

**REPORT OF THE  
MIGRANT DATA AND TECHNOLOGY WORKGROUP**

**Meeting on February 25, 1993  
Holiday Inn Crowne Plaza  
Rockville, Maryland**

**Resource ID#: 2691**

**Report of the Migrant Data and Technology  
Workgroup**

TABLE OF CONTENTS

Preface ..... x

Participants ..... xi

Welcome and Introductions ..... 1

**PART ONE: INFORMATIONAL SESSION**

Current Medical System Technology ..... 3

    Current/Emerging Technologies ..... 3

    Health Data Transfer in Migrant Health ..... 6

    Approaches to Health Data Transfer ..... 8

    Potential Pilot Projects ..... 10

Clinical Indicators Technology Impact ..... 11

    The Bureau's Data Strategy ..... 11

    Clinical Indicators and Data Transfer ..... 12

MCN Initiatives in Migrant Data and Technology .... 14

    Needs, Trends, and Opportunities..... 14

    Levels of Needs ..... 16

    MCN Activities ..... 16

Demonstrations ..... 18

    Forms ..... 18

    Software ..... 19

**PART TWO: BRAINSTORMING SESSION**

Desired Results ..... 21

The Current System ..... 22

Footnotes re. the Current System .....	24
Basic Assumptions .....	25
Footnotes re. Basic Assumptions .....	26
Essential Features/Components of Data System .....	27
Footnotes re. Essential Features/Components ....	29
Criteria for Pilot Projects and National System ...	31
Footnotes re. Criteria .....	32
Suggested Pilot Projects .....	35

## PREFACE

As the first of a series of deliberations to address the issues in data transfer among migrant health centers, a meeting was convened on February 25, 1993 by the Migrant Health Program in cooperation with the Migrant Clinicians Network (MCN), Ricards International Incorporated (RII), and The MITRE Corporation at the Holiday Inn Crowne Plaza in Rockville, Maryland. Participants included a broad variety of migrant health practitioners, Federal office staff, and others with knowledge and experience in this subject.

The purpose of this meeting was two-fold: (1) to provide information about current and emerging data transfer technologies, and (2) to brainstorm about the issues associated with data transfer in migrant health settings and to identify possible solutions to problems in past and current data transfer approaches. In order to accommodate these two purposes, the meeting was divided into two parts; both are summarized in this report. Of special significance are the group's recommendations for three pilot projects that are expected to serve as the basis for future system(s) of data transfer among migrant health centers throughout the U.S.

## PARTICIPANTS

Participants in this "Migrant Data and Technology Workgroup" were as follows:

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Ellen J. Belzer of Belzer Broderick & Associates, Kansas  
City, Missouri, served as the afternoon facilitator.

## WELCOME AND INTRODUCTIONS

### Comments by Antonio Duran Director, Migrant Health Program

Mr. Duran welcomed the group and thanked participants for their willingness to discuss the issue of data transfer among migrant health centers. To stress the importance of data transfer among caregivers, he offered an analogy of portable records that are used to inform foster families about the histories of children who are placed in their homes. While the vast majority of social service agencies do not provide such records to foster families, those who receive such information find it much easier to meet each child's specific needs.

The same principle also applies to transferring the medical records of migrant and seasonal farmworkers and their families, Mr. Duran said. That is, in any area of service, it is essential to obtain the best and most timely information possible.

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"... As you receive these families in your clinics, I'm sure you realize that if you only had information you could do an even better job of helping these families as they come in."

Antonio Duran, Director  
Migrant Health Program

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Referring to a February 24 memorandum by E. Roberta Ryder of the National Migrant Resource Program, Mr. Duran pointed out that the exploration of data transfer systems could be traced back to the late 1970s. Although these efforts have continued ever since, he expressed his hope that, by pooling the lessons learned from past efforts, this workshop will be a positive step toward the development of a data transfer system that works.

Comments by Jack Egan  
Deputy Director, Migrant Health Program

Mr. Egan first described the information that had been provided to participants in advance of this workshop. Among those materials, he noted that several types of information had been compiled including: articles about computer technology and how such technology can be applied to medical practices; examples of portable medical records; activities of the Migrant Clinicians Network (MCN); and, the results of a study by The Mitre Corporation on providers' perceptions about the effectiveness of various types of data systems in Migrant Health Program (MHP) clinical projects.

In an overview of the workshop agenda, Mr. Egan noted that the workshop was organized into two parts in order to be both informational and participatory. During the first part of the meeting, he said that information would be provided on topics including: the state of the art of medical system technology; clinical indicators; the Bureau's data collection strategy; and MCN initiatives in this area. After various software demonstrations, the second portion of the meeting would be devoted to a facilitated brainstorming session so that participants can identify problems, solutions, and short-term objectives related to data transfer.

Finally, Mr. Egan pointed out that there may be a need for additional meetings, either of this group or another configuration. Follow-up activities will be determined after this workshop, he said.

**PART ONE:**  
**INFORMATIONAL SESSION**

CURRENT MEDICAL SYSTEM TECHNOLOGY  
Comments by J. Carter Crafford, Jr.  
with Barbara D. Kerlin  
The MITRE Corporation

J. Carter Crafford, Jr. of The MITRE Corporation next described current and emerging automation technologies and the issue of health data transfer in migrant health.

Current/Emerging Technologies

To put the discussion of emerging technologies into perspective, Mr. Crafford first pointed out that micro-computer technology is advancing more rapidly than ever before. Because each generation of new computers is so much more powerful and faster than its predecessors, today's computers are fast becoming obsolete.

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**"Whatever you purchased six months ago, you can buy a better machine for the same price now."**

**J. Carter Crafford, Jr.  
The MITRE Corporation**

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Micro-Computer Technology

In addition to personal computers (PCs), Mr. Crafford also described the current popularity of computer notebooks (which are portable and approximately 6.5 pounds) and subnotebooks (which are even more portable at 3.5 pounds). Other computers that will become increasingly targeted to clinicians include "pen/tablets" (in which a special pen can be used to point, write, or draw), and "palmtop" computers (which function by touching the screen, using the keyboard, or using a pen with which the user can draw and save pictures).

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**"In general, (computers) are getting smaller, more portable, cheaper, and more robust."**

**J. Carter Crafford, Jr.  
The MITRE Corporation**

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## Data Capture Technology

Entering data into automated medical records traditionally has been done using keyboards. As graphical user interfaces such as the Microsoft Windows environment has become more prevalent, however, medical users also have entered data with mouse and trackball devices. Other methods include the "touch screen," "pen-based computing" and "scanners." To describe the use of scanners, Mr. Crafford cited the example of a county health authority in Florida which used scanners in order to facilitate the entry of school immunization data. Instead of relying on the much slower process of manual data entry, using scanners (with "mark sense readers" that read markings on forms) has proven to be so cost-effective and efficient that the health authority now plans to expand their use to a statewide basis.

Another method of capturing data is through "optical character recognition" (OCR) which allows the user to read and enter data from either markings or handwriting. Using commercial "Teleform" software, OCR also can be used to read data that is transmitted over facsimile (FAX) machines and enter it directly into the database. Mr. Crafford noted that this method would be particularly applicable to migrant health centers which rely heavily on FAX machines for data transfer.

Another way data can be entered into computer systems is through voice activated systems. In the Kurzweil radiology system, for example, users can enter voice patterns and templates for reports so that the computer can expand words into phrases or respond to simple requests, e.g., reports on patient conditions. [Note: While direct "voice-to-text" technology is available today and mainly used in radiology, pathology, and emergency medicine, its use is somewhat limited to the limitations and operating environment of the machine. An improved version, "continuous voice technology", is expected to be available in approximately five years.]<sup>1</sup>

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<sup>1</sup>Kenneth A. Marcoux. "Opportunities About for Automating the Patient Record." MGM Journal. December 1992, p. 55.

## Data Storage Technology

Once data is obtained and entered into an automated medical records system, it also is important to consider how to store it. A well-known method is to store information on floptical diskettes which now are designed to store much more information (up to 20 million characters) than the floppy diskettes of years past (which only could store up to 1 million characters). Hard disks and compact disks are commonly used to store large volumes of text, sound, and graphical information.

Data also can be stored on "softstrips" which are applied to small credit cards and bar-coded for multiple types of conditions. Another variation, the "magnetic stripe card," is not as reliable since data can be erased inadvertently by contact with static electricity. Newer and safer methods are "chip cards" (which contain a computer chip), "smart cards," (which contain a computer chip and also protect information with an electronic lock)<sup>1</sup>; and "laser cards" (which store information as tiny black dots burned into the surface of the card by a laser in a special computer terminal).<sup>2</sup> Like other technologies, the prices of these cards are being reduced with their expanded usage, and now cost approximately \$5 per card.

Other types of data storage mechanisms include "integrated circuit memory cards" (which may be programmed and erased); "optical disks" (which are non-electronic records similar to microfiche);<sup>3</sup> and Random Access Tape Pack (RATPACK) holographic storage.

## Data Management Technologies

Mr. Crafford next listed several types of data management technologies including flat file database packages; hierarchical database packages; relational database management systems; programmable vs. non-programmable

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<sup>1</sup> G. Berton Latamore. "Smart Cards Get Smarter." High Technology Business. September 1987, p. 36.

<sup>2</sup> Ibid., p. 35.

<sup>3</sup> Kenneth A. Marcoux. "Opportunities About for Automating the Patient Record." MGM Journal. December 1992, p. 55.

scripting; Windows graphical databases; and database server and client server technologies.

### Data Transmission/Telecommunications

Mr. Crafford also noted that data can be transmitted through several different methods or combinations: telephone/audio systems; facsimile (FAX); electronic bulletin boards, electronic mail (E-mail), and public data networks; video conferencing; Integrated Services Digital Network (ISDN) for telemedicine; and wireless technologies.

### Health Data Transfer in Migrant Health

During this discussion, Mr. Crafford explained (1) the objectives of health data transfer; (2) issues that need to be considered; (3) current migrant health data systems; (4) the East Coast Migrant Head Start Project system; and (5) the results of the 1991 migrant health data transfer survey.

### Objectives of Health Data Transfer

Mr. Crafford stated that the objectives related to health data transfer are to: promote continuity in the health care delivered to migrating patients; "empower the provider" to reduce time, effort, and expense required to determine patient health and treatment history; "empower patients" to take an active role in their health; reduce redundant or unnecessary treatment or testing (e.g., reimmunization); improve the quality of care delivered; promote completeness of the home base medical record; and facilitate teamwork among migrant health clinics.

### Issues to Consider

When developing a data transfer system, issues that should be taken into account include: the ease of use and acceptability of the data transfer mechanism; the costs and benefits of the technology used; the confidentiality/privacy of information; the utility of the transfer mechanism in non-migrant clinics; patient involvement; staffing; and training and support.

### Current Migrant Health Data Systems

Mr. Crafford noted that data now is being transferred among migrant health centers in various ways. In some centers, patients are carrying photocopies of their medical and referral records while, in others, the centers mail or FAX records to other sites. He also pointed out that portable medical records resources are available through the National Migrant Resource Program.

### The East Coast Migrant Head Start Project System

Mr. Crafford next described the East Coast Migrant Head Start Project system, noting that a manual filing system is used to maintain records of 6,000 migrant children at the project's central office in Arlington, Virginia. To use this system, delegate agencies which need specific children's records call the central office. The central office then places a form in the child's file and sends the master record to the delegate agency via UPS overnight service. Currently, the project is seeking to methodically replace this cumbersome manual system with an automated one which now is being tested in four sites.

### Results of the 1991 Migrant Health Data Transfer Survey

A survey of 103 ambulatory health centers was conducted in 1991 to identify the perceptions of migrant clinicians, administrators, and others about the issues and roadblocks related to data transfer. Contacts at these centers also were asked for their ideas and suggestions on ways to improve the transfer of health information for migrant farmworkers and their families.

The Need for Health Data. In the survey, respondents cited a need for historical health data in three areas: immunization compliance, perinatal care, and chronic care.

Current Data Transfer Methods. The majority of respondents (75%) noted that they do not see patients carrying any information from prior clinics. Of patients who do carry information, however, most bring a photocopy of their medical records. On a less

frequent basis, patients bring special referral/follow up forms, registration or encounter forms, a clinic business card, or a portable health record.

Barriers to Data Transfer. Among the barriers to effective data transfer, the most frequent response concerned the migration schedule; i.e., clinicians do not know in advance when patients are leaving the area. Other barriers include difficulties in identifying the clinic where patients received prior care and patients not remembering to bring their records.

Suggestions for Improvement. Respondents also were asked for their suggestions on the tools or strategies that would best support the health data transfer mechanism in the migrant setting. Most respondents favored patient-carried records. In order for this method to work, however, respondents pointed out the importance of educating patients to carry the records and motivating clinicians to use them. To illustrate this point, Mr. Crafford referred to a nurse in the midwest who distributed more than 2000 MCN (patient carried) cards but saw only a few of the cards ever return on the patients' visits in subsequent years.

#### Approaches to Health Data Transfer

Mr. Crafford next described three broad approaches to migrant health data transfer: patient carried records; telecommunications; and a hybrid approach.

Patient Carried Records. In this approach, the records may be photocopies of clinic forms, standardized portable records, or electronic cards such as the softstrip or smart card.

Telecommunications. This category entails transferring data verbally over the telephone, by FAX, FAX modem, or advanced image transfer methods such as televideo or teleradiology.

Hybrid Approach. In this approach, two or more methods are combined, e.g., a patient carried record is used in conjunction with some form of telecommunications.

### Characteristics of Various Approaches

Each of the three approaches has at least some of the following characteristics: it is convenient for staff; it is easy to transport; it involves the patient; it is economical; the patient controls access; information is secure; information is standardized; it is universally usable; and it has automated capabilities.

There are advantages to both patient carried records and automated systems. As Mr. Crafford noted, patient carried records are convenient, easy to transport, and have the benefit of directly involving the patient. They also are universally usable since other organizations (e.g., state health departments) can easily read paper records but may have more difficulty reading automated records if their systems are incompatible. Automated systems have several distinct advantages, however. For example, these systems make it easier to collect and analyze data and conduct research on various aspects of patient care.

### Operational Scenarios

There are three main ways that health data could be transferred from one migrant health center to another: from clinic-to-clinic, from the clinic to a data gatekeeper, and from the clinic directly to information resources.

Clinic-to-Clinic. In this method, a clinic transmits health information to other clinics by telephone, FAX, automated FAX modems, mail, or through other means. This category also includes the use of patient carried records.

Clinic to Data Gatekeeper. In this method, a clinic transfers health information to a data gatekeeper who is responsible for maintaining, processing, and tracking the data. The data gatekeeper can be designated for a particular stream, a national entity, or an organization with information resource capabilities. To use the gatekeeper system, clinics should be equipped with automated systems or, at the minimum, facsimile machines.

## Potential Pilot Projects

To set the stage for the afternoon's brainstorming session, Mr. Crafford listed several ways to conduct pilot projects. Examples include:

Pilot project between sites of a single, multistate project. This method involves testing the same data transfer system at various sites in a single clinical organization that has clinical sites in more than one state. Systems that could be tested by using this method include standardized portable paper records or electronic cards, FAX networks, or a centralized automated data registry.

Pilot project between clustered homebase and upstream clinics. This would involve conducting pilot tests in various clinics within a particular stream. The types of data transfer systems that would be conducive to this method include paper records or a FAX network.

Pilot project with a patient data gatekeeper in one migrant stream. In this type of pilot project, a patient data gatekeeper would be designated to coordinate data transfer within a migrant stream. Data could be transferred through an electronic registry of sentinel health conditions and events, telephone and facsimile interface, or by electronic bulletin boards or E-mail.

CLINICAL INDICATORS TECHNOLOGY IMPACT  
Comments by David Stevens, M.D.  
and Nancy Paquin  
Bureau of Primary Health Care

David Stevens, M.D. and Ms. Nancy Paquin of the Bureau of Primary Health Care each presented talks on the Bureau of Primary Health Care's new data strategy. Both of their comments are combined in this section.

The Bureau's Data Strategy

The purpose of the new strategy is to overcome several problems with reporting systems that have been used by the Bureau in past years to collect information on programs and their patients. Specifically, these systems were duplicative, outdated, or not conducive to collecting the types of information needed by the Bureau for evaluation, policy analysis, and research.

Although the Bureau's new data strategy is not particularly patient-centered, it includes many of the questions that need to be asked of Bureau-funded programs. Key components of the strategy include the following:

Universal/Core Data Form. Each year, the Bureau will disseminate a universal form to grantees in order to collect basic program data and cost information. In addition, specific modules will focus on the unique requirements of each program. For example, one of the modules will be specific to migrant health centers.

Sample Forms. In order to acquire more in-depth information on specific age and sex groups, conditions, and services (e.g., perinatal care, young children, HIV, and preventive services), a representative sampling of grantees will be asked to complete forms that address these areas. Because selected migrant health centers and other grantees will be given these forms one year in advance of their due date, the centers can collect the needed data on an ongoing basis as the year progresses.

User and Provider Surveys. Patient and provider surveys used by the National Center for Health Statistics (NCHS) now are being adapted for use in Bureau programs. After first testing these surveys in community health centers,

they will be modified for use in homeless programs and migrant health centers as well.

Because of the need to study patients as well as practices, the Bureau also plans to conduct studies in practice-based networks.

### Clinical Indicators and Data Transfer

#### Prenatal Care

Beginning with a study of prenatal care, the Bureau plans to adapt clinical indicators to migrant practices and to explore the issue of data transfer among migrant health centers. The results of this effort will be applicable to community health centers, homeless centers, and other centers with mobile populations.

#### Immunizations

The budget for fiscal year 1993 contains a \$300 million supplement for immunizations, with an additional \$500-600 million expected in fiscal year 1994. Of these amounts, the Centers for Disease Control and Prevention has proposed that it use \$25 million to develop a data system for child immunizations. Migrant health and other clinics utilizing this data system (also referred to as a "national registry") would be required to use specific software to log children's immunization records. The names of each child would be kept in a central data bank. Whenever a participating health center wishes to retrieve a child's immunization records, it simply would enter the child's name into its computer which then would feed the request to the central data bank. The central data bank then would identify the center where the records are stored and transfer the record to the center that requests it.

It is likely that several public and private agencies will be involved in various aspects of this effort if the proposal is accepted. A substantial amount of the funding request for this project would be earmarked for software, equipment, and training for user clinics.

### Discussion Period

During group discussion, a participant stressed the importance of ensuring that surveys and pilot projects related to data collection and data transfer provide immediate benefits to migrant health centers as well as to those who initiate the surveys or tests. Such two-way benefits will help to motivate migrant health centers to be involved in such efforts, the participant said.

Another participant stressed the need to develop a national profile of the health status of migrant and seasonal farmworkers and their families that can be viewed in comparison to the general population. It also was suggested that monies be made available to migrant health centers to help them defray the cost of collecting new types of information.

MCN INITIATIVES IN MIGRANT DATA AND TECHNOLOGY  
Comments by Karen Mountain, R.N., M.S.N., M.B.A.  
Executive Director, Migrant Clinicians Network

Karen Mountain next provided an update of activities by the Migrant Clinicians Network (MCN) in the area of data technology. Starting with an historical overview, Ms. Mountain noted that MCN was established in 1986 when two nurses and a physician who met at a conference engaged in a discussion about the barriers facing migrant practices in isolated areas and the need to share ideas about common issues and problems. Although MCN remains a grassroots organization, it is now a corporation which is national in scope, and currently is in the process of seeking 501(c)3 status.

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"Much of the discussion here highlights the fact that clinicians are still at the tail end of the data technology revolution. Other areas of health care practice are benefitting first from data technology efforts. The fact is that, currently, the majority of resources are bottom line-driven and billing-driven."

Karen Mountain, R.N., M.S.N., M.B.A.  
Migrant Clinicians Network

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Needs, Trends, and Opportunities

Ms. Mountain noted the following needs, trends, and opportunities related to data technology:

- o Health care reform will make it even more necessary for clinicians to be involved in data technology. To ensure that migrant health centers survive and flourish along with health care reform, clinicians will need to explore the efficiency and effectiveness of their health care services on an ongoing basis.
- o Data collection can be made meaningful to clinicians by providing feedback. Clinicians will be more motivated to collect data if they are assured that they will receive meaningful feedback from the data they collect.

- o There is a need to develop the capacity to link information. Rather than continue developing islands of information and increase fragmentation, technology should be developed that will link information that is collected.

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"I get two to three phone calls a week from people who have wonderful information on a subset of their population, and they would desperately like to link that data for comparative reasons... Unfortunately, however, we don't have the technology to do that."

Karen Mountain, R.N., M.S.N., M.B.A.  
Migrant Clinicians Network  
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- o Emphasis should continue to be placed on public/private sector partnerships. While this currently is being done to some degree, it is essential to take greater advantage of the many opportunities to develop such partnerships in data technology.
- o A practice-based research initiative should be pursued. There are several reasons that the MCN is particularly interested in such an initiative: (1) it would result in short-term benefits to clinicians; (2) it would produce the kind of information about patients and practices that would be particularly useful to clinicians; and (3) it would enable clinicians to expand into other areas of expertise such as research and education and thus provide other meaningful career options in migrant and community health.
- o Data technology efforts must have clinical input. This will help to ensure that the collected data is meaningful to clinicians in migrant health practices.
- o A systematic approach to data collection and data transfer is essential. In order to ensure that such efforts are affordable and realistic, it is important to methodically identify sources of available funding opportunities at the local, state, and regional levels.

### Levels of Needs

In order to envision what a meaningful data technology system would "look like", Ms. Mountain noted that the MCN has identified four levels of need that each require solutions:

The need to coordinate data collection within the migrant health center. The first level of need is to coordinate data collection efforts among clinicians, outreach workers, health educators, and other migrant health professionals within the migrant health center. Such coordination will help to avoid the costly and time consuming duplication of effort and maximize the use of scarce resources. By helping migrant health center personnel understand what is being spent for certain procedures, collaborative data collection also will lead to improved decision making and management.

The need to transfer data from one site to another. Because many migrant health centers have several sites under an umbrella corporation, there is a need to improve the efficient transfer of information among those sites.

The need to share information through a central clearinghouse. This involves the need to download information on individual clients and practices into a central clearinghouse so that data collected in various sites along a migrant stream can be analyzed.

The need to transfer information on clients. In addition to developing data transfer priorities, it also is necessary to share information about patient care. This should include information that patients either are reticent to discuss or cannot explain due to language barriers.

### MCN Activities

MCN has worked diligently to develop low-tech data collection and transfer products such as the MCN portable OB record, an adult and child care record, occupational health histories, various types of referral forms, outreach posters, etc. None of these products has been entirely successful, Ms. Mountain said.

MCN also is investigating the feasibility of starting its own not-for-profit company to provide data technology services and products to migrant health centers. Toward this end, MCN has made contacts with several large and small business system vendors to explore the possibility of entering into bulk purchasing arrangements. Currently, MCN is working to identify public and private sources of seed monies for the new company, with the hope that it eventually will become self-sufficient.

Through a grant from the Office of Migrant Health and the Bureau of Health Professions, Division of Nursing, MCN also has developed an electronic bulletin board system which is expected to become operational within the next couple of months. The system will be used for several purposes: to conduct joint conferences and forums; to send and receive public and private electronic mail; to view or download list files (such as directory information); and to access various health databases.

#### Discussion

During the discussion that followed, one participant stressed the importance of developing a data system with flexibility so that the entire system does not have to be changed if there is a need for new types of information.

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"I think that if we continue using the grassroots method with structure on top of it, people won't feel like they're slaves to the data input mode."

Workshop Participant  
(Unidentified)

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DEMONSTRATIONS  
Comments by Dr. Richard Andrews  
of Delmarva Rural Ministries  
with Karen Mountain  
of the Migrant Clinicians Network

Review of Forms

During this segment of the workshop, participants first reviewed examples of forms that can be used to collect various types of data.

As Dr. Andrews explained, data from many types of existing paper records (e.g., the MCN OB record) can be transferred easily to the computer and have a similar appearance to the way it looks on paper. This makes it easier for personnel who are accustomed to manual data entry to make the transition to using computers. It also makes it much less likely that outreach workers and others who initially use paper records to record data will make transcription errors when they enter the data into the computer.

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"Certainly you are all going to have to learn new things as we computerize. There is no way around that. So the way we do it should be as user friendly and nonthreatening as possible."

Dr. Richard Andrews  
Delmarva Rural Ministries

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There are several time-saving advantages to entering data from paper records into the computer. First, the computer can be programmed so that some line items can be filled in automatically. Second, because data about a patient which does not change (e.g., demographic information, date of birth, ethnicity, health history, etc.) is entered into the computer only once, computers help to avoid the redundancies inherent in many paper record systems. Also, any data that already has been entered by someone else will appear on new forms by connecting it to that person's data record. For example, patient data that already has been entered onto a registration form will automatically be entered onto that patient's MCN OB record.

## Review of Software

Next, Dr. Andrews demonstrated two types of software. Highlights of this discussion appear below.

### Perform Pro Plus with WinFax

This software has numerous capabilities:

- o It is the first Window software with the capability of taking information from a computer screen and "faxing" it to another computer or facsimile machine.
- o It has electronic bulletin board capabilities, (i.e., the software makes it possible to transfer data back and forth, even to those who are not linked with an electronic bulletin board or who have a FAX machine but no computer).
- o It can be used to design paper forms.
- o It can ensure the use of uniform terminology so that different words are not used to describe the same condition.
- o It can be used to enter data into other forms such as referral forms, disability forms, etc. (e.g., if a physician determines that a patient qualifies for disability, the computer will automatically fill in the patient's history and other data).
- o It can be configured to sort through patient charts to identify trends, e.g., trends in a particular lab test.
- o It can generate charts, e.g., growth charts, weight gain charts, etc.

### C.H.I.M.P.

Dr. Andrews next described a computerized patient record system that he developed for migrant (and community) health centers which he named "Computerized Health Info-system for Migrant Patients" or "CHIMP." This acronym was selected because it was felt to be nonthreatening to persons who do not have a lot of computer experience, and also because

"computers are very good at doing boring, repetitive tasks that call for an IQ about equal to that of a chimpanzee."

This Windows-based program requires a high-end 386 or a 486 IBM compatible computer with four to eight megabytes of RAM, and a pointing device (either a mouse, track ball, or pen/tablet instrument). Although it would be somewhat more expensive, a computer with touch-screen technology can be used in lieu of a pointing device.

Features of this software include the following:

- o It is capable of generating quality improvement (QI) forms automatically.
- o It can readily extract clinical indicators or other specific information.
- o It is a user friendly system that is easy for clinicians to set up.
- o The first screen contains a list of the most common diagnoses of the particular population. Clinicians would select a diagnosis category, and that form would show on the screen along with the patient's demographic data which was entered beforehand.

Because only a small amount of data is unique from visit-to-visit, there is a lot of repetitive information that can be entered automatically by using a minimum of key strokes. Standard terminology is built into the software.

**PART TWO:**  
**BRAINSTORMING SESSION**

BRAINSTORMING SESSION  
Facilitated by Ellen J. Belzer

To introduce the brainstorming session, Ms. Belzer noted that the group's task would be to establish priorities and develop short-term and long-term objectives for the development of a national data linkage system. Toward this end, she suggested that the group: discuss the current system (what does and does not work); develop a set of basic assumptions that should underlie a national data linkage system; develop criteria that the pilot projects and the national system should meet (minimal, desirable, and optimal criteria); and develop short-term solutions, i.e., recommendations for pilot projects that eventually will contribute to the long-term solutions.

In the lists that appear in this section, the following should be noted:

- o An asterisk (\*) indicates that there was not complete consensus on that item.
- o The footnotes indicate that explanations or additional comments will appear at the end of the section.

Desired Results

When asked about what they would like to achieve as a result of this discussion, participants said they would like to:

- o Develop plans for one or more pilot projects;
- o Discuss the strengths of various organizations concerned with migrant health in order to determine how each of these parties can best contribute to the development of a data linkage system and what their roles should be; and
- o Determine how the various organizations which will participate in this effort can collaborate most effectively.

## THE CURRENT SYSTEM

During this discussion, participants described the current "system" of transferring data among migrant health centers. The intent of this discussion was to identify aspects of the current system that should be reinforced and other aspects which should be avoided in the development of a new system. (Footnotes for this section appear on page 24.)

### Characteristics

Participants characterized the current "system" as follows:

- o There isn't one.
- o Chaos.
- o No uniformity.
- o There is an informal system in place.(1)
- o Some OB and immunization records currently are being transferred.(2)
- o Lack of linkages.
- \* o The current system does not necessarily lend itself to positive health outcomes.(3)

### Positive Aspects (What Works)

Next, participants identified the positive features of the current system that should be reinforced in a new system:

- o Fiscal information is being transferred.
- o The system is working well at the receiving end (i.e., the central office).
- o Locally, physicians are diligent about documentation.
- o (Migrant health professionals) are predisposed to deal with this issue.
- o Some OB and immunization records are being transferred.

- o Professionals in migrant health centers know who is upstream and downstream.
- o There are some effective informal working relationships between sites.(4)
- o Stream and regional meetings have helped to improve communications.

Negative Aspects  
(What Does Not Work)

- o Efforts to develop low tech solutions have not been successful, e.g., the MCN portable record.(5)
- o (Handwritten records) are labor intensive.
- o Patients frequently are not able to identify the migrant health center they last visited or which center is available to them at another site or system.(6)
- o Information can be easily lost, destroyed, or damaged.
- o There are problems determining some patients' true identities.(7)
- o The Bureau can extract aggregate information but not specific health indicators.
- o Data is being submitted in different ways.
- o The quality of submitted data is not uniform.
- o The system only is reliable on a sporadic, intermittent basis.

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Footnotes  
(The Current System)

- (1) As one participant noted, "You might talk to some people and they would say, 'we FAX things back and forth and don't have any problem.'"
  - (2) In addition to OB and immunization records sometimes being transferred, there also is the transfer of some public health type records such as alerts on active tuberculosis.
  - (3) This point was controversial and no consensus was reached.
  - (4) It was noted that, while this is true of some sites, it is not true in others.
  - (5) It was noted that the MCN portable record is now out of print and is not going to be reprinted.
  - (6) This makes it difficult for migrant health professionals to contact other migrant health centers to obtain or pass along a patient's medical records.
  - (7) Illegal aliens may use various aliases rather than their real names, making it difficult to ensure the continuity of information from site to site.
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## BASIC ASSUMPTIONS

The group next identified several basic assumptions that should underlie a national data linkage system. Those assumptions are listed below; footnotes appear on page 26.

### General

- o Data technology needs are greater than the mere transfer of specific patient information from one site to another.
- o Resources are limited.(1)
- o Creativity is unlimited.
- o The migrant health system is not a closed system.
- o Short-term and long-term strategies and solutions may differ.(2)
- o Data transfer will improve outcomes.

### About Patient Records

- o Not all clinical information is clinically relevant.(3)
- o Some conditions and health information (e.g., OB and immunization) require continuity in the records.
- o Patients will not carry records unless doing so is perceived to be important.

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Footnotes  
(Basic Assumptions)

- (1) This may have several implications. For example, it would be desirable to develop a data linkage system that utilizes existing staff rather than one that requires additional staff.
  - (2) During the discussion, it was noted that the long-term solutions may be entirely different than the short-term solutions; as such, the long-term solutions may be more than just a larger scale version of the short-term solutions.
  - (3) In regard to this point, it was noted that approximately 90% or more of that conditions that migrant/seasonal farmworkers and their families present are acute problems which may not be relevant on their next visit. For example, if a patient came to a migrant health center for treatment of a rash, and subsequently came for treatment of a sprained ankle on another visit, a record containing an extensive description of the rash would not be particularly helpful to the clinician in treating the ankle.
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## ESSENTIAL FEATURES/COMPONENTS OF A DATA LINKAGE SYSTEM

During the discussion about assumptions, participants also developed several recommendations about the various features and components that are integral to a new data linkage system. Those recommendations appear below; footnotes for this section are contained on page 29.

### Purpose

- o All efforts to develop a national data linkage system should be designed to enhance the delivery of migrant health services.

### General Features

- o Any system that is developed -- for the short-term as well as for the long-term -- should be as simple as possible.
- o The process of data transfer must be designed to be acceptable to migrant health center staff.
- o The system should be as nondisruptive to migrant health centers as possible.
- o The system must be flexible.(1)
- o To avoid unnecessary problems, expectations between programs should be clearly identified.
- o Specific information should be easy for clinicians and others to retrieve.
- o Ongoing training/technical assistance (TA) for staff is essential, even if the system that is developed is a relatively simple one.

### Re. Patient Records

- o One of the purposes of any system using computer-based patient records should be to enhance patient care and improve outcomes.(2)

- o Patient carried records must be designed so that information can be added to the records after the patient's visit. (3)
- \* o Consideration should be given as to whether patient carried forms are bilingual. (4)
- o If patient carried records are used, efforts should be made to identify the reasons that patients do or do not carry the cards that are given to them and what size of record they are most likely to carry. (5)
- o Patients are not likely to consider it important to carry their records unless they receive appropriate education and reinforcement by migrant health professionals. (6)

#### Resources

- o Migrant health centers will require additional resources in order to implement a data linkage system.
- o Contingency plans should be made so a data transfer system can continue even if sources of support diminish for some reason.

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Footnotes  
(Essential Features/Components)

- (1) Because data must be kept current, any system that is developed must make it easy for users to update information at will.
- (2) As one clinician noted, "(The system) clearly needs to be connected with improved patient care. I would be willing to do an extra step if it clearly would benefit the patient and, if it does, the system would be much more likely to be used even if extra steps are involved."

Another participant noted, "In terms of the records, the patient is the most important criteria."

Also in regard to this point, a reference was made to a 1991 book by the Institute of Medicine entitled The Computer-Based Patient Record and Essential Technology for Health Care which notes that an intelligently designed computer-based patient record serves both administrative and health needs; that is, the two are not incompatible if the system is designed correctly.

- (3) On this point, it was noted that most of the medical record is not generated at the time the patient walks out the door. Due to the need to wait for lab results and to transcribe dictated notes, it may take a couple of days to complete the documentation. Thus, if the medical record is to be given to patients when they walk out the door, a mechanism needs to be developed to allow for subsequent adjustments.
- (4) There was considerable controversy in regard to this point. One participant who has had extensive experience with patient carried records noted that bilingual portable records were found to be duplicative when the only purpose was to transfer critical information between providers. If the form is intended to be useful to the patient, she said that the form should be bilingual; however, she noted that there are other ways to make the client aware of their health status.

Another participant noted that he was intrigued by the idea of a bilingual form which could be used in cross-border care, e.g., the U.S., Mexico, and Haiti.

"Patients should have their own records in their own language so that they can take them back and forth," he said. "One out of a hundred brings their records from Mexico with them."

Since consensus was not reached on this point, it may be desirable to debate this point further at a future meeting.

- (5) When identifying why patients do or do not carry records with them to the migrant health center, questions should be designed to get more information than anecdotal information alone. In regard to the size of cards, it was noted that patients would be more likely to carry wallet-sized cards rather than "a bunch of papers."
- (6) While patients bear some of the responsibility for carrying their records, the responsibility also rests with migrant health professionals who must explain to patients why carrying their records is important. This point also must be reinforced at other migrant health centers by having migrant health professionals request the patient's records.

It also was noted that some of the reinforcement can be integrated into the patient carried record itself. For example, information is provided on the pediatric record that describes the importance of the form to patients and why it is necessary to carry it. Visual images of a child's growth and development may be useful to the patient.

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CRITERIA FOR PILOT PROJECTS AND THE  
NATIONAL DATA LINKAGE SYSTEM

Next, participants developed lists of essential, desirable, and optimal criteria that the pilot projects and the national system should meet. Footnotes for this section are listed on page 32.

Use of the System

Participants agreed that the data system should be designed to be used by the following individuals or organizations:

<u>Individual/Organization</u>	<u>Category</u>
Providers(1)	Essential
Patients(2)	Desirable
Researchers	Essential/Desirable
Primary care associations	Essential
Federal agencies	Essential

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Footnotes

- (1) At the very minimum, a data system should be designed to be used by migrant health center personnel, including all administrative and clinical staff. Such a data system should be designed to: enhance continuity, result in better outcomes, enable clinicians to provide better care at lower cost, provide care without waiting for records, increase provider satisfaction, and reduce stress.
  
- (2) As participants noted, it is desirable for data systems to be designed for use by patients (in addition to migrant health centers) *as long as it is done simply*. This would be beneficial because it would encourage patients to become more responsible for their own health care.

It may be necessary to develop two sets of information; one for use by patients, and one for use by clinicians.

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### What a Data System Should Do

Next, participants identified the essential, desirable, and optimal characteristics of a national data linkage system.

#### Essential

An essential system should:

- o be a slight improvement over the existing system;
- o be designed to handle the basic collection and transfer of information;
- o at very the least, be able to transfer information on: prenatal, chronic illnesses, and public health issues;
- o ensure that information is conducive to research, analysis, and evaluation, i.e., that the system makes it easy for other agencies, researchers, or administrative/financial professionals with compatible systems and equipment to add or retrieve information.

#### Desirable

A desirable system should:

- o be a big improvement over the existing system;
- o be both quantitative and qualitative, but primarily the latter;
- o emphasize clinical care;
- o be capable of transferring patient summaries.

#### Optimal

An optimal system should:

- o be an even bigger improvement over the existing system;
- o be capable of all items listed above, and more.

### Methods of Data Transmission

Participants cited the following methods of data transmission that could be utilized in various pilot projects:

- o Oral records (i.e., via telephone)
- o Portable records (i.e., patient carried and non-patient carried)
- o Facsimile (FAX) machines
- o Photocopies
- o Automated systems (e.g., computerized systems, interactive video, etc.)
- o Electronic bulletin boards
- o Medical Alert systems

## SUGGESTED PILOT PROJECTS

Based on this discussion, participants recommended the development of various pilot projects (or, demonstrations) which can be viewed as short-term solutions. Participants expressed their hope that the results of these pilot tests eventually will contribute to long-term solutions.

### Pilot Project #1

In this computer-based pilot project, patient record summaries will be compiled, incorporating both demographic and clinical data. Such computer-stored summaries lend themselves readily to (1) data transfer, (2) practice-based research, and (3) administrative and Central Office data needs. At a minimum, data on immunizations and prenatal care would be collected and transferred. In order to build in redundancies, facsimile machines and patient-carried records would be used in addition to computers.

The purpose of this demonstration would be to determine the effectiveness of computers, facsimile machines, and patient-carried records, when used in concert with one another.

This project would be spearheaded by Dr. Richard Andrews of Delmarva Rural Ministries, which is a multi-state, multi-site clinical organization.

### Pilot Project #2

This project would be developed to study the Center for Disease Control and Prevention's plans for collecting and transferring immunization data, and to determine whether it is possible or desirable to adapt their methods for use in migrant health centers. This study would include a look at the CDC's expectations of its end-users and the types of equipment and software that would be required.

This project would be managed by the Migrant Clinicians Network in cooperation with the Bureau of Primary Health Care (with Dr. David Stevens).

### Pilot Project #3

This project would explore ways to collect and transfer prenatal care data in border sites in Regions VI and IX specifically. The types of data transfer methods that would be used (e.g., computers, patient carried records, facsimile machines, etc.) would be determined through a negotiated agreement with involved migrant health centers in Mexico.

This project would be managed by the Alliance for Primary Care in cooperation with the Bureau of Primary Health Care.

### Other Demonstrations

During this discussion, participants made the following additional recommendations:

- o That electronic bulletin board systems be tested in concert with all three pilot projects listed above;
- o That guidelines be developed for all of the pilot projects, with special emphasis on patient confidentiality; and
- o That Medical Alerts be studied in two ways: (a) by including them in electronic bulletin board systems, and (b) by studying the desirability of using Medical Alert bracelets as a means to inform providers about allergic reactions or certain chronic conditions.

### All Projects

In addition, participants recommended that all of the pilot projects listed above should:

- o start with the development of a measurement mechanism in order to evaluate effectiveness;
- o be developed by determining real costs;
- o be designed to gather data from management, clinical planning, and research perspectives;
- o be tested throughout upstream and downstream sites;
- o focus on data transfer.

It was noted that all of the pilot projects would be defined further at a future meeting.

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