TO: State Health Officers
State Medicaid Directors

FROM: Administrator, Health Care Financing Administration
Adminstrator, Health Resources and Services Administration
Director, Centers for Disease Control and Prevention

SUBJECT: Facilitating Collaborations for Data Sharing between State Medicaid and Health Agencies

HCFA, HRSA and CDC share common goals to assure access and improve quality of care provided to vulnerable populations. We have joined together to launch a coordinated strategy aimed at reducing barriers to sharing data between Medicaid and health agencies and supporting innovative approaches to the design and implementation of State information systems that foster collaboration among these programs. This commitment is formally embodied in an inter-agency agreement between HCFA and HRSA which will be implemented in partnership with CDC, and through collaboration with States. This letter provides information on the first set of activities we will conduct to support collaborations for data sharing between State Medicaid and health agencies.

Model Data Sharing Agreement

The first activity described in the interagency agreement is the development and dissemination of a model data sharing agreement. This agreement provides a generic framework that includes all Federal confidentiality requirements and other restrictions on the use of information regarding Medicaid beneficiaries. HCFA has approved this model agreement for use by State Medicaid and health agencies as a tool for collaborations involving data sharing. We hope that this tool will help to standardize the process and clarify issues related to the appropriate and optimal uses of Medicaid data. HCFA can also provide States with standard data use agreements if access to national Medicaid and Medicare databases is necessary to support program design and improvement.

Technical Assistance Activities

The interagency agreement also addresses coordinated technical assistance activities which we hope will support collaborations involving data sharing as well as innovative information systems designs. Our initial efforts will focus on three areas:

- HCFA, HRSA and CDC will conduct an inventory of existing activities and models that we directly support and disseminate this information through a coordinated effort. This inventory will not duplicate other Federal and privately-sponsored efforts to collect information on these activities; rather we hope to complement and organize this information in a form that will be readily accessible to interested parties.

- HRSA and CDC recently announced a new approach for States seeking greater flexibility in using categorical grant funding to plan and implement integrated public health information systems. The process is described in materials available on the CDC and HRSA Websites (www.cdc.gov/funds/invest7.htm or www.hrsa.dhhs.gov/investment.htm) or by calling the contacts listed at the end of this letter. HCFA supports the direction articulated by HRSA and CDC because it will directly benefit State Medicaid agencies by coordinating public health information systems development and improve the value of data available through these systems. In addition, HCFA is developing new policies and guidelines on State Medicaid Management Information Systems (MMIS) that will recognize the new business environment of State Medicaid programs (including the benefits associated with coordination and integration with public health information systems) and complement the HRSA/CDC process.
- The third element in this strategy will involve consultation with States and other interested parties regarding priorities for future Federal technical assistance activities. We will consult with the Association of State and Territorial Health Officials and National Association of State Medicaid Directors, and other organizations and individuals interested in facilitating the use of existing data sources to support Medicaid and health program design and implementation. In this context, we enclose information on various activities we are currently conducting that focus on improvement of immunization rates, particularly for children. We hope to refine and expand on these activities, and focus on additional areas based on the feedback we receive. Particular emphasis will be placed on assisting States in data collection and analysis necessary to meet specific goals established through the Government Performance Results Act.

Contacts and Future Initiatives

The interagency agreement, in conjunction with CDC, commits our agencies to coordinating Federal efforts that support State-level data sharing and information systems that will meet key population health assessment and improvement goals. The following individuals have been identified as the lead contacts to request information and conduct Federal coordination activities:

HCFA:
Stanley Nachimson, Technical Director
Data and Systems Group
Center for Medicaid and State Operations
Phone: 410-786-6153
E-mail: Snachimson@hcfa.gov

HRSA:
Mike Millman, Ph.D.
Research Coordinator
Office of Research, Policy and Legislation
Phone: 301-443-0368
E-mail: Mmillman@hrsa.dhhs.gov

CDC:
Raul Romaguera, DMD, MPH

Chief, Applied Sciences Branch
Division of Public Health Surveillance and Informatics
Epidemiology Program Office
Phone: 404-639-0225
E-mail: rar2@cdc.gov

We will communicate with you on a regular basis to share updates on these activities and announce new initiatives designed to improve the quality and effectiveness of health care for vulnerable populations. You should contact any of the agency leads identified above to share ideas on how we can make this process work for you.

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Nancy-Ann DeParle
Administrator, HCFA

_____
Claude Earl Fox, MD, MPH
Adminstrator, HRSA

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Jeffrey P Kaplan, MD, MPH
Director, CDC

Attachments:

HCFA/HRSA Interagency Agreement
HCFA Model Medicaid Data Sharing Agreement
Summary of Related Immunization Data Activities

DATA SHARING AGREEMENT
Background

Medicaid data is a key source for understanding the relationship between service delivery and improved outcomes for low income populations. For example, the characteristics of prenatal and maternity services from Medicaid payment records can be linked to background information on the mother's health and sociodemographic characteristics from birth/death records to better understand determinants of pregnancy outcomes. While there are tremendous benefits accompanying Medicaid data, section 1092 (a) (7) of the Social Security Act limits the use of individually identifiable Medicaid data to purposes directly connected to the administration of Medicaid. It is in this context that the purposes of data sharing as well as the benefits must be evaluated.

The Health Care Financing Administration, in cooperation with the Health Resource Services Administration and the Centers for Disease Control and Prevention, have created a model data sharing agreement to guide the permissible sharing and

dissemination of Medicaid data among State Medicaid and Public Health agencies. Collaboration among these agencies could benefit from the use of Medicaid data to support policy initiatives as well as providing cogent analysis in the areas of public health surveillance, resource management and quality and performance measure which in turn will improve the administration of the Medicaid program and outcomes for the Medicaid population.

Examples of benefits which can be derived from these cooperative efforts include:

- Encouraging the development of integrated information systems at the State level to support the evolving role of State government in assuring appropriate, accessible, cost-effective care for vulnerable populations.
- Improving the technical capacity of States to analyze data from multiple sources to support policy decision making and program monitoring.
- Promoting the development and implementation of common performance measures across multiple programs to improve their effectiveness.
- To better utilize Medicaid encounter data to assist in public health surveillance to ensure appropriate care for the Medicaid population.

DEPARTMENT OF HEALTH/STATE MEDICAID AGENCY
INTER-AGENCY
DATA-SHARING AGREEMENT
State of_____

Requester

Agency Name_____
Data User_____
Title_____
Address_____
_____
Phone_____

Data Provider

Agency Name_____
Custodian_____
Title_____
Address_____
_____
Phone_____

I. PURPOSE

In this section, both parties must state in non-technical language the purpose(s) for which they are entering into the agreement, i.e., how the data will be used, what

studies will be performed, or what the desired outcomes are perceived to be as a result of obtaining the data. The source of the data will come from any and all public health or claims databases. The data will only be used for research and/or analytical purposes only and will not be used to determine eligibility or to make any other determinations affecting an individual. Furthermore, as the data will be shared within a State, it will be subjected to all applicable requirements regarding privacy and confidentiality that are described herein.

III. PERIOD OF AGREEMENT

The period of agreement shall extend from_____ to _____.

IV. JUSTIFICATION FOR ACCESS

A. Federal requirements: Section 1902 (a) (7) of the Social Security Act (as amended) provides for safeguards which restrict the use or disclosure of information concerning Medicaid applicants and recipients to purposes directly connected with the administration of the State plan. Regulations at 42 CFR 431.302 specify the purposes directly related to State plan administration. These include (a) establishing eligibility; (b) determining the amount of medical assistance; providing services for recipients; and (d) conducting or assisting an investigation, prosecution, or civil or criminal proceeding related to the administration of the plan.

If the State Medicaid agency is a party to this agreement, specifically as the provider of information being sought by the requestor, it must be demonstrated in this section how the disclosure of information meets the above requirements.

An example of permissible data matching/sharing arrangements is the matching of data with a registry of vaccines or diseases for the purposes of improving outreach or expanding Medicaid coverage of populations being served under Medicaid.

States should identify any additional requirements that are needed for the release of additional data in this section

B. State requirements: Cite specific State statutes, regulations, or guidelines (See Appendices)

V. DESCRIPTION OF DATA

In this section, the parties provide specific detailed information concerning the data to be shared or exchanged.

VI. METHOD OF DATA ACCESS OR TRANSFER

A description of the method of data access or transfer will be provided in this section. The requestor and its agents will establish specific safeguards to assure the confidentiality and security of individually identifiable records or record information. If encrypted identifiable information is transferred electronically through means such as the Internet, then said transmissions will be consistent with the rules and standards promulgated by Federal statutory requirements regarding the electronic transmission of identifiable information.

VII. LOCATION OF MATCHED DATA AND CUSTODIAL RESPONSIBILITY

The parties mutually agree that one State agency will be designated as "Custodian" of the file(s) and will be responsible for the observance of all conditions for use and for establishment and maintenance of security agreements as specified in this agreement to prevent unauthorized use. Where and how the data will be stored and maintained will also be specified in this section.

This agreement represents and warrants further that, except as specified in an attachment or except as authorized in writing, that such data shall not be disclosed, released, revealed, showed, sold, rented, leased, loaned or otherwise have access granted to the data covered by this agreement to any person. Access to the data covered by this agreement shall be limited to the minimum number of individuals necessary to achieve the purpose stated in this section and to those individuals on a need-to-know basis only.

Note that, if all individually identifiable Medicaid data remains within the purview of the State Medicaid agency, matching with any other data is permissible. Any results of the data matching which contains individually identifiable data cannot be released outside the agency unless the release meets the conditions of Section IV.

Any summary results, however, can be shared. Summary results are those items which cannot be used to identify any individual. It should be noted that the stripping of an individual's name or individual identification number does not preclude the identification of that individual, and therefore is not sufficient to protect the confidentiality of individual data.

VIII. CONFIDENTIALITY

The User agrees to establish appropriate administrative, technical, and physical safeguards to protect the confidentiality of the data and to prevent unauthorized use or access to it. The safeguards shall provide a level and scope of security that is not less than the level and scope of security established by the Office of Management and Budget (OMB) in OMB Circular No. A-130, Appendix III -- Security of Federal Automated Information System, which sets forth guidelines for security plans for automated information systems in Federal agencies.

Federal Privacy Act requirements will usually not apply if this agreement is entered into by agencies of the State and no Federal agencies are involved. The same applies

to the Computer Matching and Privacy Protection Act of 1988. However, State laws, regulations, and guidelines governing privacy and confidentiality will apply.

It is strongly suggested that the guidelines presented in the Model State Vital Statistics Act be applied. The guidelines are available from the U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control and Prevention, National Center for Health Statistics, Hyattsville, Maryland (DHHS) Publication No. (PHS) 95-1115.

Where States have enacted laws based on this model, the actual provisions of the statute take precedence.

IX. DISPOSITION OF DATA

(Sample Language)

The requestor and its agents will destroy all confidential information associated with actual records as soon as the purposes of the project have been accomplished and notify the providing agency to this effect in writing. Once the project is complete, the requester will:

1. Destroy all hard copies containing confidential data (e.g., shredding or burning)
2. Archive and store electronic data containing confidential information off line in a secure place, and delete all on line confidential data.
3. All other data will be erased or maintained in a secured area.

X. DATA-SHARING PROJECT COSTS

In this section, it should be stated in detail how the costs associated with the sharing or matching of data are to be met. If these can be absorbed by the "salaries and expenses," and the partner providing the requested data is agreeable to absorbing such costs, that should be noted here. If there are extra costs to be assumed, the parties need to specify here how they will be met. If the requesting party is to bear the burden of specific extra costs, or the party providing the data is unable or unwilling to bear such, these special requirements are to be formalized in this section.

XI. RESOURCES

The types and number of personnel involved in the data sharing project, the level of effort required, as well as any other non-personnel resources and material, which are required, are to be listed here.

XII. SIGNATURES

In witness whereof, the Agencies' authorized representatives as designated by the Medicaid Director and Health Commissioner attest to and execute this agreement effective with this signing for the period set forth in Article III.

(Name) (Name)

_____ _____

(Title) (Title)

_____ _____

(Date) (Date)

_____ _____

ATTACHMENT 3 - MEASURING CHILDHOOD IMMUNIZATION RATES: CURRENT FEDERAL INITIATIVES

Immunization is an important marker for childhood health services. Research shows that promoting immunization helps to better serve the overall health needs of children. Children who fail to receive timely immunizations tend to utilize fewer other clinical preventive services such as screening for lead exposure, screening for anemia, and well child visits, placing them at higher risk of adverse outcomes from preventable diseases. Given the central importance of immunization as a marker of child health status, HCFA, HRSA and CDC have initiated coordinated efforts to improve systems that measure immunization status in order to promote increased immunization rates. The following is a brief description of these initiatives:

The Health Care Financing Administration (HCFA) has developed a performance goal for FFY 2000 under the Government Performance and Results Act (GPRA), which will be conducted in partnership with State Medicaid agencies;

- The goal is to measure the percentage of two-year old children enrolled in Medicaid by State who are fully immunized, and increases in this rate over time.
- The HEDIS Childhood Immunization Measure, which estimates the percentage of children in an MCO who have received all of their appropriate immunizations by their second birthday, will be one data collection method used to evaluate this GPRA measure.

The Maternal and Child Health Services Bureau (MCHB) of the Health Resources and Services Administration (HRSA)
has also developed a GPRA measure, linked to Title V funding, that tracks childhood immunization rates;

- HRSA is collaborating with the Centers for Disease Control and Prevention (CDC) to provide technical assistance to support State and local health department immunization programs.

- MCHB's Application Guidance for the Maternal and Child Health Services Block Grant Program has been revise to include the Healthy People 2000 goals of having 90 percent of two-year olds fully immunized. Many States who have reached this goal will set higher targets as part of their MCH program activities.
- Community and Migrant health centers are required by the Bureau of Primary Health Care to report immunization rates as a performance measure. State and Regional Primary Care Associations have established pilot projects to seek ways of improving review, audit and reporting processes.

To address President Clinton's recent charge to Secretary Shalala to ensure that all children receive their proper series of vaccinations by age two, the **Centers for Disease Control and Prevention (CDC)** have been working to:

- Implement immunization registries in every state that monitor the number of children who need immunizations, determines what series of vaccinations are needed, provides recall service to alert parents and providers to children who need vaccinations, and details the series of vaccinations given to each child.
- Promote use of the Clinical Assessment Software Application (CASA), which is public domain software developed by the CDC to evaluate the immunizations rates and effectiveness within a state, city or county.
- Implement refinements to the National Immunization Survey to improve tracking of low-income households and reported childhood immunization rates.