Multi-state Health Care Data Base: The Journey

Denise Love

Washington Business Group on Health and NAHDO Letter
October 1987

- ***"State health data bases are goldmines and need to be used"***
- Called for a cooperative effort to demonstrate power of health data
- Something no one has been able to accomplish to date
- Proposed creation of a research institute within NAHDO
- Requested letters of support from state health data organizations
  - Supporting the establishment of a ***multi-state data base***
  - Create a ***system of access*** to data for health services research
- State letters of commitment and willingness to help support this effort
- NCHSR/DHHS provided a start-up grant

Washington Business Group on Health

October 11, 1987

James J. Bracher
Executive Director
Florida Hospital Cost Containment Board
Woodcrest Office Park
Building L, Suite 101
325 John Knox Road
Tallahassee, FL 32302

Dear Jim:

I am writing to ask that you write a letter supporting the establishment of a multi-state health database, to which you would both contribute and have access. From the very beginning, a NAHDO objective has been to initiate research by member organizations and create a system of access to data for the health services research community. Another important NAHDO objective is to ensure member access to the very latest proven and experimental methods and techniques. A logical approach toward realization of these two objectives is the creation of a research institute within NAHDO.

Regarding the first objective stated above, this research institute would maintain a library of data tapes from member organizations which have been converted to a uniform format. NAHDO would collect data from state data agencies, run them through the conversion program, return the original tapes and

STATE OF FLORIDA

HOSPITAL COST CONTAINMENT BOARD

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October 30, 1987

Ms. Marlene Larks, Executive Director
National Association of Health Data
Organizations
Suite 202
316 Pennsylvania Avenue, S.E.
Washington, D.C. 20003

Dear Marlene:

I am responding to your letter of October 11, 1987.

As I have previously stated, I fully support the establishment of a research institute affiliated with NAHDO with responsibility for the development of a multistate data base. As you know, our statutes will be reviewed by the Florida Legislature during its 1988 session so the ability to do interstate comparisons would be particularly valuable to me.

The Hospital Cost Containment Board has just recently begun to collect individual hospital patient data. The Board has yet to develop a release policy for this data. The Board will be reviewing a proposal to release individual patient data in the near future; but at this point, I can only release aggregate data by DRG by hospital.

I look forward to assisting in the exciting and useful development.

NCHSR becomes Agency for Health Care Research & Policy (AHCPR)

March 26, 1990

- Legislation creating the Agency for Health Care Policy and Research
- Authority over outcomes and effectiveness research
- Renewed effort on the quality and uniformity of national data sets
- The Office of Science and Data Development/AHCPR working with NAHDO and state health data organizations to develop uniformity of health data
  - Uniform definitions
  - Common reporting formats and linkages
  - Standards to ensure the security/confidentiality and accuracy of health data

National Association of Health Data Organizations

NAHDO NEWS

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AHCPR OFFICIAL

Legislation creating the Agency for Health Care Policy Research was signed on March 26, 1990. With a budget of approximately $100 million in FY 1990, AHCPR has the funding as well as the mission to develop a comprehensive agenda for health services research. The agency, with J. Jarrett Clinton, M.D., as Acting Administrator, has authority over outcomes and effectiveness research as well as renewed concentration on the quality and uniformity of national data sets.

The FY 1990 two-fold increase from the amount budgeted in FY 1989 provides the agency an opportunity to support a wide range of activities. AHCPR supports the collection and analysis of new data as well as secondary analyses of data and syntheses of research findings. AHCPR also supports the investigation of the validity and accuracy of existing patient data and enhancement to make them more useful for patient outcomes research.

AHCPR has the primary responsibility for implementing the Medical Treatment Effectiveness Program (MEDTEP) within DHHS. By developing and disseminating scientific information on the effects of currently used health care services and procedures on patient outcome, MEDTEP will work to improve effectiveness and appropriateness of medical practice. MEDTEP has a 1990 budget of about $37 million for research, emphasizing three major areas: 1) medical effectiveness/patient outcomes; 2) data base development; and 3) dissemination methods.

Within the agency, the Office of Science and Data Development is looking to NAHDO and state health data organizations for guidance in developing uniformity of health data, including the development of uniform data definitions, common reporting formats and linkages, and standards to ensure the security, confidentiality, and accuracy of health data.

[note: The AHCPR Office of Science and Data Development invited NAHDO Executive Director, Mark Epstein, to represent our members at its workshop on Developing Data for Medical Effectiveness Research.]

Healthcare Cost and Utilization Project (HCUP) Evolutions

- HCUP 1: Longitudinal data base of hospitals/patients
  - Years 1**970-1977** and **1980-1987**
  - Sixteen years of data on sample of >500 hospital
  - Over 65 million hospital discharges collected, edited, converted into uniform format
- Developments leading to extend HCUP:
  - Trend toward in-house discharge data processing (away from abstracting services)
  - Growth of statewide discharge data programs (**5 in 1984 to 30 in 1990**)
  - Expansion and evolution of health services research agenda

AHCPR awards contract to assess feasibility of creating a national data base

September 26, 1990

- A 13-month contract awarded to SysteMetrics and NAHDO to assess the feasibility of creating a national data base of hospitals and patients
  - As state-level organizations have begun to assemble and maintain data on hospitals and patients, ***"the opportunity to create a multi-state health care data base has increased"***
  - Evaluate the content, accuracy, reliability, timeliness, accessibility, and cost of state data
  - Assess whether state data can be transformed into a common format and integrated
  - Study the viability of making the data available to public agencies and other stakeholders
  - Assess availability of other data such as ambulatory surgery, outpatient care, long-term care for integration with hospital data

National Association of Health Data Organizations

NAHDO NEWS

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AHCPR AWARDS CONTRACT TO NAHDO

On September 26, 1990, the Agency for Health Care Policy and Research (AHCPR) awarded a 13-month contract to the project team of the National Association of Health Data Organizations (NAHDO), Syste-Metrics, and Information Strategies to assess the feasibility of creating a national data base of hospitals and their patients using state-wide data bases. NAHDO will evaluate the content, accuracy, reliability, timeliness, accessibility and cost of state data, and whether those data can be transformed into a common format and integrated. NAHDO will also study the viability of making the proposed data base available to public agencies and other organizations and individuals involved in health services research and health policy analysis. A special "kick-off" meeting to describe the study will be held at NAHDO's 5th Annual Meeting in Washington, D.C., Nov. 15-16, 1990.

AHCPR Hospital Cost Data Base Feasibility Study (1992)

- Virtually all 36 statewide data sources collect minimal data elements
- National Standards Uniform Hospital Discharge Data Set (UHDDS):
  - Common core, uniform data for all discharges
  - 1974 for Medicare/Medicaid
  - 14 variables selected for: utility, availability, preservation of confidentiality
  - Uniform Bill 1982
- But even with the UHDDS and UB-92, states varied in implementation of standards
  - For example, 5 different ways of coding "sex"

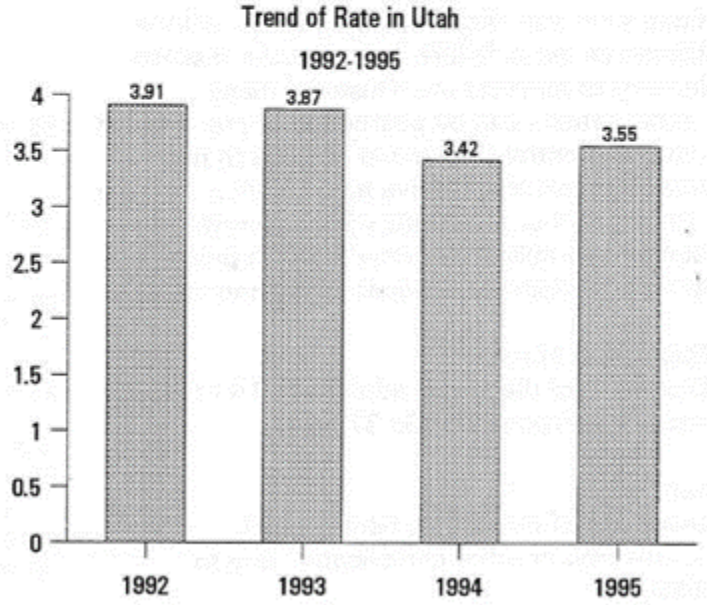
1992 Recommendations to AHCPR

- "…it is feasible to utilize currently available data from statewide data sources to form a multi-state data base"
- "The data base would provide a powerful, analytic tool for AHCPR"
- "By exerting leadership at the national level, AHCPR is in a unique position to develop a data resource….enhance analytical capabilities of the various States, and respond to the needs of health policy makers at all levels of government"

HCUP Quality Indicators

- Quality Indicators were developed by AHCPR through the Healthcare Cost and Utilization Project (HCUP-3).
  - QIs for twelve HCUP states were calculated by AHCPR from the HCUP Inpatient Database**s**, 1992-1995.
  - The indicators were calculated using a standardized method**s** from uniform data sources.
  - Indicators were based on measures in published literature

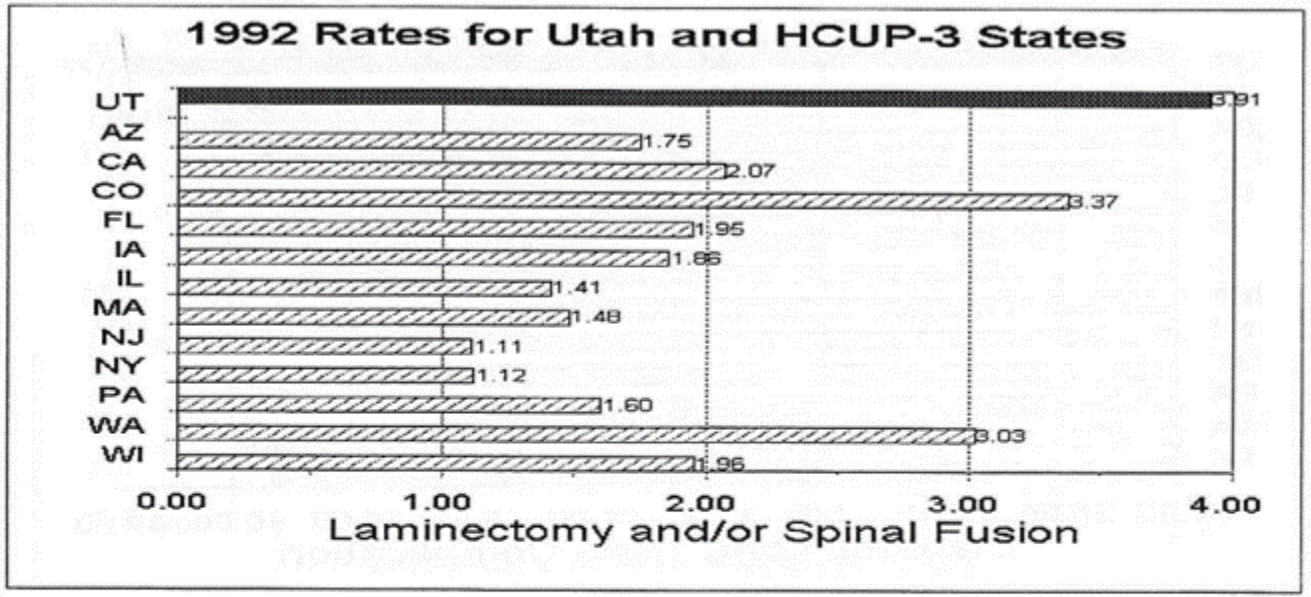
Studies suggest that laminectomy (removal of a portion of a vertebra) and spinal fusion (joining two or more vertebrae for stabilization) are not superior to non-surgical therapies for back pain and may, in fact, be inferior. Yet, rates for laminectomy and spinal fusion have grown rapidly in recent years. Although the overall laminectomy rate cannot determine inappropriate use, it may identify areas where laminectomy rates can be reduced.



Population at risk:
Adults age 18+; exclude deliveries (DRGs 370-375)

Outcome:
Laminectomy, spinal exploration, excision or destruction of intervertebral disc, and/or spinal fusion

Simple rate:
Number of procedures per 100 discharges



Laminectomy and/or Spinal Fusion

Studies suggest that laminectomy (removal of a portion of a vertebra) and spinal fusion (joining two or more vertebrae for stabilization) are not superior to nonsurgical therapies for back pain and may, in fact, be inferior. Yet, the rates for laminectomy and spinal fusion in the U.S. have grown rapidly in recent years. Although the overall laminectomy rate cannot determine inappropriate use, it may identify areas where laminectomy rates can be reduced. The Utah rate has declined from 3.91 in 1992 to 3.53 in 1996.

Outcome:
Laminectomy, spinal exploration, excision or destruction of intervertebral disc, and/or spinal fusion

Population at risk:
Adults age 18+; exclude deliveries (DRGs 370-375)

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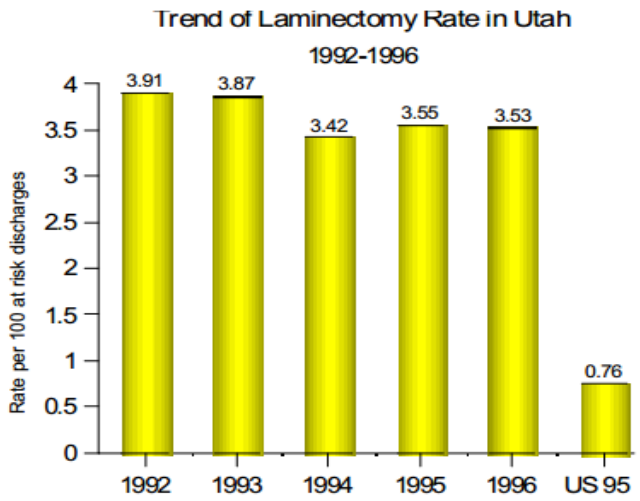

Source: Utah Hospital Discharge Database, 1992-1996.

Individual Hospital Rates, 1996

#	Peer	Hospital	At Risk Pop	Outcome	Rate
125	1	University of Utah	12,262	555	4.53
121	1	LDS	14,279	752	5.27
120	2	Salt Lake Regional	4,033	98	2.43
141	2	McKay-Dee	7,411	261	3.52
124	2	St. Mark's	9,080	358	3.94
138	2	Utah Valley Regional	10,383	902	8.69
107	3	Lakeview	2,344	17	0.73
108	3	Davis Hospital	3,552	39	1.10
126	3	Pioneer Valley	2,832	42	1.48
142	3	Ogden Regional	4,505	110	2.44
137	3	Mountain View	2,446	136	5.56
119	3	Cottonwood	6,050	682	11.27
136	4	American Fork	1,778	1	0.06
143	4	PHC**	3,743	9	0.24
118	4	Alta View	2,397	12	0.50
134	5	Ashley Valley	898	0	0.00
140	5	Dixie Medical Center	5,172	11	0.21
105	5	Logan Regional	3,282	19	0.58
112	5	Valley View	640	6	0.94
106	5	Castleview	1,695	18	1.06
103	5	Brigham City	834	22	2.64
139	6	Wasatch County	230	7	3.04
122	N	Primary Children's	321	12	3.74
Do not offer this procedure					
135	4	Orem Community	194	0	0.00
117	4	Jordan Valley	1,188	0	0.00
130	6	Sanpete Valley	197	0	0.00
133	6	Tooele Valley	147	0	0.00
132	6	Sevier Valley	947	0	0.00
129	6	Gunnison Valley	446	0	0.00
111	6	Allen Memorial	426	0	0.00
113	6	Central Valley	349	0	0.00
110	6	Garfield Memorial	230	0	0.00
104	6	Bear River Valley	219	0	0.00
109	6	Uintah Basin	849	0	0.00
114	6	Kane County	233	0	0.00
102	6	Milford Valley	301	0	0.00
101	6	Beaver Valley	255	0	0.00
128	6	San Juan	210	0	0.00
115	6	Fillmore Community	143	0	0.00
116	6	Delta Community	164	0	0.00

** *Closed 6-16-97*