are to successfully accomplish their mission of providing the highest level of quality health care to Indian people.



# Appendices





## Appendix A

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## Appendix B

### Agenda

*Following are topics/agenda items that will be used to focus the discussion.*

#### **Tuesday, August 12, 1997 (8:30 am-5:00 pm)**

- 8:30 am Continental Breakfast
- 9:00 am Welcome  
*Dr. Michael Trujillo, Director,  
Indian Health Service*
- 10:00 am Background Information  
*Tony D'Angelo, Program Statistics Team  
and Jim Garvie, Information Resources  
Management Team, IHS*
- 10:30 am Introduction of Participants
- 10:45 am Review of Agenda
- 11:00 am What are the advantages and disadvantages of the current I/T/U information system structure? Group discussion.
- 12:30 pm Lunch and Group Discussion
- 1:30 pm What steps can be taken with respect to the I/T/U information system structure to improve T/U participation in the system and improve I/T/U data quality? Group discussion.

#### **Wednesday, August 13, 1997 (8:30 am-5:00 pm)**

- What are the changing environmental conditions (e.g., Health Care Reform, Welfare Reform, potential Medicare reform, Performance Partnership Grants, Federal responsibilities being shifted to the States, health care industry developments, new information system technologies) that will require changes in I/T/U information system structure? Group discussion.
- Which new information system technologies will assist in the evolution of the I/T/U information system structure and are feasible to implement within I/T/U budget constraints? Group discussion.

#### **Thursday, August 14, 1997 (8:30 am-12:30 pm)**

- What are feasible strategies (3 or 4 alternatives) for the future I/T/U information system structure that should be considered by the I/T/U? Group discussion.
- Closeout  
*Facilitator*



## Appendix C

### History of Indian Health Service's Federal Trust Responsibility

The Federal trust responsibility for American Indian/Alaska Native health care is based on Article I, Section 8, of the United States Constitution, treaty obligations, laws, Supreme Court decisions, Executive Orders, and the Snyder Act of 1921 (P.L. 83-568), as well as historical obligations. It represents the unique government-to-government relationship between the Indian sovereign nations and the United States of America. The Snyder Act, when amended in 1954 as the Transfer Act, placed this trust responsibility for Indian health programs under the Surgeon General of the United States. The Indian Health Service (IHS) was set up within the Public Health Service as the principal Federal health provider and health advocate for the Indian people. Its mission is to raise the health status of Indian people to the highest possible level.

The 1975 Indian Self-Determination and Education Act (P.L. 93-638) was amended in 1988, 1992, and 1994 to give Tribes the option of manning and managing the IHS programs in their communities and to provide for funding to increase the Tribes' ability to contract for health care services. Title I of the Act provides for self-determination contracts and Title III provides for self-governance compacts. The 1976 Indian Health Care Improvement Act (P.L. 94-437), as amended, established Title V programs to improve health care access for Indian

people living in urban areas. It also authorized higher resource levels in the IHS budget to increase the number of Indian health professionals to service Indian needs, expand health services, build and renovate medical facilities, and construct safe drinking water and sanitary disposal facilities.

IHS has a service responsibility to those Indian people residing in or near reservations. It has developed a comprehensive health services delivery system including preventive, curative, rehabilitative, and environmental services. The system integrates health services delivered directly through IHS-operated facilities, through contractual arrangements with private sector providers, and through Tribally operated and Urban Indian health programs.

In addition to the health services delivery system, IHS ensures that those involved in health care programs are aware of the entitlement of Indian people, as American citizens, to all Federal, State, and local programs that are outside the IHS and Tribal services. Besides its advocacy role in regard to Congress, IHS is the principal Federal health advocate for the Indian people in building health coalitions, networks, and partnerships with Tribal nations, other government agencies (Federal and State), and non-Federal organizations such as universities and foundations.





## Appendix D

### Documents Submitted by Participants

*Baseline Measures Workgroup Final Report.* September 1996. Prepared for the American Indian and Alaska Native People and the Indian Health Service.

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Joseph DeLuca Associates (JDA). September 21, 1994. "Strategic Long Range Planning Application Functionality Analysis." Draft report prepared for Bristol Bay Area Health Corporation. Maniilaq Association and Yukon-Kuskokwim Health Corporation.

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Yonashiro, Larry Y. November 1996. "Strategic Information Systems Plan, Fiscal Years 1997-1999." Bristol Bay Area Health Corporation.



# **FINAL REPORT**

## **Profile of the State of Indian Children and Youth**

**In support of  
the Domestic Policy Council Workgroup on Indian Youth**

**For and on Behalf of:**

**Indian Health Service  
Department of Health and Human Services**

**November 1997**

