Prioritization of Data Needs for State Encounter Data Sets

For Public Health and Research Applications

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PROJECT OVERVIEW

With the advent of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), opportunities to improve the standardization of discharge databases have emerged. HIPAA led to the establishment of the Public Health Data Standards Consortium--a partnership of public health and research working together to understand and utilize the standards setting process as outlined in HIPAA. This document is the final report on one of the projects undertaken by the Consortium, entitled "HIPAA Inpatient State Encounter Data Practices and Priorities Project."

THE PUBLIC HEALTH DATA STANDARDS CONSORTIUM

On November 2-3, 1998, the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention, in conjunction with the Agency for Healthcare Research and Quality (AHRQ) and the National Committee on Vital and Health Statistics (NCVHS), convened a workshop on "The Implications of HIPAA's Administrative Simplification Provisions for Public Health and Health Services Research." Among the outcomes of the workshop, participated in by 85 leaders in health statistics, research, and informatics, was a consensus recommendation for establishing a consortium to organize the public health and health services research communities on data standards issues. This consortium would serve as a mechanism for ongoing representation of public health and health services research interests in HIPAA implementation and other data standards setting processes.²

The Public Health Data Standards Consortium was officially established and held its first meeting on January 24-25, 1999, in conjunction with the annual meeting of the National Association of Health Data Organizations (NAHDO). The Consortium adopted a three-fold mission:

- 1) Improve the health and health care of the population through improved information by expanding involvement in existing health data standards and content organizations.
- 2) Facilitate the use of existing standards and the development of new data standards for public health and all areas of health services research.
- 3) Educate the public health and the health services research communities about HIPAA and other health data standards issues.

Many important activities continued through 1999 and into 2000 for the Consortium. The National Uniform Billing Committee and National Uniform Claim Committee both approved Consortium representation on their respective committees. In September 1999, NCHS contracted with NAHDO

¹ The Administrative Simplification (AS) provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) are intended to reduce the costs and administrative burdens of health care by making possible the standardized, electronic transmission of many administrative and financial transactions that are currently carried out manually on paper. See http://aspe.hhs.gov/admnsimp/Index.htm for details.

² Public Health Consortium Fact Sheet, National Center for Health Statistics of the Centers for Disease Control and Prevention, 1999

to assist in identifying the priority encounter data elements that are most urgent to the needs of public health and health services research. This report summarizes the activities conducted under this project, the processes followed, the outcomes achieved, and the recommendations offered.

OBJECTIVES OF THE PROJECT

The HIPAA Inpatient State Encounter Data Practice and Priorities study is intended to provide planning and educational direction to the educational activities of the Consortium and serve as the basis for the development of a Consortium work plan. The project was composed of two components: education, and data element prioritization. The objectives are described below.

Education

- Educate Consortium members about the standards setting process and models in practice by ANSI ASC X12 and HL7.
- Educate the industry and national Standards Development Organizations (SDOs) about the need for uniform data for public health and research purposes and the value of these data to the industry and the public.
- Promote the use of standards in public health, using existing Health Level 7 (HL 7) or ANSI X12N standards where applicable and encouraging participation in the standards process where current standards do not meet public health needs.

Prioritization

The objective of the prioritization study was to evaluate data elements commonly collected by states that are directly related to policy analysis and public health surveillance at the state level. The study included those elements that states said they would continue to collect even if they were excluded from HIPAA Administrative Simplification X12N core standards³. By working to solve concrete and defined data needs in a collaborative process, a positive outcome of this study has been to lay the foundation for future, more challenging standards initiatives.

The study's purpose was to prioritize the common data elements most needed for improved health information for public health and research. The scope of this study was limited to statewide encounter data systems, recognizing that the data needs for public health and research go well beyond administrative data sets.

³ National Association of Health Data Organizations (NAHDO) Administrative Simplification Survey of States, 1998.

SIGNIFICANCE OF THE PROJECT

Discharge data systems are becoming an important component of state and national health data systems. Over forty states collect inpatient discharge data⁴, which provide information about the patterns of care, the health burden, and the costs associated with major morbidity. Despite the limitations, large administrative data sets are used to assess issues of health care access, cost, and quality⁵. The systematic collection of discharge data offers a relatively uniform and cost-effective source of health services.

For the purposes of this study, discharge data are defined as a collection of demographic, clinical, and billing data reported for all patients admitted as an inpatient or outpatient to a health care facility.

Because discharge data systems are derived from the UB92 or other industry standards, the challenges and opportunities posed by HIPAA will affect these data systems immediately. The Consortium is concerned with HIPAA's impact on statewide encounter data systems and believes that experiences and lessons learned with discharge data can be transferred to other major health data sets. State and local public health entities are uncertain about the affect on major health data systems. Learning how the HIPAA standards process works is an important first step in reducing the uncertainty and assuring that the public health information infrastructure is maintained and improved.

PROJECT ACTIVITIES, OCTOBER, 1999-OCTOBER, 2000

The activities undertaken during the year covered in this report revolved around three areas: (1) Education and Outreach, (2) Data Collection and Analysis, and (3) Feedback Processing and Consensus Building. Each area is briefly described below.

Education and Outreach

A national conference call was held December 7, 1999 to address HIPAA implementation and the standards process and data standards. The teleconference marked the beginning of the educational and outreach process and provided an opportunity to begin gathering information from states about state-unique fields. Many of these participants were from state Medicaid agencies eager to learn about HIPAA implementation issues. (Unlike public health, which is largely exempt from many HIPAA Administrative Simplification provisions, Medicaid agencies must comply).

In recognition of the important role of education in the Consortium's goals, at the March 21, 2000, Steering Committee meeting a standing Education Work Group was established to develop and implement an educational strategy for the Consortium.

⁴ Healthcare Cost and Utilization Project (HCUP) 1999 Partners Inventory, Agency for Healthcare Research and Quality (AHRQ)

⁵ Elixhauser, A., "The Importance of Administrative Data Sets for Public Health and Research", 1998.

Data Collection and Analysis

Three data sources were used for the project:

- 1) The Healthcare Cost and Utilization Project's 1998 Statewide Encounter Data Availability Inventory (HCUP Partners Inventory) conducted by the National Association of Health Data Organizations (NAHDO) and the MEDSTAT Group in 1999 for the Agency for Healthcare Research and Quality (AHRQ).
- 2) The 1998 NAHDO Administrative Simplification Committee Survey of State Data Agencies, conducted by NAHDO staff and the Minnesota Health Data Institute.
- 3) Interviews conducted with state health data organization staff, late 1999.

Consensus building and feedback

NAHDO presented its preliminary findings at a meeting of the Consortium Steering Committee on March 21, 2000. Several work groups were established to address the data elements ranked of highest priority by meeting participants. The Work Groups assisted NAHDO in its current NCHS study, and developed the business cases for requesting specific data elements be added to the national HIPAA Standards and Implementation Guides. The meeting generated the commitment by organizational members to each name a Principal Member and an Alternate to the Consortium's Steering Committee; a Planning Group also was established.

Findings were presented to the PHDSC at its March 21, 2000 meeting in Washington DC. Discussion and feedback were integrated into the preliminary report and shaped the final recommendations.

FINDINGS AND OUTCOMES

INITIAL LIST OF DATA ELEMENTS CONSIDERED FOR PRIORITIZATION

Based on the results of the NAHDO Survey, the HCUP Inventory, and interviews with selected state agency representatives, NAHDO identified twenty-two high-priority and non-ANSI X12N 837 data elements collected by statewide discharge data systems and grouped these data elements into domains or categories (Table 1).

Table 1: NON-X12N 837 and HIGH-PRIORITY DATA ELEMENTS COLLECTED BY STATES, 1998

Patient	Patient Status	Clinical Variables	Linkage	Financial	Other
Demographics	Variables		Variables	Variables	Variables
Race and	Present on	Number of E-codes	Unique Patient	Payer Type	Patient Consent
Ethnicity	Admission		ID		on
	Indicator	Pharmacy Values		Total	Immunization
County Code		-	Physician ID	Provider	Record
	Do Not	Gestational		Paid	
Marital Status	Resuscitate	Age/newborn	Mothers	Amount	Observation
			Medical Record		Days
Patient Living	Patient	Birth weight/	Number on		
Arrangement	Functional	Newborn record	newborn record		
	Status				
Education		Admitting vitals	EMS Run		
			Number/record		
Occupation					

These data elements were cross-walked to the 837 X12N Implementation Guide (version 4010). NAHDO then obtained case study and anecdotal information about these priority data elements from a cross-section of states collecting these elements. These states were asked about the method of data collection (voluntary or mandated), year first collection, reporting compliance, barriers to the collection of the data element, and how the data element is used.

PRELIMINARY RECOMMENDATIONS TO PHDSC FOR PRIORITY ACTION

NAHDO presented preliminary recommendations for priority action to the PHDSC at its March 21, 2000 meeting in Washington D.C.:

Data elements contained in the X12N Implementation Guide promoted for state collection:

- Present on Admission Indicator (promote collection by states)
- Birth weight on Newborn Records (promote collection by states)
- Race and Ethnicity (development of business case for inclusion into X12N standards and promote collection by states)

Data elements for PHDSC Action:

- Principal External Cause of Injury Code (business case development for expanding the number of E-codes)
- Type of Payer (review of the existing X12N typology for public health/research applications)
- Mothers Medical Record Number on Newborn Record (business case development for inclusion into 837 Core Data Standards)
- Do Not Resuscitate (business case development for inclusion into 837 Core Data Standards)
- County Code (business case development for inclusion into 837 Core Data Standards)

Data content issues, more study needed:

- Pharmacy Data/Values
- Patient Demographic Data (Marital Status, Education/Income/Occupation Patient's Relationship to Subscriber (as proxy measures for patient living arrangement)
- Patient Functional Status
- EMS Run Number with Emergency Department Encounters
- Patient Consent for Immunization Encounters
- Observation Days

Data elements likely to be addressed by federal regulations:

- National Provider ID
- (Health) Plan ID

PRIORITY DATA ELEMENTS FOR STANDARDIZATION

After PHDSC discussion, consensus was obtained and the following data elements were selected, in order, by majority vote, as priorities for standardization. PHDSC ad hoc work groups were also established to develop a business case for specific data elements. The list of priority data elements and the Workgroup charges were as follows⁶:

- 1. E-codes (accommodated by 837) This Work Group will develop justification and recommendations for expanding the collection of External Cause-of Injury Codes in the 837.
- 2. Payer Type (within 837) This Work Group will develop justification and recommendations for modifying and expanding the payer types currently collected in the 837.
- 3. Mother's Medical Record Number (not within the 837) This Work Group will develop justification and recommendations for collecting the Mother's Medical Record Number in the 837 for the Newborn to facilitate linkage of mother and newborn encounter records.

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⁶ Minutes of meetings of the PHDSC workgroups.

- 4. Readmission or Repeat Admissions (not within the 837) This Work Group will explore options and develop justification and recommendations for collecting information in the 837 concerning readmissions or repeat admissions to the hospital.
- 5. Individual ID (accommodated by 837) This Work Group will explore options and develop justification and recommendations for collecting a unique individual identification number in the 837.
- 6. Source of Admission (within the 837) This Work Group will develop justification and recommendations for modifying and expanding the sources of admission currently collected in the 837.
- 7. Provider ID (NPI) (accommodated by the 837) This Work Group will explore the ability of the National Provider ID System, proposed by the Department of Health and Human Services in a Notice of Proposed Rulemaking, to adequately enumerate all providers to meet the needs of public health and health services research and will make recommendations.
- 8. County (accommodated by the 837) This Work Group will explore the ability of the 837 to collect county of patient and will develop justification and recommendations.
- 9. Patient Functional Status (condition indicators in 837) This Work Group will explore the desirability and feasibility of collecting functional status in the 837. It will coordinate with a similar exploration being undertaken by the National Committee on Vital and Health Statistics Subcommittee on Populations.

Emerging also from the discussion was a consensus recommendation that the Consortium play a role in educating the states regarding the need for, and benefit of, standards, the present content of the 837, and the need for work on closing the many data gaps for adequate and accurate health information. Therefore, a standing Education Group was established to address such topics as education, communication, public relations, HIPAA implementation, technical assistance, and user-friendly data dictionaries.

SUMMARY OF SPECIFIC RECOMMENDATIONS AND NEXT STEPS⁷

The following four sections show a composite of the primary findings of this project. Each section is fully discussed in the body of the report including recommendations, current implementation status, and suggested next steps for each data element. Additionally, a matrix, Appendix A, shows each data element, the number of states collecting it, an indicator of whether it's an NCVHS core data element, and the existing national definitions. The recommendations are grouped as follows:

Priority Data Elements Recommended for Consortium Action

- External Cause of Injury Coding, Place of Injury field for primary cause of injury
- Source of Payment (i.e. Payer Type or Health Plan)
- County Code
- Race and Ethnicity*
- Mother's Medical Record Number**

Priority Data Elements with Unresolved Issues Needing Further Study

- External Cause of Injury Coding, Adverse Effect of Medical Treatment
- Source of Admission
- Patient Demographics
- Patient Marital Status
- Patient Living Arrangement
- Current or Most Recent Occupation/Industry
- Patient Functional Status

The Department of Health and Human Services (DHHS) has named the Designated Standard Maintenance Organizations (DSMOs). These organizations maintain standards for health care transactions adopted by the Secretary, and receive and process requests for adopting a new standard or modifying an adopted standard. In the case of a standard that has been developed, adopted, or modified by a standard setting organization (SSO), the SSO is to consult with the above-named groups during such development, adoption, or modification. In the case of any other standard, the Secretary is required to consult with each of the above-named groups before adopting the standard and must also comply with the provisions of section 1172(f) of the Act regarding consultation with the National Committee on Vital and Health Statistics.

These DSMOs include the following:

- Accredited Standards Committee X12.
- Dental Content Committee of the American Dental Association.
- Health Level Seven.
- National Council for Prescription Drug Programs.
- National Uniform Billing Committee.
- National Uniform Claim Committee.

^{*}approved for inclusion in next X12N 837 Implementation Guide

^{**}approved for inclusion into X12N standard

⁷ In all these recommendations, NAHDO assumes that the PHDSC will collaborate and use a consensus process to forward standards according to the national process outlined in HIPAA:

- Readmission Indicator
- Do Not Resuscitate (DNR) indicator
- Gestational age on newborn record

Education of State Health Data Agencies to Promote Adoption in State Practice (837 institutional guide)

- Mothers Medical Record Number on newborn record
- Race and Ethnicity fields
- Present on Admission Indicator
- Birthweight of newborn

Consortium Action Determined Following Release of Final Federal Regulations

- Plan ID
- Unique Patient Identifier
- Medicaid Provider Identifier Number

PRELIMINARY PROJECT EVALUATION

Early Successes

Two of the study objectives were achieved early in the course of this project: 1) education of public health about the standards setting process and 2) utilizing the X12N process to include race and ethnicity in the Demographic segment of the X12N Implementation Guide (version 4031) for Institutional 837 claims.

- The December 7, 1999 national HIPAA teleconference was an overwhelming success with more than 100 participants, many of whom continue to participate in follow-up discussions on the NAHDO Administrative Simplification Listserv.
- Race and ethnicity were the first data elements to be tested through the Consortium process and it demonstrated the power of combining a strong business case with communication between Consortium members. On March 11, 2000, Dr. Bill Braithwaite (DHHS) successfully made the case to the X12N Task Group 2 and Workgroup 2 for the inclusion of the expanded codes for Race and Ethnicity in the X12N Implementation Guide. Key to the business case, was the fact that 27 states currently collect race/ethnicity with their discharge data. A similar success was realized when Mother's Medical Record Number on the Newborn Record was successfully forwarded through the X12N Workgroup process.

Lessons Learned

- States will need education and technical assistance to make the transition to ANSI X12N standards and will benefit from adopting these uniform and expanded standards
- The Public Health Consortium is an effective mechanism for coordinating and facilitating the national standards setting process
- Future standards studies should assess data needs for performance measurement and policy

Limitations

The scope of elements studied was limited to those data elements most commonly collected in state discharge data systems. Many important data needs were not addressed, such as clinical data elements used in performance measurement. For example, the Healthplan Employer Data and Information Set (HEDIS) defines performance measures that are derived from both administrative and clinical data systems. Adding key elements to X12N data standards may significantly lower the cost to report HEDIS by eliminating or reducing the need for abstracting information from the medical record (e.g. Beta Blocker with Acute Myocardial Infarction encounters).

ACKNOWLEDGEMENTS

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DATA ELEMENT RECOMMENDATIONS AND NEXT STEPS

The following four sections include the recommendations, current implementation status, and suggested next steps for each data element. Additionally, a matrix, Appendix A, shows each data element, the number of states collecting it, an indicator of whether it's an NCVHS core data element, and the existing national definitions.

PRIORITY DATA ELEMENTS FOR HIPAA NATIONAL STANDARDS PROCESS

Data Element

External Cause of Injury Coding Standards: Cause of Injury (Part 1 of E-code recommendation)

Recommendation

NAHDO recommends expanding the required primary diagnosis fields in the X12N HI Diagnosis segment to accommodate an additional diagnosis field, "Place of Injury." Additionally, NAHDO recommends assessing the feasibility of and process for future expansion to accommodate an additional E-code field, "Adverse Effect of Medical Care." Immediate consideration is recommended for Place of Injury code as additional field.

Diagnosis coding is as follows in the current X12N Implementation Guide:

Principal Diagnosis segment:

HI 01, required: principal diagnosis

HI 02, required: admitting diagnosis

HI 03, situational: principal External Cause of Injury code

Proposed: Expand required coding to accommodate two additional primary diagnosis fields:

1. HI 04, Place of Injury, situational: if 03 is used then 04 must have the Place of Injury E-codes (ICD-9 code set) -- for immediate implementation.

Deferred: Further expansion of E-code reporting to accommodate a third E-code field, "Adverse Effect of Medical Care":

2. HI 05, Adverse Effect of Medical Care, situational: if a state/jurisdiction requires such reporting for codes E 870-E879 or E 930-E949.9 -- for discussion and future implementation.

Deferred: Expansion of HI segments to accommodate additional E-codes beyond principal and adverse effect E-codes.

NAHDO forwards this proposal for systematic data collection in statewide hospital discharge data reporting to the Public Health Consortium for discussion and consideration.

Current Practice

Collection of E-Code Data

ICD-9-CM ⁸ defines the External Cause of Injury as the ICD-9-CM code for the external cause of an injury, poisoning, or adverse effect and defines the priorities:

- 1. Principal diagnosis of an injury or poisoning
- 2. Other diagnosis of an injury, poisoning, or adverse effect directly related to the principal diagnosis
- 3. Other diagnosis with an external cause

In October 1997, the Injury Control and Emergency Health Services Section of the American Public Health Association (APHA) conducted a survey of all 50 states, the District of Columbia (DC), and Puerto Rico to assess the availability of external cause-of-injury data in statewide hospital discharge data systems (HDDS), hospital emergency department data systems (HEDDS), and other ambulatory care data systems. The report on the findings of the analysis, "How States are Collecting and Using Cause of Injury Data⁹," includes recommendations for improving the quality and availability of statewide injury-related data for injury-prevention activities.

The APHA survey findings indicated that 36 states and DC routinely collect external cause-of-injury data in their HDDS. Of these, 23 have laws or mandates requiring external cause-of-injury coding. Eleven states have developed the capacity to provide external cause-of-injury data on injury-related visits in their statewide HEDDS, nine of which have laws or mandates requiring external cause-of-injury coding.

The technical specifications for the capture of external cause of injury coding in statewide discharge data systems vary across states. Thirty-eight out of 42 states responding to the Healthcare Cost and Utilization Project (HCUP)¹⁰ 1998 Data Inventory reported that they collect External Cause of Injury Codes as a part of their inpatient data systems, but that the number of E-codes collected ranged from one to "all" E-codes¹¹. The capture of secondary E-codes may be a function of the number of total diagnosis codes collected by that state (which ranges from 9 to 24 total diagnosis codes). Out of twenty-two HCUP partner states, twelve reported at least one in every ten-discharge record with one or more E-Codes.

The National Committee on Vital and Health Statistics (NCVHS) recommends the inclusion of the principal External Cause of Injury code in the Uniform Hospital Discharge Data Set; the Uniform Ambulatory Care Data Set and as included in the HCFA UB-92.

⁸ U.S. Department of Health and Human Services. (1998). <u>St. Anthony's ICD9-CM Code Book</u>. Reston, Virginia: St. Anthony's Publishing.

⁹ Annest JL, Conn JM, McLoughlin E, Fingerhut LA, Pickett D, Gallagher S. How states are collecting and using cause of injury data. San Francisco, California: Trauma Foundation at San Francisco General Hospital, 1998.

¹⁰ Agency for Healthcare Research and Quality. (March 2000) <u>Healthcare Cost and Utilization Project</u>. See also: http://www.ahrq.gov/data/hcup.

¹¹ National Association of Health Data Organizations. Inventory of States. 1998.

Quality of E-Code Data as Currently Collected

In the 1997 APHA survey, twenty-three of the 36 states that were routinely collecting some level of E-Codes had conducted an evaluation of the E-Codes for completeness and accuracy in their statewide HDDS. California and New York have ongoing evaluations for completeness of E coding. Eighteen of the twenty-three states that conducted an evaluation indicated over 70% of their injury-related discharge records were E-coded. States with mandated E coding were more likely to have a higher percentage of E-coded injury discharges than states without mandated E coding.

Seven states and the District of Columbia had plans to conduct or were conducting an evaluation of the E-Codes. Missouri and New Hampshire were among those that submitted reports of their results. Evaluations conducted in both states indicated that 95% or more of the injury-related ED records were E-coded.

Nebraska's Department of Health and Human Services System is among the state data agencies that use hospital discharge data as source of E-code data. Beginning in January 1, 1995, hospitals in Nebraska are required to submit to the Nebraska Health and Human Services System's Department of Regulation and Licensure (HHSS-R&L) information regarding the external cause of injury, poisoning, or adverse effect (E-code) for every patient for whom such a code would be appropriate. To facilitate the implementation of this law, HHSS-R&L chose to use the Hospital Discharge Data of the Nebraska Association of Hospitals and Health Systems (NAHHS) as the source of reporting, thus eliminating the need for hospitals to submit a separate reporting form.

In 1998, HHSS-R&L reported 70.6% compliance by hospitals to the E-code reporting requirement. Compliance was 80.1% for records where injury was the primary diagnosis and 55.4% for records where injury was a secondary diagnosis. Compliance among the 91 hospitals reporting inpatient injury records ranged from 14% (one hospital) to 100% (five hospitals). A total of 49 (54%) hospitals achieved a compliance level of 70% or more. Overall, hospitals with 101 to 200 beds had the highest compliance level (82.7%; the lowest compliance level was observed in hospitals with more than 200 beds (60%).

The highest level of compliance with E-coding (100%) occurred with "superficial injuries" and "crushing injuries". The lowest level of compliance (45%) occurred with "complications of surgical and medical care not elsewhere classified".

An unpublished analysis by one state data organization of their discharge data demonstrates the opportunities and challenges in using E-codes. In this state's 1997 Emergency Department administrative database, the frequency with which the first listed E-code was the Place-of-Injury code is presented:

PRINCIPAL E-CODE Frequency Percent E849 28 1.1 12.5 Home 318 Farm 4 .2 .2 Mine and quarry 6 Industrial place and premises 1611 63.5 Place for recreation and sport 89 3.5 85 Street and Highway 3 **Public Building** 32 1.3 Residential Institution 22 .9 Other Places 54 2.1 Unspecified Place 297 11.7

Table 2: Counts Of Emergency Department Admissions For All Injuries (1997)

This means that E-codes noting the cause of injury were not a primary E-code. To overcome the challenges in analyzing E-coded data for injury, this state reports that, for ICD-9 injury codes (800-999), if the E-code field does not contain a Cause-of-Injury E-code, they then use the first listed E-code found in the diagnosis fields.

Use of E-Code Data

Despite the variance in data capture and the technical challenges in their use, states are using the E-code to measure the burden of injury and target interventions. In the 1997 APHA survey eighteen of the 36 states that routinely collect E-Codes also published reports of the E-coded data; six published annual reports, and another 12 states published reports periodically. The data were used most often for monitoring trends, assessing injury-related health care costs, and program planning. Many of the states also use E-coded data for setting priorities, evaluating programs, and making policy decisions. Of the 36 states that routinely collected E-Code data, only six reported using them to assess quality of care. California's uses of E-Code range from providing statistical information to the public to influencing legislation and policy, to developing programs 12,13,14,15,16,17.

¹² Epidemiology and Prevention for Injury Control, California Department of Health Services California's. <u>Motorcycle Helmet Law (Has Saved Lives and Tax Dollars Since 1992!)</u>

¹³ State and Territorial Injury Prevention Directors' Association. (September, 1999) <u>Consensus Recommendations for Injury Surveillance in State Health Departments</u> (Planning Comprehensive Injury Surveillance in State Health Departments Working Group Report). Marietta, GA.

¹⁴State and Territorial Injury Prevention Directors' Association. (September, 1999) <u>Consensus Recommendations for Injury Surveillance in State Health Departments</u> (Planning Comprehensive Injury Surveillance in State Health Departments Working Group Report). Marietta, GA.

¹⁵ Ellis, A.A. and Trent, R.B. (January/February 1997). "Swimming Pool Drownings and Near Drownings Among California Preschoolers. Public Health Reports. Sacramento, CA.

¹⁶ Kim, Allegra N. and Roger B. Trent. (1998) "Firearm-Related Injury Surveillance in California". <u>Am J Prev Med</u> 1998:15(3s).

¹⁷ California Department of Health Services, EPIC. (October 1997) <u>Injury Tables, California, 1996: Deaths and Nonfatal Hospitalizations.</u>

While many data organizations have examined their hospital discharge data for occurrence of adverse events in their respective states in reaction to the IOM report, few have made their findings published. In 2000, the Florida Agency for Health Care Administration released a report on adverse drug effect hospitalizations reported by Florida hospitals from 1992 to 1998. The full range of ICD-9 CM codes for frequent types of adverse drug effects reported in the study were from E9300 to E9499 encompassing the section "Drugs, Medicinal, and Biological Substances Causing Adverse Effects in Therapeutic Use," of the ICD9-CM. They found that the number of hospitalizations reported was about half that calculate from the national estimates reported in a previous study, and fewer deaths were reported. The study did not find a marked increase in adverse drug effects from 1992 to 1998.

As a Core Data Element: Pros and Cons

Justification for standardizing the collection of E-codes:

External cause of injury coding provides a framework for systematically collecting population-based information on occurrence, outcomes, and costs of medical treatment. Primary Ecode, linked to occurrence code, is important for injury surveillance, domestic violence, workplace injury, and other prevention and public health programs.

Injuries and poisonings account for a significant number of inpatient and Emergency Department encounters each year. Injury is one of the leading causes of death and disability in the U.S. Work-related injuries and illnesses place an enormous burden on U.S. workers and the economy, costing \$121 billion in medical care, lost productivity, and wages (NCHS, 1997). The U.S. Surgeon General, recognizing suicide as a major health problem, has recommended a comprehensive national strategy to prevent suicides. Among the priorities of the Healthy People 2010 Objectives¹⁹ is reduction of the rates in preventable injuries caused by motor vehicle accidents, falls, firearms-related deaths and injuries, and other intentional and unintentional injuries.

Understanding the incidence, causes, and patterns of intentional and unintentional injury is important to public health, prevention of domestic violence, research, employer productivity, and community planning. Surveillance data systems provide an important source of community and national utilization, cost, and outcomes data.

A coordinated effort among states is needed to develop standard methods for collecting, coding, analyzing, and presenting injury-related data from statewide data systems. Timely dissemination of uniform, population-based injury morbidity data to hospital administrators, public health professionals, and policy makers will enhance their usefulness for injury-prevention efforts.

Zach, Andye (Arturo Coto) describes situations in which 2 e-codes will not be sufficient to capture the information needed (email correspondence)²⁰

¹⁸ Florida Agency for Health Care Administration, Florida.

¹⁹ Department of Health and Human Services. <u>Healthy People 2010.</u>

²⁰ Email correspondence; workgroup discussions.

Recommended Steps Toward Implementation

The Public Health Data Standards Consortium will continue to address this issue and discuss strategies for implementation of the recommendations outlined in this report. NAHDO recommends different tracks of implementation for the two data elements. Immediate consideration is recommended for Place of Injury code as additional field. The next step is therefore to initiate request to X12N.

Additional study is recommended to consider the optimal number of E-codes that should be captured in the HI segment of the 837 institutional claim. These E-codes are currently listed in the diagnosis fields, but there is no standard structure for ordering and reporting these additional E-code fields.

Data Element

Payer Type

The Public Health Data Standards Consortium Payer Type Workgroup proposes a "Source of Payment" Typology for classifying the patient's primary and secondary insurance coverage for institutional encounters. The typology proposed by the Payer Type Workgroup is shown in Table 1 with notes on how the proposed scheme compares with the current X12N code list.

Modeled loosely after the ICD typology for classifying medical conditions, the proposed typology identifies broad payer categories with related sub-categories that are more specific for first, second, and third payers. Providing different levels of detail in the proposed scheme is intended to allow flexibility and expandability, giving states the option to add more specific codes for local use as needed but roll these up into an aggregate broader category for comparative analyses across payers and locations.

Table 3: Source Of Payment Typology Proposed By PHDSC/Payer Workgroup

Proposed Codes/Payer Categories	X12 EQUIVALENT
1. Worker's Compensation	WC
2. Auto insurance	AM, LI?
3. Medicare	AW, LI:
	17
3.1 Medicare (managed care)	16
3.2 Medicare (non-managed care)	MB
4. Medicaid	MC (a)
4.1 Medicaid (managed care)	
4.1.1 Type of managed care plan (codes to be developed)	
4.2 Medicaid (non- managed care plan)	
4.3 Medicaid/SCHIP	
5. Private Health Insurance—Indemnity	15, CI?
5.1 BC Indemnity (e.g. high option/low option)	BL (b)
5.2 BC ERISA ASO plan	BL
5.3 Commercial Indemnity	CI, LI?
5.4 Self-insured (ERISA) ASO plan	
5.5 Medicare supplemental policy (as second payer)	
6. Private Health Insurance—Managed Care	
6.1 BC managed care—HMO	BL, 12
6.3 BC managed care—POS	BL, 13
6.4 Commercial managed care—HMO	CI
6.5 Commercial managed care—PPO	CI, 12
6.6 Commercial managed carePOS	CI, 13
6.7 Exclusive provider organization	14
6.8 Other private managed care (not otherwise specified)	CI?
7. Government	

Proposed Codes/Payer Categories	X12 EQUIVALENT
7.1 CHAMPUS	СН
7.1.1. CHAMPUS—indemnity	СН
7.1.2 CHAMPUS—managed care	CH, 12,13
7.2 VA	VA
7.2.1. V A—regular	VA
7.2.2 VA—managed care	VA, 12, 13
7.3 Other Military	OF
7.4 Indian Health Service	
7.4.1 Indian Health Service—regular	OF
7.4.2 Indian Health Service—contract	OF
7.4.3 Indian Health Service—managed care	OF, 12, 13
7.5 HRSA program	OF
7.5.1 Title V (MCH Block Grant)	TV
Cont	
7.5.2 Migrant health program	
7.5.3 Ryan White Act	
7.5.4	
7.6 SCHIP, not Medicaid	OF
7.7 State, not otherwise specified	
7.8 Local, not otherwise specified	
8. Departments of Corrections	
8.1 Corrections Federal	OF
8.2 Corrections State	11
8.3 Corrections Local	11
9. No payment from an organization/agency/program listed	
9.1 Self-pay	9
9.2 No charge	
9.2.1 Charity	
9.2.2 Professional courtesy???	
9.2.3 Research/Clinical Trial????	
10. Miscellaneous/Other	
10.1 Foreign National	11
10.2 Other (non-government)	11
10.3 Disability insurance	DS (c)
10.4 Long-term care insurance	
10.5 Missing	
11. Invalid	
12. Missing	

Notes:

- (a) No X12 differentiation of Medicaid managed and non-managed care.
- (b) No X12 differentiation among different types of BC/BS plans.
- (c) Not sure where disability or long-term care insurance would go.
- (d) X12 Codes not classified: Central certification (10); Mutually defined (ZZ); Liability (LI)

States would be encouraged to incorporate the Typology into current collection and coding practices and continue to collect Payer Source (payer organization name and/or number).

Current Practice

The Workgroup recognizes that:

- Most discharge and administrative data systems currently capture Payer Source in a text field, which is often the payer organization name.
- A single Payer Source field is insufficient for analysis of outcomes and utilization according to payment or reimbursement factors.
- Most state health data agencies currently add the Payer Type field to their discharge data systems, but the methods of coding and classifying this field vary, thus diminishing the ability to make multi-state and national comparisons.
- The current X12N payer categories are insufficient for public health and research purposes.
- The final regulations for a national Payer Identifier are expected during 2001 and it is not known whether the type of insurance product (Payer Type) will be a component.

Given the importance of the Payer Type field and the uncertainty surrounding the pending Payer Identifier final rules, the Workgroup recommends a staged approach to standardizing how states code and collect payer information in their discharge data systems:

Stage 1: The Payer Type Workgroup proposes a typology for classifying Payer Source fields, the "Possible Source of Payment Typology" (Table 1) for coding and grouping payers of health care services. This typology will be distributed to state health data organizations for incorporation into their data collection and use practices.

Stage 2: Once the Payer Identifier final rules are released, the Public Health Data Standards Consortium will determine whether to proceed with forwarding the Payment Typology through national Standards Development processes.

Statewide Discharge Data Systems

All states with discharge data systems collect one or more fields for the insurer or payer of services. X states collect the Source of Payment field for the first, second, and third payer²¹. Approximately x states add a second field (Payer Type) but vary in how the second field is captured:

- a) Coded by the agency from the Source of Payment field;
- b) Coded by the hospital from a unique state Payer Type list.

²¹ National Association of Health Data Organizations (NAHDO), <u>Inventory of States</u>, 1998.

Two examples of states collecting and using payer type categories are Massachusetts and California.

The Massachusetts Division of Health Care Finance and Policy (DHCFP) case mix data base required hospitals to code and report a field called "Payer Type" which is composed of general categories (e.g. HMO, Commercial) for many years. In 1994, a second field, the "Payer Source" field was added to the reporting requirements which expanded the previous payer data, adding more than 150 new and extensive payer sourcE-Codes. This additional field permits hospitals to report the exact plan of a particular carrier, displaying the patient's exact plan such as Fallon Community Health Plan and Medicare HMO Fallon Senior Plan. The combination of these fields permits the user to perform a more detailed level of payer analysis.

Massachusetts conducted a detailed validation study to determine the quality of the Payer Source and Payer Type data in its case mix data system. In May 1998, a report summarizing the DHCFP Case Mix Payer Validation Project, in which the DHCFP, in partnership with providers and four major payers, conducted a baseline validation of case mix payer data. Detailed analysis of non-matches between the Payer Type and Payer Source fields indicated that the combination of these two fields yields valid and reliable information for policy and market purposes. In fact, this study documented that few records could not be associated with the specific payer and the majority of case mix data reported the payer's precise plan (citation).

Beginning January 1, 1999, the California Office of Statewide Health Planning and Development (OSHPD) expanded Expected Source of Payment reporting to three fields²²: Payer Category, Type of Coverage, and Name of Plan. The coding and categories are as follows:

1) <u>Payer Category</u>

01 Medicare 05 County Indigent Program

02 Medi-Cal 06 Other Government

03 Private Coverage 07 Other Indigent

04 Workers Compensation 08 Self Pay

09 Other Payer

2) Type of Coverage

Managed Care, Knox-Keene, MCOHS

Managed Care—Other

Traditional Coverage

3) Name of Plan

1110-9999 Plan Code Name (e.g. MedPartners Provider Network =0345)

X12N Categories

The Payer Workgroup reviewed current X12N 837 categories for coding of payer type. The Workgroup determined that the X12N categories, though detailed, were not mutually exclusive and did not meet the needs of public health and research. The Workgroup is uncertain about how (or if)

²² Office of Statewide Health Planning and Development, California Patient Discharge Data Reporting Manual, Third Edition.

these categories are used. In the future, if the Public Health Data Standards Consortium proposes the Payment Source Typology to the X12N Workgroup, discussions with industry will reveal the utility of the current categories and determine the strategies for revising these in the implementation guide.

Justification for Standardizing Payer Type Coding in Discharge Data Systems

The value of payer fields is undisputed and hundreds of examples exist. Adding consistency to how the payer information is coded provides for more exacting and detailed analyses—important in a dynamic health care environment in which accountability, purchasing, and performance concerns are growing.

A standard payer typology provides a framework for grouping and comparing patterns of utilization and outcomes by reimbursement mechanism. Public health uses these statistics for planning and assessment of health care resources, especially in traditionally under-served areas.

Analyses of health care utilization by payer add market and policy value to statewide discharge data. Public health researchers, program planners, and policy makers recognize insurance status as an important source of variation in disease prevalence, health care utilization rates and outcomes, and consequently of health status. Payer variation in measures of access to quality health care will continue to be an important area of inquiry. The past decade has seen the proliferation of health plan report card activities both locally and nationally. Due largely to standardization of performance measures, report card projects have successfully been implemented in many states.

However, current performance measurement efforts remain at the aggregate level and therefore do not allow detailed analysis by enrollee or patient characteristic. Payer variation in disease incidence and health care utilization rates may suggest differential access to care. For example, hospitalization for ambulatory sensitive conditions, or illness conditions which would have been avoided if adequate primary care were provided, is considered as a proxy measure of access to primary care. Examining payer variation for various subgroups of the population adds an important dimension to such an analysis. Such a level of flexibility in could be achieved only by using encounter level data that allow payer-level analysis.

Some states have successfully used and disseminated information on payer variation in health care utilization. Some examples include a managed care report card based on payer data by the Pennsylvania Health Care Cost Containment Council²³ and Utah's report on Cesarean Section²⁴. These studies are based on local definitions of payer categories.

Lack of standardization in payer category definitions compromises multi-state analyses. The Healthcare Cost and Utilization Project (HCUP)²⁵, conducted by the Agency for Healthcare Research and Quality (AHRQ), combines inpatient discharge data from 22 states and provides

²³ Pennsylvania Health Care Cost Containment Council, "Health Plans - Measuring the Quality of Pennsylvania's HMO's - A Managed Care Performance Report", http://www.phc4.org/reports/hmo99/default.htm.

²⁴ Utah Department of Health, Office of Health Care Statistics, "Cesarean Section Deliveries in Utah Hospitals, 1992-1997", http://www.healthdata.state.ut.us.

²⁵ Agency for Healthcare Research and Quality. (March 2000) <u>Healthcare Cost and Utilization Project</u>. See also: http://www.ahrq.gov/data/hcup.

important information about current practice in coding and capturing payer fields. HCUP data contain a minimum number of Payer Type categories, losing much detail for public health and research purposes. Analyses of variation in utilization indicators by payer using combined data from several HCUP states are limited to very broad categories because expected payer is the least standard data elements across state and hospital association databases.

In addition to limiting multi-state comparative analyses, lack of national standards in payer categories limits states' ability to impose an acceptable level of compliance to specifications. Without standards serving as guidelines, most agencies collecting payer data provide loose guidelines to hospitals, which in turn base their coding on what makes the best business sense to them. Some states have reported inability to make effective use of their payer data due to questionable quality and comparability, and unacceptable completeness. For example, in the HCUP Quality Indicators On-line system²⁶, the payer type category "other or unknown" had the greatest proportion of Laminectomy cases among 18-34 year-old patients.

States that have used both recommended fields (Payer Type and Payer Source) together have documented reliability and validity in identifying reimbursement method. The experiences of these states provide positive indications of the potentials of these fields for public health research

Recommended Steps Toward Implementation

Because of the uncertainty surrounding the Payer Identifier, the Workgroup recommends PHDSC ratification of the proposed typology, education of states as to the consensus categories proposed in the Typology, and use of these categories by researchers and in state publications.

The suggested next steps are as follows:

- 1. Distribute the proposed typology to the PHDSC and to other interested individuals and agencies, particularly state data agencies, hospital associations collecting payer data, and relevant research organizations.
- 2. Allow 30 days for review and comments.
- 3. Compile and process comments, including in-person solicitation of feedback at NAHDO's annual meeting in December.
- 4. Revise typology and present to PHDSC Payer workgroup for further discussion and consensus.
- 5. Following the release of the final Payer Identifier regulations, assess the need for initiation of the request to the 837 X12N workgroup.

²⁶ National Association of Health Data Organizations. HCUP Quality Indicators Online, www.nahdo.org/ahcpr/main.index.htm.

Data Element

County Code

Recommendation

NAHDO recommends a national standard for collecting county code with discharge data. The current 837 Standard supports the collection of county code:

N4 segment DE 309 Location Qualifier DE 310 Location Identifier

These 2 data elements support the reporting of local county codes (code value CO) as well as the Federal Information Processing Standards (FIPS codes)²⁷ (code value FI) along with the associated county code value or text states currently collect. It is recommended that these be included in X12N Implementation Guide.

For disclosure of county-level information, it is recommended that the Consortium monitor the activities in the collaborative project between NAHDO and NAPHSIS to establish consensus and a national framework for the release of public health statistics.

Current Practice

In 1998, thirteen out of thirty three states with discharge data systems reported collecting or assigning county codes for each record. Rates of utilization and associated outcomes are typically reported by county, for use primarily by local health departments for surveillance and resource analysis, hospitals for market share analysis, and for other purposes.

One example of analysis of geographic variations in hospital use among small areas was performed in Maryland using patient discharge records from acute care hospitals for 1985- 1987 and small area population estimates by age, gender, race, and income (Gittelson and Powe, 1995). The study found excess geographic variability among Maryland's 115 areas. The hypothesis of uniform rates was rejected for most DRGs. The researchers observed that hospital use was related to demography, morbidity, medical resources, access, selection for care, and physician practice patterns. Heterogeneity of these factors ensures that uniform delivery of health care rarely holds. They found little evidence that incidence of surgical disease is the main source of variation in use of discretionary surgery, and that access plays an important role. They concluded that geographic analysis could identify variation and relate incidence to socioeconomic and specific local effects.

²⁷ (Federal Information Processing Standards (FIPS) FIPS codes: Standardized systems of numeric and/or alphabetic coding issued by the National Institute of Standards and Technology (NIST), for use by the Federal Government and others. Several series of FIPS identify standard geographic codes for States, counties, metropolitan areas, congressional districts, foreign geographic entities, and named populated and related local and national entities).

Justification for Collection of County Code

Geographic coding is an important component of discharge data applications, providing information for community assessment, market studies, and small area variation analyses. Significant geographic variation in incidence of certain diseases or hospitalization for ambulatory sensitive conditions, for example, may signal differential access to preventive or primary care.

The availability of geographic codes in health care databases allows researchers to conduct small area analysis (SAA). Through SAA researchers can use large administrative databases to obtain population-based measures of utilization and resource allocation. SAA is useful for studying the effects of differing practice styles on health care utilization rates. When rates of utilization among neighboring communities are compared, variation NOT related to demand (and/or errors in the data) could be explained by the way physicians make diagnoses or recommend treatments.

Overall rates of hospitalization or surgery for a population can be attributed to four factors: (1) rates of illness, (2) patients' likelihood of seeking treatment, (3) likelihood of correct diagnosis, and (4) effectiveness of treatment. By statistically adjusting for variations in factors 1, 2 and 3, SAA can reveal the effects of different clinical decision making (factor 4) on hospital utilization. Additionally, SAA could be used to examine variations in the probabilities of having an operation as well as variations in per capita expenditures and resource allocations among communities.

Recommended Steps Toward Implementation:

The Public Health Data Standards Consortium will evaluate the feasibility of proceeding to implement the steps necessary to promote this request to the X12N Workgroup.

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Data Element

Race and Ethnicity

This document presents a summary of NAHDO's recommendations for the consideration of Race and Ethnicity into the 837 X12N Health Care Claim Institutional Guide.

These recommendations are based on NAHDO's research and consultation with experts in state health data and public health research, review of the current state practices regarding race and ethnicity data, careful consideration of the issues for collection of race and ethnicity data, and examination of the need for standards in race and ethnicity data for public health surveillance and research. Such standards will facilitate collaboration by federal, state, and local organizations in the collection, analysis, and reporting of population and health statistics and consequently strengthen public health surveillance of racial and ethnic populations in the United States.

Recommendation

As presented to the X12N TG2 WG2:

For inclusion into the fifth element in the DMG or the Demographic Segment of the X12N Implementation Guide 4030 for the Institutional 837 claims, two new coding entries were added to the existing X12 code source to accommodate expanded racial and ethnic codes (Classification of Race or Ethnicity) with additional detail to indicate the method of collection (self-report versus observer identification).

Workgroup Request:

• Change DMG05 usage from "not used" to "situational" with the three composite elements as follows:

DMG05-1: Race/Ethnicity Code, 1109, situational

DMG05-2 Qualifier Code, 1270, situational

DMG05-3 Industry Code, 1271, situational

- Make DMG10 usage "situational. Add a data element note that refers to thE-Code source, the samE-Code source as REC references
- Make DMG11 usage "situational", Collection method code.
- DMG05: Condition Statement:

Used when reporting patient race or ethnicity with health care claim or encounter data is required by State or Federal law or regulation or when reporting this data on a voluntary basis is permitted by State and Federal law or regulation.

Workgroup Result

The end result after discussion was to leave the particular usage for DMG05-1 as "not used."

OMB Standards on Race and Ethnicity: Summary

The Office of Management (OMB) promulgated new Race and Ethnicity standards on October 30, 1997 (now referred to as "Standards for the Classification of Federal Data on Race and Ethnicity)". These new standards, previously known as OMB Directive 15, "Race and Administrative Reporting," allow a person to designate more than one race, and outline principles for the categorization of race and ethnicity in federal statistics. The purpose of the new Standards, as

well as of the earlier OMB Directive 15, is to standardize publication of racial and ethnic data among federal agencies and, as required by legislation in 1976, to increase available information on persons of Hispanic origin.

The Standards were not developed to define the concept of race or ethnicity. Instead, OMB and the agencies of the Executive Branch whose data collection the standards regulate (e.g., CDC and Bureau of the Census) explicitly note the absence of scientific considerations in the designation of categories of race and ethnicity:

OMB STANDARDS Codes set consists of two tables:

5 races:

American Indicator or Alaska Native Asian Black or African American Native Hawaiian or Other Pacific Islander White

Ethnicity: Hispanic or Latino Not Hispanic or Latino Race

These classifications should not be interpreted as being scientific or anthropological in nature, nor should they be viewed as determinants of eligibility for participation in any federal program. They have been developed in response to needs expressed by both the executive branch and Congress to provide for the collection and use of compatible exchangeable racial and ethnic data by Federal agencies.

The OMB Standards present brief rules for classification of persons into racial or ethnic categories, using four defining features: a) descent from "the original specified region, b) a specific cultural origin, c) cultural identification or affiliation, and d) race. For example, "American Indian having origins in any of the original peoples of North America, and who maintains cultural identification through tribal affiliations or community recognition," while "black" is defined as "a person having origins in any of the black racial groups of Africa.

The validity of health statistics for racial /minority groups is based on four assumptions: 1) the categories of race and ethnicity and specific racial and ethnic group designations are consistently defined and ascertained; 2) the categories and designations are understood by the populations questioned; 3) survey enumeration, participation, and response rates are high and similar for all populations; and 4) the responses of persons are consistent in different times (10). Evidence suggests, however, that these assumptions frequently are not met-particularly for the American Indian, Asian/Pacific Islander, and Hispanic populations (10-12). The cultural diversity and rapid changes in demographics pose further challenges for the surveillance of health status in the United States.

Collection of Race and Ethnicity in Discharge Data Systems

State Discharge Data Systems

States with hospital discharge data systems vary widely in the collection and use of Race and Ethnicity data. Approximately 85 percent of the states responding to the 1999 inventory reported using a Uniform Bill for Hospitals (UB92) format for collecting discharge data. Race and ethnicity are not included in the UB92 core billing standards, as this field is not necessary to pay a claim. Despite its exclusion in the UB92 standards, twenty-seven states (55%) collected data on patient race and ethnicity as a part of their inpatient data using state fields. States find that the inclusion of race and ethnicity into their discharge data reporting requirements enhances the utility of the data they collect. These fields have the potential to provide important patient demographic data for analyzing variance in utilization, access, cost, and quality measures.

As valuable as these fields are to public health and research communities, the present practice of collecting race and ethnicity, and the sensitivities surrounding the collection of these variables at the point of care, result in its uneven collection and under-use.

Because there has been no national standard in the core UB92 data set, states vary in their collection methodologies and definitions of race and ethnicity data. Agencies responsible for maintaining the discharge data systems may or may not require the submission of race/ethnicity and design the edit protocols accordingly. States do not use a standard definition for race and ethnicity (1995 Source Data Values, HCUP).

Concerns in the provider and research communities about the accuracy and completeness of these fields have limited its use in states (e.g. Maine, New Mexico and Utah). Besides variance in definitions, how the data are collected (self-reported by patient or coded by the admitting clerk based on observation of patient characteristics) contribute to the limitations in its analytic utility.

Compliance means that the data suppliers report race/ethnicity data to the state agency maintaining the discharge data system. States may mandate the reporting of discharge data, but not require race/ethnicity to be a part of the record or may not edit the field.

States that require the reporting of race/ethnicity as a part of the discharge data submission show higher rates of compliance than states that collect the data voluntarily or do not require resubmission of the data if it is missing or invalid (96 percent compliance for mandated reporting versus 83 percent compliance for voluntary submission of this field).

TABLE 4: Compliance rates by collection directive

Mandatory collection of race/ethnicity data Voluntary collection of race/ethnicity data

		%	% compliance			% missing	%
		missing					compliance
	Average	3.2%	96.8%		Average	17.07%	82.9%
Range	Minimum	.076%	92.6%	Range	Minimum	0.00%	23.4%
	Maximum	7.45%	99.9%		Maximum	76%	100%

Data Sources 1998 Data Inventory for HCUP Partners (1999 collection) 1997 HCUP statistics Telephone interviews with states, January 2000

States were contacted about their methodology for collecting this field and several "best practice" states were identified: Wisconsin, California, New York, and New Jersey. These states require the reporting of this field for all patients, require data supplier resubmission for invalid or missing values, and are most likely to use the data for public health and research purposes.

States with low compliance to race/ethnicity reporting are likely to not enforce its collection from providers or obtain the field "incidentally" (providers include this field without specific reporting requirements). These states are likely to report that they have never released or used the data because they did not trust its quality or completeness.

National Hospital Discharge Survey

Nationally, a discharge data system is comprised of data from the National Hospital Discharge Survey (NHDS) conducted by the National Center for Health Statistics. The National Hospital Discharge Survey provides information annually on the inpatient use of hospitals in the United States. Data are collected on diagnoses, surgical and non-surgical procedures, and patient characteristics from a national sample of approximately 500 non-Federal, short-stay hospitals or approximately 8% of the universe. The information is abstracted from a sample of medical records from each sample hospital for a total sample of about 270,000 records each year. The record unit in the database is a hospital discharge. Medical information is coded according to the International Classification of Diseases, 9th Revision, Clinical Modification. Race and ethnicity arE-Coded in the NHDS according to Directive 15. Race is not stated in approximately 20% of the records; ethnicity is not stated in 75% of the records and is not on public use tapes.

ANSI ASC X12N 837

ANSI ASC X12N 837 (abbreviated as X12N) is a set of standards for a wide range of data related to medical claims and encounters, intended to be transmitted electronically. The Federal Health Insurance Portability and Accountability Act (HIPAA) of 1996 requires hospitals and payers to collect a specific set of core data elements, and DHHS recommended adopting X12N as the standard for electronic transactions. The X12N includes a standard definition for race and ethnicity, but the definition differs from the OMB Standards and many state definitions. Additionally, race and ethnicity are designated as "not used" in the X12N Implementation Guide for the claim/encounter (837).

Uses of race/ethnicity for public health surveillance

The collection of race and ethnicity information has been an important component of public health surveillance efforts used to identify differences in health status among racial/ethnic minorities. Sources for surveillance information regarding the health status of the total U.S population and racial /ethnic groups include state agencies and multiple federal agencies such as CDC, Bureau of the Census, the National Cancer Institute (NCI), the Indian Health Service (IHS), and the Immigration and Naturalization Service (INS). Categories and types of information collected include births, deaths, population size and migration, disease and injury morbidity, health behavior

and attitudes and health service utilization. Such information may serve administrative, management, legal, research and evaluation, and archival purposes.

Although information is collected by separate agencies, published health statistics are frequently based on data from several sources. Data combined in three interrelated ways: a) counts from one source may be used in the estimation of counts in another source (e.g., birth, death, and immigration records to estimate postcensal populations); b) counts from one source may be used in evaluation of counts in another source (e.g., natality records to evaluate the completeness of census counts); and c) counts from separate sources may be used in the estimation of combined statistics (e.g., rates and ratios).

Through its Healthy People 2000 Objectives, the U.S. Public Health Services has developed a set of indicators of population health status. Healthy People 2000 and Health People 2010 include measures of mortality, disease incidence, low birth weight, prenatal care outcomes, childhood poverty, and air quality standards. Objectives highlight the narrowing of racial disparities in health as a major goal of the nation.

Health status differs according to characteristics such as race, gender, and socioeconomic status, NCHS 1995) and the differences are substantial. Although, the nation's mortality rate is down, there is a mixed picture of progress for racial and ethnic population groups. Significant health disparities between these groups and the white population continue to exist. For instance, the infant death rate among African Americans is still more than double that of whites. American Indians and Alaska Natives have an infant death rate almost double that of whites. Hispanics living in the United States are almost twice as likely to die from diabetes than are non-Hispanic whites. On average, Asian and Pacific Islanders have indicators of being one of the healthiest population groups in the United States; however, there are significant health disparities within this diverse group. (http://www.health.gov/healthypeople).

Race/Ethnicity Data Collection Concerns

Some of the concerns about collecting these data elements with discharge data include:

- This is considered by some to be a sensitive data element and collecting this from patients at the point of service raise perceptions of opportunity for discrimination;
- Definitions are not clear, including the issue of multiple-race classification;
- States collecting these data elements voluntarily or in a different format may have to make adjustments to their systems.

States who have had the most extensive experience with collecting race/ethnicity data are the same ones with demonstrated success in using it. If their classification is different from the OMB standard and if they have to change to comply, then there may be a loss of trend data if state-specific breakouts of race are lost.

Recommended Steps Toward Implementation

Although HHS was successful in obtaining X12N Workgroup 2 approval for including race and ethnicity into the next Institutional Implementation Guide (version 4030), the retention of this these fields in future Implementation Guides is not guaranteed. NAHDO recommends that the research and public health community continue to document the value of race and ethnicity data to discharge data systems and support its inclusion in future Implementation Guides. Additionally, NAHDO recommends educational and technical assistance to state agencies to adopt these race and ethnicity standards into statewide reporting requirements.

Data Element

Mother's Medical Record Number on Newborn Record

(Summary of Proposal to X12N for Revision of X12 Standard and Institutional 837 Implementation Guide for Mother's Medical Record Number in Accordance with State Business Needs: provided by Robert Davis, NYDOH).

Recommendation

NAHDO's recommendation to include MMRN in the X12 Standard and Institutional Implementation Guide 4030 or higher has been achieved.

NAHDO recommends state implementation and education.

Conditional Statement Segment Note 1

This segment is used when necessary to identify the Mother's Medical Record Number when mandated by state or federal health reporting requirements or when needed for payer processing or reference to the mother's record. Newborns are identified by a valid newborn ICD9-CM Principal Diagnosis code.

Data Element Usage REF01 and REF02 are required. REF03 and REF04 are not used.

Statement of Business Case

The proposed change will provide a vehicle to collect Mother's Medical Record Number on a newborn claim submission consistent with the reporting of other clinical and billing data using ANSI ASC X12 standards.

Hospital discharge records have become a major source for both program and research activities in the area of maternal and child health. The Mother's Medical Record Number collected for each inpatient newborn discharge facilitates linkage between the mother's and baby's hospital records. The health of a baby's mother is a documented risk factor in determining current and future treatment needs for newborns. The data is used to facilitate research and augment the treatment decision-making process for newborn patients. Providing a reliable linkage variable reduces the human and fiscal resources necessary to enable appropriate short and long-term decisions related to the care and treatment of newborns in this country. Some state laws require the collection of the Mother's Medical Record Number in their discharge data systems.

Another use of this data element would accommodate Medicaid rules. If a mother were a Medicaid recipient, then her newborn child would also qualify for Medicaid benefits. The collection of the Mother's Medical Record number would facilitate the linking of Medicaid eligible mothers to their newborn's records for enrolling these qualified recipients. Current New York State law requires babies born from Medicaid eligible mothers to be issued a Medicaid insurance card within 15 days of birth. The mother's medical record number facilitates the necessary linkage of the newborn and mother's birth records.

Finally, some payers also retroactively request the Mother's Medical Record Number on newborn claims to justify payment for services provided.

The assignment of a mother's medical record number code in the X12 standard anticipates the multiple potential uses of this data element.

Collection Issues

Differing state statutes related to the collection of the mother and newborn records have a significant impact on the need for the Mother's Medical Record Number variable. For instance states requiring mother and newborn records to be reported as one record effect potential would be less apt to require the reporting of the Mother's Medical Record number than states requiring the separation of mother and newborn records. In states where this variable is required by statute vendors under current contracts would be obligated to support the necessary system changes to comply with regulatory mandates. State systems collecting this data element would also be obligated to protect the privacy of the mother and the newborn.

Statement of Accommodation by Current ANSI X12 Standards

On the ANSI ASC X12 Health Claim Transaction Set (837) the mother's medical record would already be included as a REF number with an *EA* REF Identification Qualifier in the Subscriber loop when the mother's insurance is used in payment of the newborn claim. When the mother is not the subscriber for the newborn claim the mother's medical record number would not be reported on a routine 837 claim. Currently, no other ANSI transaction would contain this information.

Institutional 837 Implementation Guide 4030 or higher

Add code to Data Element 128 for a Mother's Medical Record Number Qualifier to be used in a REF segment.

Add appropriate language in the Institutional 837 Implementation Guide to accommodate situational use of an additional REF segment titled Mother's Medical Record Number in Loop 2300 - Claim Information. This segment should have one repeat and be situational, with the data condition as shown on the attached request document.

Current Practice

Five states are known to collect the Mother's Medical Record Number on the newborn's record (HCUP Inventory, 1999). These states are more likely to routinely link their discharge databases with vital records data (birth and death certificates). Out of 33 respondents to the 1998 NAHDO Administrative Simplification survey of states, 18 states report that they link discharge data with other health data bases to track readmission rates and evaluate outcomes of interest. These states report that data collection can reduce the amount of data collected from providers and promote data integration with other health agencies.

Newborn records are less likely to contain a unique identifier (such as social security number or name), challenging the linkage between major health data sets (discharge data and vital records). This linkage enables the creation of measures that provide information about maternal and newborn outcomes of interest in populations at risk.

Justification for standardizing the collection of Mothers Medical Record

Maternal and newborn health and health outcomes measurement is growing as an important state and federal issue. Accountability of federal and state funding of maternal programs is increasing. The Title V Block grant, administered by the Health Services Resource Administration (HRSA)/Maternal Child Health Bureau (MCHB) is a partnership between the federal government and states which provided nearly \$2.7 billion in fiscal year 1997 for services and programs at the State and local level in 59 jurisdictions. The MCHB requires states receiving Title V funding to report on core and elective performance measures that address specific maternal and child health needs that, when successfully addressed, can lead to a better health outcome within a specific time frame. These measures are reported nationally and are a part of the HRSA's Government Performance and Results Act (GPRA) reporting. Under GPRA funding decisions are linked with performance in a government-wide effort to establish measurable performance goals that can be reported as part of the budgetary process.

The integration of major health data bases and the ability to more effectively monitor health and health outcomes of populations-at-risk is a critical state issue, but also is a payer and provider issue in an era of growing accountability and privatization of health care delivery. Measuring and monitoring the health of a plan's population requires plans to adopt many of the epidemiological tools and processes in practice in public health. The Health Plan Employer Data and Information Set (HEDIS) is one example in which systematic and targeted integration of private/public and provider/vital records data may replace labor-intensive abstraction of data. Over ten states and many Medicaid HMO agencies require HEDIS reporting---which merges administrative and clinical data for specific populations.

Concerns:

In our research of states collecting this field, no major concerns were raised. Compliance to reporting of this field by providers was high and states that currently collect this data element with discharge data reported that little resistance from their provider community when this field was added.

Recommended Steps Toward Implementation

Educate and promote state implementation.

PRIORITY DATA ELEMENTS FOR FURTHER RESEARCH AND FUTURE ACTION

Data Element

External Cause of Injury Code Part 2: Adverse Effects of Medical Treatment

Recommendation

To inform national and state medical errors discussions, NAHDO recommends the validation of adverse effect E-codes (E 870-879 and E 930-949.9 in discharge data systems.

NAHDO recommends also that the PHDSC participate in the National Quality Forum's Research and Quality Improvement Council, charged with proposing national standards for measuring and reporting medical errors and quality measures. The PHDSC and NAHDO should advocate for a national disclosure framework that provides guidance for public disclosure of sensitive health data for state and local agencies.

Additionally, NAHDO and the PHDSC should track state reporting initiatives and conduct case studies to document best practices and challenges in analyzing and reporting medical errors information.

Justification for validating and using adverse effect E-Codes

A recent report from the Institute of Medicine (IOM) of the National Academy of Sciences established a comprehensive strategy for government, industry, consumers and health providers to reduce medical errors. The Quality Interagency Coordination Task Force (QuIC), in its February 2000 report to the President²⁸, voices support for the development of state-based systems on preventable, adverse events with public disclosure components that prevent the information from being used as a tool for punitive action by State and local authorities. The QuIC supports an adverse event mandatory reporting systems in all 50 states in 3 years. Use of existing codes and data collection mechanisms will facilitate state-level reporting. Requiring adverse event diagnosis codes (E 870-E879 or E 930-E 949.9) to be reported in the X12N HI diagnosis segment provides a systematic and available mechanism for medical errors reporting.

Adverse medical event coding, while defined in standards, is in practice a very sensitive issue. Questions about the validity of the incidence of these events have been raised, with the presumption that these events are under-reported. The collection and use of these data will be a major public policy issue over the next few years.

States are beginning to more closely analyze their existing data sources for clues about adverse medical events and to guide planning for strategies to address this issue. One state shared with NAHDO preliminary statistics from their Emergency Department database. In this state's 1997

²⁸ Quality Interagency Coordination Task Force. (February 2000) Doing What Counts for Patient Safety: Federal Actions to Reduce Medical Errors and Their Impact. Report to the President.

Emergency Department database, almost 30 percent of records contained an adverse event code (in the range of E 870-879 or E930-E949.9):

E-code in any ICD-9 field 23.6 percent E-code in E-code field only 19.7 percent

An example of a state's preliminary analysis is included below showing the relatively consistent percentage of adverse event codes present in inpatient hospital discharge data reporting over 7 years.

Year Inpatient Data Collection	Percent Adverse Effect Codes (E870-879 and E930-949.9)
1992	2.78
1993	2.77
1994	3.23
1995	4.45
1996	4.93
1997	6.03
1998	4.96

Table 5: Adverse Effect Codes in Inpatient Data Set by Year

These findings were consistent with another state's analysis of the incidence of multiple year adverse effects in inpatient discharge data. ThesE-Codes provide only limited information about this important issue; it may be useful as a screening or surveillance tool, if the proper disclosure protections are in place.

Bates (1995) estimated that 28% of adverse drug events were preventable and 42% of life-threatening and serious adverse drug events were preventable. The definition of adverse drug event used in the study was an injury resulting from medical intervention related to a drug.²⁹

Lazarou and Corey (1998) estimated the incidence of serious and fatal adverse drug reactions among hospitalized patients. Estimates were obtained by analyzing prospective studies of adverse drug reactions in hospitals performed from 1966 to 1996. An adverse drug reaction was defined as any noxious, unintended, and undesired effect of a drug that occurs at doses used in humans for prophylaxis, diagnosis, or therapy and excludes therapeutic failures, accidental poisoning and drug abuse. The researches estimated that there were 2.2 million adverse drug reactions and 106,000 fatal adverse drug reactions among hospitalized patients in 1994 in the United States.³⁰

The development of comparative state statistics would enhance our knowledge of adverse drug effects and the Healthcare Cost and Utilization Projects (HCUP) Quality Indicators is one model that has combined and used multi-state data sets to evaluate measures of quality and

²⁹ Bates, D.W. "Incidence of Adverse Drug Events and Potential Adverse Drug Events". (July 5, 1995) <u>JAMA</u>, 274(1), 28-34.

³⁰ Lazarou, J., Pomeranz, B.H., Corey, P.N. "Incidence of Adverse Drug Reactions in Hospitalized Patients." JAMA, 279(15) April 15, 1998, 1200-1205.

utilization and state and regional variation³¹. It may be possible to use statewide hospitalization databases to produce comparative state statistics or a national sample of adverse drug effects.

 31 National Association of Health Data Organizations. HCUP Quality Indicators Online, www.nahdo.org/ahcpr/main.index.htm

Source of Admission

UB92:

"A code to indicate the admitting source for recommending additional health care services to be provided by a facility. A code to indicate the admitting source for recommending additional health care services to be provided by the facility.

Medicare requires the reporting of this code for all inpatient and outpatient claims whereas, Many other third-party payers do not require the coding of this data element for inpatient claims.

Recommendation

Expand reporting of Source of Admission to all payers. Develop a business case and forward comments to the National Uniform Billing Committee (NUBC) and proceed with request to revise the X12 Standard and Institution 837 Implementation Guide in Accordance with State Business Needs.

Other UB Fields for PHDSC Consideration and Evaluation:

Expanded fields for Admitting Diagnosis

Present Symptom or Complaint

Patient Demographics

Marital Status

Patient Living Arrangement

Current or Most Recent Occupation or Industry

Patient Functional Status

Current Practice

Providers do not routinely collect patient demographic information beyond age and gender as part of the admission process. Thus, most statewide discharge databases based on administrative (billing) data do not include them as core data elements. Most analyses of demographic variation in health status, utilization, and outcome, are based on health surveys that normally ask respondents' socio-economic background.

Recommendations

NAHDO considers these expanded patient demographic fields to be an open issue for more study.

The PHDSC needs to document the use of these data elements with discharge data and justify the reporting burden to suppliers.

Readmission Indicator

Recommendations

NAHDO does not recommend the collection of readmission indicator from providers.

NAHDO recommends the monitoring of proposed federal privacy regulations and patient identifier regulations to assure the ability for public health and research linkages between major health data sets to derive this indicator.

Do Not Resuscitate

Recommendation

NAHDO invites discussion as to the value of Do Not Resuscitate as a core field for discharge data reporting.

Current Practice

In 1999, NAHDO conducted an inventory of state data collection practices for the Health Care Utilization Project (HCUP), funded by the Agency for Healthcare Research and Quality (AHRQ). Three states reported they collect DNR as a part of their discharge data reporting requirements.

As a Core Data Element: Pros and Cons

Justification for collection:

One state reports that this field is a value-added element supported by providers. The DNR field improves the ability to conduct outcome studies by serving as adjustment factor, as it considers patient preferences when evaluating in-hospital mortality.

Concerns:

Another state has dropped the DNR field, claiming that it was not being used by the provider community or for health services research or public health. This lack of use made it difficult for state officials to justify the provider cost to report this field.

Recommended Steps Toward Implementation

NAHDO welcomes a discussion about the utility of this data element for public health and health services research.

Gestational Age of Newborn on the Newborn Record

Recommendation

NAHDO invites Consortium discussion about including Gestational Age as a core data element in hospital discharge data reporting. Does the value justify the cost to report? Are there alternatives and what are these?

Current Practice

One state reports that they collect the Gestational Age on the newborn discharge data record (out of 42 responding to the HCUP Partner Inventory, 1999). This state uses the data for birth outcomes and maternal child health evaluations.

As a Core Data Element: Pros and Cons

This data element is important to maternal and child health (Title V performance measures tied to federal funding) and the Agency for Health Care Research and Quality's new national database specific to children (0-18 years).

Collection with discharge record may be preferable to linkage. Newborns often do not have a unique identifier (such as social security number), making the linkage between the discharge record and the newborn record difficult.

Justification

May be an important data element for maternal and child research.

Concern

Redundant reporting by providers who report this field on birth certificates.

Recommended Steps Toward Implementation

Open to further discussion.

PRIORITY DATA ELEMENTS FOR EDUCATIONS OF STATE HEALTH DATA AGENCIES

Data Element

Present on Admission Indicator (POA)

Recommendation

NAHDO recommends the education of state health data agencies about the availability of this data element in the X12N Implementation Guide as well as further studies on the value of this data element to public health and research. This will be key in assuring its retention in future X12N Implementation Guides.

X12N Implementation Guide

Situational: C022-09 would only need to be reported to data collectors requiring this information when C022-01 is "BF" (Diagnosis Code) and range of diagnosis codes were NOT given in C022-08.

09 C022-09 is used to identify the diagnosis onset as it relates to the diagnosis reported in C022-02.

Y= onset occurred prior to admission to the hospital;

N=onset did NOT occur prior to admission to the hospital

U=unknown whether the onset occurred prior to admission to the hospital or not

Current Practice

In 1999, NAHDO conducted an inventory of state data collection practices for the Healthcare Cost and Utilization Project (HCUP), funded by the Agency for Healthcare Research and Quality (AHRQ). Two out of 42 states collecting inpatient discharge data reported they collect POA as a part of their discharge data reporting requirements.

As a Core Data Element: Pros and Cons

Justification for collection:

One of the core fields recommended by the National Committee for Vital and Health Statistics (NCVHS) for inclusion in the Uniform Hospital Discharge Data Set, this field is used to distinguish between admitting diagnoses (conditions present on admission) versus those that manifested during the hospital stay.

California uses this field to monitor adverse events linked to staffing ratios (survey). Quality improvement and outcomes studies can differentiate hospital-acquired diagnoses from those existing at the time of admission.

Concerns:

In the two states collecting this field, providers supported its collection and resistance was limited.

Recommended Steps Toward Implementation

NAHDO recommends:

- Assurance that this field is retained in the next Implementation Guide and that the Public Health Consortium monitor its status
- Education of discharge data agencies as to the inclusion of this field in the current X12N implementation guide, the value of the field to outcomes studies, and technical support to enable its collection where needed.

Birthweight of Newborn on the Newborn Record

Recommendation

X12N Implementation Guide Standard includes a birthweight standard in the Patient segment:

PAT 07: Qualifier, grams

PAT 08: Weight, required for delivery services

NAHDO recommends education of state data agencies that this standard exists in the X12N Implementation Guide.

Current Practice

Fifteen out of forty two states that responded to an HCUP Partner inventory (1999) reported collecting birth weight with the newborn record. This data element provides important information about birth outcomes, including low and very low birthweight deliveries.

As a Core Data Element: Pros and Cons

Justification

Over a third of the states already collect this element. This data element is important to maternal and child health (Title V performance measures tied to federal funding) and the Agency for Health Care Research and Quality's new national database specific to children (0-18 years).

Collection with discharge record may be preferable to linkage. Newborns often do not have a unique identifier (such as social security number), making the linkage between the discharge record and the newborn record difficult.

Concerns

Redundant reporting by providers who report this field on Birth Certificates.

Recommended Steps Toward Implementation

Encourage states to collect and use this data element as a part of their discharge data reporting system and continue to document the utility of this element to maternal child health issues.

OUTPATIENT ELEMENTS

Data Element

Observation Stays

Recommendation

NO RECOMMENDATION. THIS IS A STATE POLICY ISSUE IMPORTANT TO STATES.

Medicare's definition of observation services is:

"those services furnished on a hospital's premises which are reasonable and necessary to determine the need for possible admission to the hospital. These services include the use of a bed and periodic monitoring by a hospital's physician, nursing, and other staff".

Current Practice

With the exception of one state (Massachusetts), statewide discharge data systems do not routinely or intentionally capture observation stays with inpatient, ambulatory surgical, or emergency department reporting.

As a Core Data Element: Pros and Cons

Justification for collection:

Patterns of inpatient and non-inpatient care are shifting and little is understood about the affect of limited stays on patient outcomes, access, or costs. One state has found that the cost-benefit of additional data collection to include observation stays may be justified:

A study of ambulatory sensitive conditions done in Massachusetts suggests that recent drops in inpatient preventable hospitalizations for certain diagnoses (e.g., asthma and gastroenteritis) my simply reflect a shit in the setting of care to observation/outpatient rather than better primary care delivery. Over one-third of observations stays were 24 hours or longer in length (though common belief was that observations stays were 23 hours or less). Community hospitals were found to consistently use observation stays at higher rates than teaching hospitals and this finding held across diagnoses, payer type, and severity of illness.

Concerns:

Little is known about the impact of observation stays on inpatient and outpatient utilization. Data collection methodologies may vary and the use of this type of stay may reflect more the payer policy than patient health status.

Recommended Steps Toward Implementation

States vary in their ability to expand data collection to non-inpatient settings. As the experience of states currently collecting these stays increase, more states will consider expanded data collection. (Additional literature review, Medicare findings would help make the case for state collection).

Patient Consent HL7 Code in X12 Claim Data File

Recommendation

NAHDO recommends that a patient consent/protection indicator be included in the core data set proposed by the Public Health Consortium as a situational data element. We further recommend adopting this indicator in the HL7 coding standard:

Label of the Data Element (see HL7 2.3.1):

Protection indicator (PD1 3.3.9. 12, ID-1, Optional) 00744

Definition

This field identifies whether access to information about this person should be kept from users who do not have adequate authority for the patient.

This field will be used by immunization registries to indicate whether or not consent has been given (or assumed) for record sharing.

Values:

- 1) Null designated by "", indicates that patient/guardian has not yet been asked to give consent to share or has not responded;
- 2) Y sharing is allowed (patient has given consent or consent is implied)
- 3) N sharing is not allowed (patient has refused consent).

Current Practice:

Immunization registries in several states have received billing/claim data to populate their registries. Since HIPAA requires patient consent for sharing medical records and the ANSI X12 837 standards do not include a patient consent field, patient consent has been handled manually in clinics and at the registries when immunization data are transferred through an EDI clearinghouse.

As Core Data Element: Pros and Cons

Electronic recording and transferring patient consent will significantly reduce the burden (time and resource) for providers and public health personnel and assure the authorized release and sharing of confidential information. However, considerable resources are also needed to design this field and reprogram it into the current X12 EDI format.

Recommended Steps Toward Implementation:

To design the field and values according to the HIPAA's requirements and existent standards such as HL7. The patient consent field should be able to distinguish various situations beyond immunization, such as communicable disease, physical, and mental health information. Withdraw of a consent should be able to record with a date of the withdrawal.

To educate health care providers, data suppliers, and EDI vendors on the HIPAA's requirements on patient consent to encourage them to collect and store the consents locally.

The development of the standard of the patient consent should be consistent with the coming revisions of the X12 and HL7 standards.

To collaborate with the X12 and HL7 national committees to integrate the consent information into their new releases.

Prioritization of Data Needs for State Encounter	
Data Sets For Public Health and Research Application	

NAHDO

APPENDICES

APPENDIX A: MATRIX OF INSTITUTIONAL AND PROFESSIONAL TRANSACTION PRIORITIES

PRIORITIZATION OF DATA NEEDS FOR STATE ENCOUNTER DATA SETS FOR PUBLIC HEALTH AND RESEARCH APPLICATIONS NATIONAL ASSOCIATION OF HEALTH DATA ORGANIZATIONS SUMMARY MATRIX OF INSTITUTIONAL TRANSACTION RECOMMENDATIONS December 29, 2000

STATE FIELD (in order of priority recommendation)	NUMBER STATES COLLECT -ING	CORE NCVHS D/E? Y/N	NATIONAL DEFINITION(S)	NAHDO RECOMMENDATION	JUSTIFICATION	IMPLEMENTATION STATUS
	PRIO	RITY DA	TA ELEMENTS FOR HIPA	A NATIONAL STA	ANDARDS PROCESS	
External Cause of Injury Coding (Reporting Protocol) Part 1: "Cause of Injury"	38/42	Y	 ICD-9-CM defines codes for external cause of an injury, poisoning, or adverse effect: Principal diagnosis of injury/poisoning Other injury, poisoning or adverse effect directly related to the principal diagnosis Other diagnosis with an external cause. X12N HI Segment, Implementation Guide, version 4010: Diagnosis segment: HI 01, required: principal diagnosis HI 02, required: admitting diagnosis HI 03, required: primary External Cause of Injury code Additional E-codes located in diagnosis fields 	Add one additional field to the 837 X12N HI Segment: HI 04, situational if 03 is used, then 04 must contain "Place of Injury". Further study to identify optimal number of additional E-codes with each patient record	Discharge data are an important source of state and national surveillance information. E-coding offers a framework for the systematic collection of population-based information on occurrence, outcome, costs of medical treatment. Primary Ecode linked to occurrence code important for injury surveillance, domestic violence, workplace injury, assaults	Forward request to X12N 837 Workgroup

Prioritization of Data Needs for State Encounter Data Sets For Public Health and Research Application

STATE FIELD (in order of priority recommendation)	NUMBER STATES COLLECT -ING	CORE NCVHS D/E? Y/N	NATIONAL DEFINITION(S)	NAHDO RECOMMENDATION	JUSTIFICATION	IMPLEMENTATION STATUS
Source of Payment (Payer Field)	42/42 (level of detail varies)	Y	UB92Payer Identification (FL 50) - There are three lines to identify primary and secondary payers, the data element requires the reporting of the name and then, if required, the identifying payer number assigned by the payer organization. X12N Payer Types in SBR 09: 09 Self-pay 10 Central Certification 11 Other Non-Federal Program 12 Preferred Provider Organization (PPO) 13 Point of Service (POS) 14 Exclusive Provider Organization (EPO) 15 Indemnity Insurance 16 Health Maintenance Organization (HMO) Medicare Risk AM Automobile Medical BL Blue Cross/Blue Shield CH Champus CI Commercial Insurance DS Disability HM Health Maintenance Organization LI Liability LM Liability Medical MB Medicare Part B MC Medicaid X12N SBR 09 Payer Types continued: OF Other Federal Prog. TV Title V VA Veteran Administration Plan WC Workers' Comp. Health Claim ZZ Mutually Defined	State implementation of Payer Typology in collection and release practice. Evaluate need for inclusion in X12N 837 after release of Payer ID final rules.	Public health researchers, program planners, and policy makers recognize insurance status as an important source of variation in disease prevalence, health care utilization rates and outcomes, and consequently of health status. Payer variation in measures of access to quality health care will continue to be an important area of inquiry. Adding consistency to how the payer information is coded provides for more exacting and detailed analyses—important in a dynamic health care environment in which accountability, purchasing, and performance concerns are growing.	Typology proposed for review and comment through December 31, 2000

Prioritization of Data Needs for State Encounter Data Sets For Public Health and Research Application

STATE FIELD (in order of priority recommendation)	NUMBER STATES COLLECT -ING	CORE NCVHS D/E? Y/N	NATIONAL DEFINITION(S)	NAHDO RECOMMENDATION	JUSTIFICATION	IMPLEMENTATION STATUS
County Code	13/33 (NAHDO 1998)		X12N Standard: N4 segment: DE 309 Location Qualifier DE 310 Location ID Federal Information Processing Standards (FIPS) FIPS codes: Standardized systems of numeric and/or alphabetic coding issued by the National Institute of Standards and Technology (NIST), for use by the Federal Government and others. Several series of FIPS identify standard geographic codes for States, counties, metropolitan areas, congressional districts, foreign geographic entities, and named populated and related local and national entities.	Collection: INCLUDE IN X12N IMPLEMENTATION GUIDE: Reporting of local county codes (code value CO) and FIPS codes (code value FI) with County value or text field in the X12N standard format. Disclosure: PHDSC should play a key role in the NAHDO/NAPHSIS project to establish consensus and a national framework for the release of public health statistics.	Geocoding is an important component of discharge data applications, providing information for community assessment, market studies, and small area variation analyses.	Proceed to X12N Workgroup

STATE FIELD (in order of priority recommendation)	NUMBER STATES COLLECT -ING	CORE NCVHS D/E? Y/N	NATIONAL DEFINITION(S)	NAHDO RECOMMENDATION	JUSTIFICATION	IMPLEMENTATION STATUS
Race and Ethnicity	27/42	Y	DMG 05 Condition statement: Used when reporting patient race or ethnicity with health care claim or encounter data is required by state or federal law or regulation or when reporting this data on a voluntary basis is permitted by state and federal law or regulation. DMG 10 usage "situational. Add a data element note that refers to the codes source, the same code source as REC references (OMB classifications) DMG 11 situational (collection method code) REC Codes set includes: 5 races: American Indicator or Alaska Native Asian Black or African American Native Hawaiian or Other Pacific Islander White Multiple Ethnicities permitted: Ethnicity: Hispanic or Latino Not Hisptanic or Latino	State implementation	Race/ethnicity data collection is essential to measuring and narrowing racial disparaities in health, improving minority population health status—a major public health goal (HP 2010, Task Force on Black Minority Health, 1985) 27/42 states collecting race/ethnicity and those with complete data are able to conduct sub-group studies.	PHDSC consensus obtained X12N 837 Institutional Workgroup approved

STATE FIELD (in order of priority recommendation)	NUMBER STATES COLLECT -ING	CORE NCVHS D/E? Y/N	NATIONAL DEFINITION(S)	NAHDO RECOMMENDATION	JUSTIFICATION	IMPLEMENTATION STATUS
Mother's Medical Record Number (MMRN) on Newborn Record	5/42	N	X12N 837 Institutional Standard REF01 REF02 DE 127 MMRN Situational: Used to identify the MMRN when mandated by state or federal reporting requirements or when required for payer processing	State implementation	Facilitates the linkage of maternal and newborn hospital stays—important for assessing birth outcomes, utilization, and cost issues. Most states require measures for MCH Title V Block Grant reporting and Medicaid and public health child and maternal health initiatives.	PHDSC consensus obtained X12N 837 Workgroup approved
	PRIORI	TY DAT	A ELEMENTS FOR FURTI	HER RESEARCH A	ND FUTURE ACTION	
External Cause of Injury Reporting: Part 2 Recommendation Expand E-coding to include Adverse Effect of Medical Treatment		Y	ICD-9-CM: E 870-E879 or E 930-E 949.9	Collection: More study needed, many unresolved issues Validation studies needed Disclosure: NAHDO and PHDSC to advocate for a national disclosure framework in national initiatives (e.g. National Quality Forum)	States will be charged with addressing medical errors as an emerging public policy issues. States will benefit from a national disclosure framework to guide local release policies	Further study and validation

STATE FIELD (in order of priority recommendation)	NUMBER STATES COLLECT -ING	CORE NCVHS D/E? Y/N	NATIONAL DEFINITION(S)	NAHDO RECOMMENDATION	JUSTIFICATION	IMPLEMENTATION STATUS
Source of Admission	42/42		UB92: a code to indicate the admitting source for recommending additional health care services to be provided by the facility. Medicare requires the reporting of this code for all inpatient and outpatient claims whereas, many other third-party payers do not require the coding of this data element for inpatient claims.	Provide PHDSC comment to NUBC for inclusion in UB02	Important to severity adjustment methodologies, distinguishing sub-groups of patients and isolate patient factors in outcomes and utilization studies Most states use this field in current practice for non-Medicare patients.	For PHDSC discussion.
Other UB fields for Discussion: Expanded fields for Admitting Diagnosis Presenting Symptom or Complaint						

STATE FIELD (in order of priority recommendation)	NUMBER STATES COLLECT -ING	CORE NCVHS D/E? Y/N	NATIONAL DEFINITION(S)	NAHDO RECOMMENDATION	JUSTIFICATION	IMPLEMENTATION STATUS
Patient Marital Status Patient living arrangement	1/42 1/33 (NAHDO 99)	Y	X12N DMG 04 1067: Marital Status Code, not used: Married Never married Widowed/not remarried Divorced/not remarried Separated legally	Open issue, need more study to identify proxy data elements (e.g. Patient's Relationship to Subscriber in X12N DMG-5) and the value of marital status to public health and research. Other X12N Standard—Patient's Relationship to Subscriber: DMG-5: 01-Spouse 04-Grandparent 05-Grandchild 06-Nephew/Niece 10-Foster Child 15-Ward 17-Stepchild 19-Child 20-Employee 21-Unknown 22-Handicapped Dependent 23-Sponsored Dependent 24-Dependent of a Minor Depend. 29-Significant Other 32-Mother 33-Father 36-Emancipated Minor 39-Organ Donor 40-Cadaver Donor 41-Injured Plaintiff 43-Child where Insured has no responsibility 53-Life Partner G8-Other Relationship	Provides important information about the patient's social support system—predictive of current and future health status. Unresolved issues with its collection by providers when patient is admitted.	Further study

STATE FIELD (in order of priority recommendation)	NUMBER STATES COLLECT -ING	CORE NCVHS D/E? Y/N	NATIONAL DEFINITION(S)	NAHDO RECOMMENDATION	JUSTIFICATION	IMPLEMENTATION STATUS
Patient Functional Status	1/42	Y	NCVHS: Self-reported health status: Excellent Very Good Good Fair Poor	Open issue, more study needed	Is discharge data the best mechanism for collecting this information and does the systematic collection have proven value?	Further study
Do Not Resuscitate (DNR)	2/42	Y	May be reported as "value code" by some states	Open issue—no recommendation	Prehospital care and patient preferences are important factors to isolate when conducting outcomes studies. State experience in collecting this field is limited and validity is an issue.	Further study
Readmission Indicator	Unknown		No national standard definition	Collection: States should include a unique patient identifier with discharge data collection accompanied with strong privacy and security provisions, data sharing agreements to link with other major health data sets to derive this indicator Disclosure: Respond to privacy and other HIPAA final regulations to assure preservation of public health linkages/integration.	Providers reporting the discharge record may not be aware of a previous admission. With a unique and stable identifier that spans providers and payers, the state agency can identify duplicate and repeat admissions.	Monitor national privacy regulations and patient identifier regulations.

Prioritization of Data Needs for State Encounter
Data Sets For Public Health and Research Application

STATE FIELD (in order of priority recommendation)	NUMBER STATES COLLECT -ING	CORE NCVHS D/E? Y/N	NATIONAL DEFINITION(S)	NAHDO RECOMMENDATION	JUSTIFICATION	IMPLEMENTATION STATUS
Gestational Age on Newborn record	1/42	Y	Birth Certificate field. Date of maternal LMP on Professional 837	Open issue—no recommendation	Encourage data integration/linkage policies using unique patient identifier. Adds value to discharge data for maternal-child health programs. Payers benefit with this information for quality, case management, reimbursement purposes.	Further study to determine benefit of collection versus adding this element through linkage
Observation days	1/42	N	None	State policy issue—no recommendation	Observation visits increasing as a proportion of inpatient visits (Massachusetts).	Further study to encourage expansion of state data collection to include non-inpatient data including observation stays
Patient Consent Field for Immunization Encounters (For Professional 837 outpatient records)	Forwarded by Registry Staff in 1 state		Situational: Immunization encounters: HL7 2.3.1: Protection indicator (PD1 3.3.9. 12, ID-1, Optional) 00744 Identified whether access to information about this person should be kept from users who do not have adequate authority for the patient. Null=patient/guardian not asked or has not responded Y-sharing is allowed (consent given or implied) N=sharing is not allowed (patient has refused consent)	OPEN DISCUSSION, NO RECOMMENDA- TION AT THIS TIME	This field may be used by immunization registries to indicate whether or not consent has been given (or assumed) for record sharing.	Further study and assessment of Privacy Regulation implementation issues around patient consent

STATE FIELD (in order of priority recommendation)	NUMBER STATES COLLECT -ING	CORE NCVHS D/E? Y/N	NATIONAL DEFINITION(S)	NAHDO RECOMMENDATION	JUSTIFICATION	IMPLEMENTATION STATUS
EDUCA'	TION OF	STATE I	HEALTH DATA AGENCIES	S TO PROMOTE A	DOPTION IN STATE PI	RACTICE
Mothers Medical l Newborn Record	Record Nun	nber on	See MMRN above			
Race and Ethnicity	y of Patient		See Race/Ethnicity Above			
Source of Paymen	t Typology		See Source of Pmt Above			
Birthweight of Newborn/newbor n record	1/42	Y	PAT 07: Qualifier, grams PAT 08: Weight required for delivery services	State implementation	Important to maternal-child health programs and research. Linkage of discharge and vital records data not always possible.	No DSMO action.
Present on Admission Indicator	2/42	Y	X12N Situational: Used to identify the diagnosis onset as it relates to the diagnosis. Y=indicates that the onset occurred prior to admission to the hospital; N=indicates that onset did not occur prior to admission to the hospital U=indicates that is unknown	State Implementation. Evaluation of interplay of this field with presenting/admittin g diagnosis field.	Documented by states using this field that this an important field for quality improvement, patient severity adjustment, to distinguish admitting and discharge diagnoses. Is used to monitor adverse event linked to staffing mix in hospitals. Little provider resistance has been documented in 2 states where this field has been added.	X12N situational—no national DSMO action

STATE FIELD (in order of priority recommendation)	NUMBER STATES COLLECT -ING	CORE NCVHS D/E? Y/N	NATIONAL DEFINITION(S) RMINED FOLLOWING TH	NAHDO RECOMMENDATION	JUSTIFICATION	IMPLEMENTATION STATUS
PAYERID	42/42 (HCUP)	Y	Pending final regulations for Payer Identifier	Open issue	Assure that numbering system meets public health and research needs	Pending release of final regulations
Unique Patient Identifier	17/33 (NAHDO 98)	Y	Pending final regulations for Patient Identifier—States adopting own methodologies ranging from patient Social Security Number to encrypted identifer derived from multiple patient demographic fields.	Monitor final privacy regulations to assure discharge data practices preserved	"Establish of a unique identifer is the most important core item" (NCVHS) To leverage linkage with other major health data sets (when appropriate and permitted by state law with strict security and privacy protections). To identify and track episodes of care, quality, and outcomes evaluation.	Pending privacy regulations—assure preservation of ability to link patient records using identifiers.
Medicaid Provider Identifier Number	27/33 states (NAHDO 98)	Y	National Provider Identifier Number pending national system	Open issue Recommend state collection of physician identifier Assess and respond to national regulations when final to assure the system meets public health/research needs	Collection: Physician profiling provides important information for quality assessment, accountability, consumer information. States have difficulty collecting accurate, stable numbers. Not all physicians have Unique Physician Identifier Numbers (UPIN). Disclosure: See Adverse Effect recommendations—PHDSC should actively be involved in establishing a national framework for the release of sensitive health information	Pending release of final regulations

NAHDO

APPENDIX B: CASE STUDY QUESTIONS

Dear State Immunization Registry Administrator:

On behalf of the Public Health Data Standards Consortium and the National center for Health Statistics (NCHS), I am requesting your assistance in developing data integration and national standards educational strategies for the public health and research communities.

NCHS has contracted with the National Association of Health Data Organizations (NAHDO), with the Lewin Group (a health care and human services policy research and management consulting firm) to develop the first phase of the educational strategy.

NAHDO has identified eight major public health data systems at the state level with significance to the public health and research communities. State Immunization Registries were one of these systems that the Consortium would like to evaluate. Understanding the standardization issues around the data collection, data quality, analysis, use and dissemination for these data systems will help design Consortium educational priorities to promote data standardization.

In the next week or so, a representative from NAHDO will call you to schedule an interview with you. This interview will last approximately 30 minutes and the following questions will guide the discussion:

- ✓ What are the technical strengths and weaknesses of Immunization Registries?
- ✓ Does your Cancer Registry use national standards for collecting, editing, using, and disseminating the data?
- ✓ If national standards have been adopted, what were the estimated budgetary impact (e.g. personnel, programming, and administrative) to adopting these standards?
- ✓ What are/were the barriers to adopting national standards in a local Immunization Registry system? Who might oppose the adoption of national standards?
- ✓ What has been/is estimated to be the effect on data reporting compliance and data quality/data completeness when adopting national standards?

If you have questions, please feel free to contact Denise Love at NAHDO (801.587-9118).

Thank you in advance for your participation.

Sincerely,

Denise Love Executive Director NAHDO

Prioritization of	Data Needs fo	or State Encou	ınter
Data Sets For Pu	ıblic Health ar	nd Research A	Application

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