Cost of Health Services Regulation Working Paper Series

Other Cost-Related Facilities Regulations

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Prepared by

Christopher J. Conover with Emily P. Zeitler

Center for Health Policy

Duke University



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Section I. Introduction

Background

This section discusses other cost-related regulations related to health facilities, including the *Patient Self-Determination Act of 1990* (PSDA) and state hospital discharge databases.

Rationale

There has been a long-standing interest in the fraction of Medicare resources devoted to the last year of life, with studies repeatedly showing that more than a quarter of Medicare spending occurs during this period. PSDA was enacted with the intent of encouraging greater use of advance directives. Hospital discharge databases originally were motivated by an interest in reducing costs by giving health planners, payers and consumers comparative information on utilization and charges across facilities; more recently, there has been interest in using these databases to provide comparative information on quality.

Statutory Authority

PSDA went into effect in December 1991. State hospital discharge databases have been in use for several decades, with 37 states having such systems in 1998 according to the most recently conducted survey we could locate (NAHDO 2003).

Key Elements

PSDA requires, as a condition of Medicare participation, that hospitals, nursing homes, hospices, MCOs and home health agencies inform all patients upon admission of their rights existing under state law to refuse medical care and make use of advance directives.¹ Documentation and education requirements were included both in the statute and regulations issued in 1995 (60 Fed. Reg 33262), but the statute itself did not specify the content of that information.

Scope

PSDA applies only to facilities participating in Medicare. State hospital discharge databases always apply to short-stay community hospitals and in some cases also to other specialty hospitals, including long-term psychiatric facilities and others. States do not have legal authority to compel Federal hospitals such as VA or military hospitals to contribute data to such discharge databases.

¹ A good summary of PSDA, its history and impact is found in Larson and Eaton 1997.

Research Questions

This working paper covers two major topic areas framed within three research questions, all of which are related to the impact of other cost-related health facilities regulation (PSDA and state hospital discharge databases) in the U.S. Our primary goal was to identify, review, and evaluate the published literature to answer the research questions with the intent of developing an interim estimate of the costs and benefits of other cost-related health facilities regulation; our secondary goal was to identify areas where no evidence exists or where the evidence has important limitations and then describe the type of data that would be needed to more fully address the question.

The questions are listed below by topic area, along with a brief description of our analytical approach, including outcomes of interest.

Costs of Other Cost-Related Health Facilities Regulation

Question 1a. What is the amount of government regulatory costs related to other cost-related health facilities regulation? This includes federal costs to monitor and enforce rules related to PSDA and state costs to monitor and enforce hospital discharge database requirements.

Question 1b. What is the amount of industry compliance costs related to other costrelated health facilities regulation? This includes all administrative costs and enforcement penalties borne by private, state or locally owned health facilities subject to federal PSDA requirements and state hospital discharge database requirements.

Benefits of Other Cost-Related Health Facilities Regulation

Question 2a. What is the net impact of other cost-related health facilities regulation on health expenditures? PSDA imposes "process" costs on medical facilities in the form of notification, documentation and education. Likewise, discharge database entail administrative costs to run the discharge data system and parallel compliance costs for hospitals to maintain the systems required to report such data.

But in theory, PSDA could be efficiency-enhancing to the extent it reduces medically unnecessary or futile end-of-life care. End-of-life care accounts for 7.5 percent of personal health expenditures (IOM 1997), or \$93 billion in 2001.² It has been estimated that 3.3% of health spending could be avoided were patients to make greater use of the advance directives and living wills about which this act was designed to better educate patients (Emanuel and Emanuel 1994). Likewise, discharge databases could also have an efficiency-enhancing impact to the extent that patients use this information to change their normal patterns of care-seeking, ultimately shifting care away from less efficient facilities. The issue in both cases is whether the regulations induce sufficient behavioral change in some patients to offset the costs imposed on facilities on behalf of all admitted patients—a question that cannot be answered by pure theory. Our search allowed for the possibility that other cost-related health facilities regulation could decrease, increase or have no impact on health expenditures.

 $^{^2}$ The 7.5% figure is based on 1987 spending data. However, other work has shown that the fraction of Medicare payments on behalf of patients in the last year of life was relatively stable between 1976 and 1988, ranging from 27.2 to 30.6% (Lubitz and Riley 1993).

Question 2b. What is the impact of other cost-related health facilities regulation on patient outcomes? While PSDA is unlikely to affect health outcomes, it theoretically might have significant positive effects on patient or family satisfaction. By facilitating health services research, hospital discharge databases in principle could improve patient outcomes.

Limitations of Working Paper

In requesting this research, DALTCP sought evidence from the medical and scientific literature to determine the magnitude of costs and benefits of other cost-related health facilities regulation as part of a broader assessment of the impact of health services regulation. Three specific questions were framed within two topic areas. The information compiled in this report may permit policymakers to identify areas in which regulatory costs appear excessive relative to benefits. This working paper is *not* designed, however, to provide specific guidance on ways in which the objectives of other cost-related health facilities regulation might be pursued more cost-effectively.

Section II. Methods

Literature Search and Review

Sources

Peer-Reviewed Literature

We performed electronic subject-based searches of the literature using the following databases:

- MEDLINE[®] (1975-June 30, 2004) and CINAHL[®] (1975-June 30, 2004) which together cover all the relevant clinical literature and leading health policy journals
- *Health Affairs*, the leading health policy journal, whose site permits full text searching of all issues from 1981-present
- ISI Web of Knowledge (1978-June 30, 2004) which includes the <u>Science</u> <u>Citation Expanded</u>[®], <u>Social Sciences Citation Index</u>[®], and <u>Arts & Humanities</u> <u>Citation Index</u>TM covering all major social sciences journals
- Lexis-Nexis (1975-June 30, 2004) which covers all major law publications
- Public Affairs Information Service (PAIS), including PAIS International and PAIS Periodicals/Publishers (1975-June 30, 2004) which together index information on politics, public policy, social policy, and the social sciences in general. Covers journals, books, government publications, and directories.
- Dissertation Abstracts (1975-June 30, 2004)
- Books in Print (1975-June 30, 2004)

A professional librarian assisted in the development of our search strategy, customizing the searches for each research question. In cases where we already had identified a previous literature synthesis that included items known to be of relevance, we developed a list of search terms based on the subject headings from these articles and from the official indexing terms of MEDLINE and other databases being used. We performed multiple searches with combinations of these terms and evaluated the results of those searches for sensitivity and specificity with respect to each topic. We also performed searches on authors known or found to have published widely on a study topic. In addition to performing electronic database searches, we consulted experts in the field for further references. Finally, we reviewed the references cited by each article that was ultimately included in the synthesis. We did not hand search any journals. This review was limited to the English-language research literature. A complete listing of search terms and results is found in Appendix A.

"Fugitive" Literature

In some cases, relevant "fugitive" literature was cited, in which case we made every effort to track it down. We also performed systematic Web searches at the following sites:

- Health law/regulation Web sites
- Health industry trade organizations

- State agency trade organizations and research centers
- Major health care/health policy consulting firms
- Health policy research organizations
- Academic health policy centers
- Major health policy foundations

These searches varied by site. In cases where a complete publications listing was readily available, it was hand-searched. In other cases, we relied on the search function within the site itself to identify documents of potential relevance. Because of the volume of literature obtained through the peer-reviewed literature, including literature syntheses, we avoided material that simply summarized existing studies. Instead, we focused on retrieval of documents in which a new cost estimate was developed based on collection of primary data (e.g., surveys of state agencies) or secondary analysis of existing data (e.g., compilation of agency enforcement costs available from some other source). We excluded studies that did not report sufficient methodological detail to permit replication of their approach to cost estimation.

Inclusion Criteria

We developed the following inclusion criteria:

- Sample: wherever results from nationally representative samples were available, these were used in favor of case studies or more limited samples.
- Multiple Publications: whenever multiple results were reported from the same database or study, we selected those that were most recent and/or most methodologically sound.
- Outcomes: we selected only studies in which a measurable impact on costs was either directly reported or could be estimated from the reported outcomes in a reasonably straightforward fashion.
- Methods: we only selected studies in which sufficient methodological detail was reported to assess the quality of the estimate provided.

Where possible, we limited the review to studies using from 1975 through June 30, 2004 reasoning that any earlier estimates could not be credibly extrapolated to the present given the sizable changes in the health care industry during the past two decades. Other exclusions were as follows:

- Unless we had no other information for a particular category of costs or benefits, we excluded qualitative estimates of impact.
- Estimates of impacts derived from unadjusted comparisons were discarded whenever high quality multivariate results were available to control for differences between states or across time.
- Estimates that focused on measuring system-wide impact generally were selected over narrower estimates (e.g., per capita health spending vs. cost per inpatient day) on grounds that savings achieved in one sector may have induced higher spending elsewhere in the system; hence narrower comparisons might inadvertently lead to an inappropriate conclusion.

Section III. Results

Empirical Evidence

We found a small amount of literature related to these regulations.

- Industry Compliance Costs: Start up Costs. We found one cost estimate based on a single facility (Johns Hopkins Hospital) that extrapolated the incremental startup costs of PSDA for all hospitals nationally, arriving at an estimate of \$43.6 to \$101.6 million (Sugarman et al. 1993).³ The lower bound included the costs of informational materials and added staffing needed to comply with PSDA; the upper bound included the additional costs of planning and training, which we view as start-up costs.
- Industry Compliance Costs: Administrative Costs. A survey in Nebraska found that ninety percent of hospitals reported taking less than 10 minutes per patient to comply with PSDA requirements and 43% said they spent less than 5 minutes (Park et al. 1994). We were unable to obtain administrative costs for hospital discharge databases from the National Association of Health Data Organizations (NAHDO) for information regarding administrative costs.
- *Indirect Benefits.* No nationally representative sample has yet been studied, but • studies of selected populations (e.g., nursing home and hospital patients) shows that between 5% and 29% of patients have advanced directives. A recent synthesis concluded that PSDA "appears to have had modest effects" (IOM 1997), while another characterized it as "only a limited success" (Larson and Eaton 1997). Five separate studies have concluded that PSDA has had no significant impact on the percent of patients with advance directives (Emanuel et al. 1993; Robinson et al. 1993; Morrison et al. 1994; Glick et al. 1995; Teno et al. 1997). One of these used pre-/post comparisons to show that following PSDA, a small increase (\sim 5%) had occurred in the fraction of seriously ill patients with advanced directives, yet oddly this increase was not related to higher rates of DNR orders or documented resuscitation discussions (Teno et al., 1997). We were unable to locate any literature demonstrating that hospital discharge data systems influence patient care-seeking patterns either in terms of seeking those with lower costs or higher quality.

Net Assessment

We have calculated the regulatory costs in the following fashion (minimum and maximum parameter estimates are shown in parentheses: full details of methods and sources are in Table C-12).

³ This was based on a survey at Hopkins, but year was not reported: figures are presumably from either 1992 or 1993.

- *Government Regulatory Costs.* Absent hard information on administrative costs for discharge data systems, we assumed each state having such a system spent an average of \$100,000 annually.
- *Industry Compliance Costs: PSDA.* For our lower bound PSDA cost, we extrapolated the estimates offered by Sugarman (1993) to 2002 using the personal health care deflator. As an upper bound, used the data from Nebraska to calculate costs for 32.7 million annual hospital admissions using an hourly wage of \$47.28 (a weighted average developed by DHHS to cost out privacy regulations) and assuming 43% used 5 minutes, 47% used 10 minutes and the remainder used 15 minutes. This resulted in an estimate roughly 70 percent higher than the lower bound estimate. We averaged these results to obtain our most likely estimate. No hard information was available in the literature regarding compliance costs for nursing homes, but they reportedly take greater efforts to educate patients (Larson and Eaton 1997), so we assume that average times were double those for hospital patients, and we adjusted hourly wages based on the ratio of nursing home to hospital wages reported by Bureau of Labor Statistics.
- *Industry Compliance Costs: Hospital Discharge Databases.* Lacking a firm estimate, we assume the ratio of industry compliance costs to government regulatory costs is 3:1 (1, 5) and estimate compliance costs accordingly.
- *Indirect Benefits*. Based on evidence that an increase in advance directives did not lead to an increase in DNR orders or documented resuscitation discussions, we could not justify including any sort of cost offset attributable to greater use of advance directives resulting from PSDA; likewise, we had no basis for calculating either cost-saving or quality improvement benefits from hospital discharge databases.
- *Social Welfare Losses: Efficiency Losses from Tax Collection*. To account for the efficiency losses associated with raising taxes to pay for government regulatory costs, we multiply the latter times the marginal cost of income tax collections (see Table B-1 for how these costs are calculated).
- Social Welfare Losses: Efficiency Losses from Regulatory Costs. All industry compliance costs are presumed to be roughly equivalent to an excise tax, i.e., raising prices and reducing demand/output correspondingly. We therefore multiply these costs times the marginal excess burden associated with output taxes, using 21% (15%, 28%) as the expected value of MEB (see Table B-1 for details of how MEB is calculated).

The overall expected cost of these regulations in 2002 is \$232 million (129, 400) while the expected benefits are \$0.

Acronyms

MCO	Managed Care Organizations
PSDA	Patient Self-Determination Act of 1990
DNR	Do Not Resuscitate
DHHS	Department of Health and Human Services

Listing of Included Studies

- "The Twilight Zone of Nancy Beth Cruzan: A Case Study of Nancy Beth Cruzan V. Director, Missouri Department of Health." <u>Howard Law Journal</u> 34 (1991): 201.
- 2. Baker, Marjorie E. "Economic, Political and Ethnic Influences on End-of-Life Decision-Making: a Decade in Review." Journal-of-Health-and-Social-Policy. 14:27-39, No 3 2002 (2002).
- Barresi, Barbara Beatty. "Advance Directives: Individual Perceptions, Attitudes and Knowledge (Patient Self-Determination Act, Bioethics, Living Wills, Durable Power of Attorney)." The Union Institute; 1033, 1997.
- 4. Bradley, E. H. <u>The Impact of Improved Consumer Information on Health Care Decision-Making: a</u> <u>Study of the Patient Self-Determination Act.</u>
- Bradley, E. H. and J. A. Rizzo. "Public Information and Private Search: Evaluating the Patient Self-Determination Act." <u>Journal of Health Politics Policy and Law</u> 24, no. 2 (April 1999): 239-73.
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- 16. Havens, G. A. D. <u>Factors Related to the Execution/Non-Execution of Advance Directives by</u> <u>Community-Dwelling Adults With Decisional Capacity</u>.

- 17. IOM Committee on Care at the End of Life. Washington, DC: National Academy Press, 1997.
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- Larson, Edward J. and Thomas A. Eaton. "The Limits of Advance Directives: a History and Assessment of the Patient Self-Determination Act." <u>Wake Forest Law Review</u> 249, no. 32 (Summer 1997).
- Lee, M. A., L. Ganzini, and R. Heintz. "The PSDA and Treatment Refusal by a Depressed Older Patient Committed to the State Mental Hospital ." <u>HEC Forum</u> 5, no. 5 (September 1993): 289-301.
- Lewis, Jeanine. "Health and Welfare: Chapter 658: California's Health Care Decisions Law." <u>McGeorge Law Review</u> 1 (Winter 2000): 155.
- 22. Lubitz, James D. and Gerald F. Riley. "Trends in Medicare Payments in the Last Year of Life." <u>New</u> <u>England Journal of Medicine</u> 328, no. 15 (April 1993): 1092-6.
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- 27. NAHDO National Association of Health Data Organizations. "National Association of Health Data Organizations FAQs." [www.nahdo.org/faq.htm]. 6 July 2003.
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- 29. Park, D. C. and others. "Implementation and Impact of the Patient Self-Determination Act." <u>Southern Medical Journal</u> 87, no. 10(October 1994): 971-7.
- Pinch, Winifred J. "Implementation of the Patient Self-Determination Act: a Survey of Nebraska Hospitals." <u>Res. Nursing and Health</u> 18, no. 59 (1995): 63-64.
- Pope, Thaddeus Mason. "The Maladaptation of Miranda to Advance Directives: a Critique of the Implementation of the Patient Self-Determination Act." <u>Health Matrix</u> 9 (Winter 1999): 139.
- 32. Robinson, Mary K. et al. "Effects of the Patient Self-Determination Act on Patient Knowledge and Behavior." Journal of Family Practice 37, no. 362, 366 (1993).
- Rutkow, Lainie. "Dying to Live: the Effect of the Patient Self-Determination Act on Hospice Care." <u>NYU Journal of Legislation and Public Policy</u> 7 (2003): 393.

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- 43. Zwahr, Melissa D. and others. "Implementation of the Patient Self-Determination Act: a Comparison of Nursing Homes to Hospitals." 16, no. 2(June 1997): 190.

Listing of Excluded Studies

Key for Reasons for Exclusion

- 1. Studies with no original data
- 2. Studies with no outcomes of interest
- 3. Studies performed outside U.S.
- 4. Studies published in abstract form only
- 5. Case-report only
- 6. Unable to obtain the article
- Baker, Marjorie Elizabeth. "Advance Directives: an Examination of the Knowledge, Attitudes and Behavior of Health Care Workers Toward End-of-Life Decision-Making (Patient Self Determination Act)." The Ohio State University; 0168, 1995.
- Glick, H. R., M. E. Cowart, and J. D. Smith. "Advance Medical Directives in U.S. Hospitals and Nursing Homes: the Implementation and Impact of the Patient Self-Determination Act." <u>Politics & the Life Sciences</u> 14, no. 1 (February 1995): 47-59.
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- 4. Park, D. C. and others. "Implementation and Impact of the Patient Self-Determination Act." <u>Southern</u> <u>Medical Journal</u> 87, no. 10 (October 1994): 971-7.
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Appendix A. Evidence Tables

 Table F-12.A1. Summary of studies of relationship between health costs, health outcomes and access to services and other cost regulations.

Study	Design/Data Sources	Regulation Measure/ Covariates	Outcome Measure	Findings				
	Indirect benefits							
IOM (1997)				PSDA "appears to have had modest effects"				
Larson and Eaton (1997)	Review of empirical literature	Patient Self- Determination Act	Individual and institutional compliance with regulation	Only limited success observed				
Emanuel et al. (1993)	Pre-post survey Two medical school-affiliated teaching hospitals with a patient population of 579 (258 pre- and 321 post- implementation)	Patient Self- Determination Act Covariates: Patient demographics Patient religion Hospitalizations	Proxies and discussions about proxies or end-of- life directives	PSDA increased the number of patients who had an advance care arrangement and the amount of discussion about such issues				
Robins-on et al. (1993)	Literature review	History of PSDA and advance directives	State-by-state outcomes of PSDA legislation	no significant impact on the percent of patients with advance directives				
Morrison et al.								

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(1994)				
Glick et al. (1995)	Telephone survey of 25 hospitals and 23 nursing homes representing each region of the US	Patient Self- Determination Act	Use and acceptance of advanced directives	Little attention is being paid to the use of advanced directives and other similar measures
Teno et al. 1997				

	Costs			Benefits			
Cost Category	Expected	Minimum	Maximum	Expected	Maximum	Minimum	Notes
Government Regulatory Costs	3.7	2.8	9.3	-	-	-	
Federal	-	-	-	-	-	-	
State	3.7	2.8	9.3	-	-	-	[A]
Industry Compliance Costs	175.1	99.1	278.0	-	-	-	
Hospitals-PSDA	143.7	76.0	211.4	-	-	-	[B]
Hospitals-discharge data	11.1	2.8	46.3	-	-	-	[C]
Nursing homes-PSDA	20.3	20.3	20.3	-	-	-	[D]
Social Welfare Losses	38.6	15.4	94.6	-	-	-	
Efficiency losses from tax collection	1.9	0.9	17.1	-	-	-	[E]
Efficiency losses from regulatory costs	36.7	14.6	77.6	-	-	-	[F]
GRAND TOTAL	217.4	117.3	381.9	-	-	-	

Table F-12.A2 Cost of Other Cost-Related Facilities Regulations (millions of 2004 dollars)

Notes:

[A] Absent information on administrative costs for discharge data systems, each state with a system [P1] was estimated to have spent \$100,000 annually on such systems [P2].

[B] The minimum was based on the adjusted compliance cost for hospitals [P14], while the maximum value was based on estimated costs in Nebraska [P7]. These figures were averaged to determine the expected cost.

[C] The ratio of compliance costs to agency costs [P3], assumed to be 3:1, was multiplied by the state regulatory costs [see A] in order to determine the cost to hospitals of the discharge data systems.

[D] Estimated total costs for nursing homes [P11] was determined by multiplying the number of patients discharged [P8], the time per NH patient [P9], and the hourly cost per NH worker [P10].

[E] Figure shown equals federal and state administrative costs times tax overhead costs [P15].

[F] All losses borne by health industry are presumed to be roughly equivalent to excise taxes, I.e., raising prices and reducing demand/output. The marginal excess burden (MEB) is intended to measure the deadweight loss associated with such reduced output. The figures shown equal industry compliance costs and external costs of uninsured times MEB [P17].

Parame	ters:	Expected	Minimum	Maximum	Notes
[P1]	States with hospital discharge data	37	37	37	[a]
[P2]	Estimated administrative cost/state (millions)	0.100	0.075	0.250	[b]
[P3]	Ratio of compliance costs to agency costs	3	1	5	[C]
[P4]	Hospital admissions, 1999	32,132	32,132	32,132	[d]
[P5]	Weighted average time per hospital patient	8.4	8.4	8.4	[e]
[P6]	Weighted hourly cost of hospital personnel	47.28	47.28	47.28	[f]
[P7]	Estimated total compliance cost for hospitals	211.4	211.4	211.4	[g]
[P8]	NH discharges, 1999	2,522	2,522	2,522	[h]
[P9]	Assumed average time per nursing home patient	16.7	16.7	16.7	[I]
[P10]	Estimated hourly wage for nursing home worker	29	29	29	[j]
[P11]	Estimated total compliance cost for nursing home	20.3	20.3	20.3	[k]
[P12]	Estimated compliance cost for hospitals, 1992	96.0	57.7	134.4	[I]
[P13]	Change in personal health care deflator, 1992-2002	1.3	1.3	1.3	[m]
[P14]	Adjusted compliance costs for hospitals, 2002	126.5	76.0	177.0	[n]
[P15]	Marginal tax overhead costs	52%	31%	185%	[o]
[P16]	Marginal excess burden	21%	15%	28%	[p]
Parame	ter Notes:				

- - The number of states reporting to the NAHDO. [a]
 - Assuming each state spends \$100,000 annually. [b]
 - Absent hard data on state expenditures, these ratios were assumed. [c]
 - Reported in Table 1 of [S5]. [d]
 - Based on a survey completed in Nebraska [S4]. [e]
 - Reported in [S1A]. [f]
 - Total hospital compliance costs are equal to total time spent with all admitted patients ([P2]/60*[P1]) multiplied by the [g] weighted hourly cost of hospital personnel [P3].
 - As reported in Table 1 of [S3]. [h]
 - Assuming that care providers spend twice as much time with NH patients as hospital-based providers. [I]
 - Adjusted from [P6] based on the ratio of nursing home to hospital wages reported by the BLS. [i]
 - Total compliance costs for NH are estimated similarly to [d] but using discharges as opposed to admissions. [k]
 - Estimated compliance costs for hospitals as reported in 1993 by [S4]. [1]
 - The change in the personal health care deflator is simply the 2002 deflator value divided by the 1992 deflator value as [m] documented by [S2].
 - Adjusted compliance costs are tabulated by multiplying estimated compliance costs for hospitals as of 1992 [S6] by the [n] change in personal health care deflator from 1992-2002.

- [0] Marginal cost of tax collections is the sum of administrative, compliance and marginal excess burden (deadweight loss): it represents the total amount of resources lost to society per dollar of revenue collected.
- [p] Marginal excess burden is the efficiency loss associated with a small increase in income taxes. It represents the share of the revenues collected that are lost due to reduced output as measured by general equilibrium models. The figures shown are weighted averages for personal and corporate income taxes using the best available estimates from the literature for each.

Sources:

- [S1A] American Hospital Association. 2002. Patients or Paperwork: The Regulatory Burden Facing America's Hospitals. American Hospital Association.
- [S1] Department of Health and Human Services. 2000. Standards for privacy of individually identifiable health information; final rule. Federal Register 65, no. 250.
- [S2] Heffler, Stephen, Sheila Smith, Greg Won, and M. Kent. 2002. Health spending projections for 2001-2011: The latest outlook. Health Affairs 21, no. 2: 207-18.
- [S3] Jones, A. 2002. The National Nursing Home Survey: 1999 summary. National Center for Health Statistics. Vital Health Stat 13(52). http://www.cdc.gov/nchs/data/series/sr_13/sr13_152.pdf (Accessed on August 10, 2004).
- [S4] Park DC. Implementation and impact of the PSDA. S. Medical Journal 1994;87:971, 974.
- [S5] Popovic, J.R. 2001. 1999 National Hospital Discharge Survey: Annual Summary with detailed diagnosis and procedure data. National Center for Health Statistics. Vital Health Stat 13(151). 2001.
- [S6] Sugarman, Jeremy., Neil R. Powe, Dorothy A. Brillantes, and Melanie K. Smith. 1993. The cost of ethics legislation: a look at the Patient Self-Determination Act. Kennedy Institute of Ethics Journal 3, no. 4: 387-99.

Appendix B. Search Strategies

Database: Ovid MEDLINE(R) <1966 to July Week 4 2004> Search Strategy #1: Costs

- 1 Patient Self-Determination Act/ec [Economics] (1)
- 2 (PSDA or Patient Self Determination Act).mp. [mp=title, original title, abstract, name of substance, mesh subject heading] (301)
- 3 (cost\$ or burden or impact).mp. [mp=title, original title, abstract, name of substance, mesh subject heading] (341621)
- 4 2 and 3 (30)
- 5 1 or 4 (30)
- 6 hospital discharge database.mp. (117)
- 7 3 and 6 (36)
- 8 5 or 7 (66)
- 9 limit 8 to (english language and yr=1975 2004) (65)
- 10 from 9 keep 1-3,11,24,26,31-32,36-37,44-47,50-65 (30)
- 11 Of these, 26 kept for detailed review due to duplication

Database: Ovid MEDLINE(R) <1966 to July Week 4 2004> Search Strategy#2: Benefits

- 1 Patient Self-Determination Act/ec [Economics] (1)
- 0 (PSDA or Patient Self Determination Act).mp. [mp=title, original title, abstract, name of substance, mesh subject heading] (301)
- 0 hospital discharge database.mp. (117)
- 0 "Outcome Assessment (Health Care)"/ or Health Status/ or Treatment Outcome/ or health outcome.mp. or "Outcome and Process Assessment (Health Care)"/ (243524)
- 0 satisfaction.mp. or Personal Satisfaction/ (30035)
- 0 4 or 5 (268258)
- 0 1 or 2 or 3 (418)
- 0 6 and 7 (30)
- 0 from 8 keep 1,12-13,22-24 (6)
- 0 Of these, 5 kept for detailed review due to duplication

Database: ISI Web of Science <1978 to July 31, 2004>

June 2006 Draft: Do Not Circulate without Author Permission Search Strategy #1: ALL (from the results below, 1 record were selected as other cost-related facilities regulation-related; hence no further searching was done in this database).

Combine Sets			Delete Sets
	Results		
#8	<u>19</u>	#7 AND #6 DocType=All document types; Language=All languages; Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=1978-2004	

Combine Sets AND COR	Results		Delete Sets
□ _{#3}	23	#2 OR #1 <i>DocType=All document types;</i> <i>Language=English;</i> <i>Databases=SCI-EXPANDED,</i> <i>SSCI, A&HCI Timespan=1978-</i> <i>2004</i>	
□ _{#2}	<u>15</u>	TS=((pharmaceutical price regulation) OR (drug price regulation)) DocType=All document types; Language=English; Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=1978- 2004	
□ #1	<u>8</u>	TS=((Medicaid Drug Rebate) OR (Veterans Health Care Act) OR (Federal Supply Schedule) OR (340B)) DocType=All document types; Language=English; Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=1978- 2004	

		1	
□ #7	<u>240</u>	#2 OR #1 DocType=All document types; Language=All languages; Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=1978-2004	
□ #6	<u>>100,000</u>	#4 OR #3 DocType=All document types; Language=All languages; Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=1978-2004	
□ _{#5}	<u>20,944</u>	TS=(health outcome OR patient satisfaction OR health status) DocType=All document types; Language=All languages; Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=1978-2004	
□ #4	<u>6,941</u>	TS=(health outcome OR patient satisfaction) DocType=All document types; Language=All languages; Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=1978-2004	
□ _{#3}	<u>>100,000</u>	TS=(cost\$ or burden or impact) DocType=All document types; Language=All languages; Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=1978-2004	
□ _{#2}	<u>104</u>	TS=(hospital discharge database) DocType=All document types; Language=All languages; Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=1978-2004	
□ #1	<u>136</u>	TS=(PSDA or Patient Self Determination Act) DocType=All document types; Language=All languages; Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=1978-2004	

Database: Lexis-Nexis <1975 to July Week 4 2004> Search Strategy #1a: PSDA

0 Guided Search on phrase appearing at least 3 times: PSDA OR Patient Self Determination Act (89)

0 Of these, 12 selected for detailed review

Database: Lexis-Nexis <1975 to July Week 4 2004>

Search Strategy #1b: hospital discharge database

- 2 hospital discharge database (2)
- 2 Of these, 1 selected for detailed review

Database: PAIS <1975 to July Week 4 2004>

Search Strategy #1: ALL

- 0 Limit set to English, Years-1975-2004
- 0 (PSDA or Patient Self Determination Act) (3)
- 0 hospital discharge database (1)
- 0 Combine 2 and 3 (4)
- 0 Of these, 1 selected for detailed review

Database: Dissertation Abstracts <1975 to July Week 4 2004>

Search Strategy #1: ALL

- 0 (kw: PSDA or ((kw: Patient and kw: Self and kw: Determination and kw: Act))) or ((kw: hospital and kw: discharge and kw: database)) and yr: 1975-2004 and In= "english" (89)
- 0 Of these, 10 selected for detailed review

Database: Books in Print <1975 to July Week 4 2004>

Search Strategy #1: ALL

- 5 (kw: PSDA or ((kw: Patient and kw: Self and kw: Determination and kw: Act))) or ((kw: hospital and kw: discharge and kw: database)) and yr: 1975-2004 and In= "english" (7)
- 5 Of these, 3 selected for detailed review

Database: Health Affairs <1981 to July Week 4 2004>

Search Strategy #1: ALL

- 0 Full article text searched for phrase: Patient Self Determination Act (1)
- 0 Full article text searched for phrase: PSDA (0)
- 0 Full article text searched for phrase: hospital discharge database (2)

Appendix C. Web Sites Used in F-12 Literature Search

Health Law/Regulation Web Sites

We began searching at Web sites known to specialize in health law and regulation generally or specific topics included in this review:

- American Health Lawyers Association http://www.healthlawyers.org/ (no documents found)
- Findlaw.com—health law <u>http://www.findlaw.com/01topics/19health/index.html</u> (no documents found)
- Health Care Compliance Association <u>http://www.hcca-info.org/</u> (no documents found)
- HealthHippo http://hippo.findlaw.com/hippohome.html (no documents found)
- National Health Care Anti-fraud Association (NHCAA) <u>http://www.nhcaa.org/</u> (no documents found – member-only site)

Health Industry Trade Organizations

Health Insurance Regulation

For health insurance regulation, we searched the following industry and state agency trade organization Web sites:

- American Association of Health Plans (AAHP) http://www.ahip.org/content/default.aspx?docid=2077
- Health Insurance Association of American (HIAA) <u>http://www.hiaa.org/index_flash.cfm</u> (no documents found)
- Blue Cross and Blue Shield Association (BCBSA) http://www.bluecares.com/ (no documents found)
- National Committee for Quality Assurance (NCQA) http://www.ncqa.org/ (no documents found)
- National Association of Insurance Commissioners (NAIC) <u>http://www.naic.org/splash.htm</u> (no documents found)

Health Facilities Regulation

For health facilities regulation, we searched the following industry and state agency trade organization Web sites:

General

- Association of Health Facility Survey Agencies <u>http://hometown.aol.com/AHFSA/index.htm</u> (no documents found)
- Healthcare Financial Management Association (HFMA) <u>http://www.hfma.org/</u> (no documents found)

• Joint Commission on Accreditation of Healthcare Organizations (JACHO) <u>http://www.jcaho.org/</u> (no documents found)

Inpatient Hospital Facilities

- American Hospital Association (AHA)
 <u>http://www.hospitalconnect.com/DesktopServlet</u>
- Federation of American Healthcare Systems (FAHS) <u>http://www.fahs.com/</u> (no documents found)
- National Association of Public Hospitals and Health Systems (NAPH) <u>http://www.naph.org/</u> (no documents found)
- National Association of Children's Hospitals & Related Institutions (NACHRI)
 - http://www.nachri.org/nachri/ (no documents found)
- National Association for State Mental Health Program Directors (NASMHPD)

http://www.nasmhpd.org/ (no documents found)

- National Association of State Alcohol and Drug Abuse Directors (NASADAD)
 - http://www.nasadad.org/ (no documents found)

Ambulatory Care Facilities

- Medical Group Management Association (MGMA) <u>http://www.mgma.com/</u> (no documents found)
- National Association of Community Health Centers (NACHC) <u>http://www.nachc.com/</u> (no documents found)
- National Rural Health Association (NRHA) <u>http://www.NRHArural.org/</u> (no documents found)
- Ambulatory Surgical Centers of American (ASCOA) http://www.ascoa.com/ (no documents found)
- National Association of Childbearing Centers (NACC) http://www.ascoa.com/ (no documents found)
- American Clinical Laboratories Association (ACLA) <u>http://www.clinical-labs.org/</u> (no documents found)

Post-Acute Care Facilities:

- National Association of Home Care and Hospice (NAHC) <u>http://www.nahc.org/home.html</u> (no documents found)
- National Hospice and Palliative Care Organization (NHPCO) <u>http://www.nhpco.org/</u> (no documents found)
- Forum of End-Stage Renal Disease Networks <u>http://www.esrdnetworks.org/index.htm</u> (no documents found)
- American Health Care Association (AHCA) http://www.ahca.org/ (no documents found)
- American Association of Homes and Services for the Aging (AASHSA) http://www.aahsa.org/ (no documents found)

State Agency Trade Organizations and Research Centers

For state agency trade organizations and health policy research centers specializing in state health policy issues not accounted for above, we searched the following Web sites:

Executive branch

- National Governors Association (NGA)
- http://www.nga.org/ (no documents found)
- National Association of State Budget Officers (NASBO) http://www.nasbo.org/ (no documents found)
- Association of State and Territorial Health Officers (ASTHO) http://www.astho.org/ (no documents found)
- National Association of Health Data Organizations (NAHDO) http://www.nahdo.org/ (no documents found)
- National Association of State Auditors, Comptrollers and Treasurers (NASACT)

http://www.nasact.org/ (no documents found)

Legislative branch

• National Conference of State Legislatures (NCSL) http://www.ncsl.org/ (no documents found)

• Council of State Governments (CSG)

- http://www.csg.org/csg/default (no documents found)
- National Academy of Public Administration (NAPA) http://www.napawash.org/ (no documents found)

State Health Policy Research Centers

- National Academy of State Policy
- http://www.nashp.org/ (no documents found)
- Pew Center on the States

http://www.stateline.org/index.do (no documents found)

• State Health Policy Web Portal Group

http://www.hpolicy.duke.edu/cyberexchange/Whatstat.htm#States

Rather than search 50 individual sites, we queried by e-mail the directors of all centers included in this group for relevant reports/studies their centers had conducted or that had been conducted by agencies in their states

Health Care/Health Policy Consulting Firms

For major health care/health policy consulting firms, we searched the following sites. Some of these specialize in human resource consulting, but were included in the event they had done industry-wide studies of regulatory costs:

• Buck Consultants Inc.

http://www.buckconsultants.com/ (no documents found)

• Deloitte & Touche

http://www.deloitte.com/vs/0%2C1616%2Csid%25253D2000%2C00.html (no documents found)

• Ernst & Young LLP

http://www.ey.com/global/content.nsf/US/Home (no documents found)

• Hewitt Associates LLC

http://was.hewitt.com/hewitt/ (no documents found)

• Milliman USA Inc. http://www.milliman.com/ (no documents found)

• PricewaterhouseCoopers LLP <u>http://www.pwcglobal.com/</u> (no documents found)

Towers Perrin <u>http://www.towers.com/towers/default.asp</u> (no documents found)
Watson Wyatt Worldwide

http://www.watsonwyatt.com/ (no documents found)

Health Policy Research Organizations

. For major health policy research organizations, including "think tanks" and some advocacy groups, we searched the following sites:

- Abt Associates http://www.abtassoc.com/ (no documents found)
- Alliance for Health Reform <u>http://www.allhealth.org/</u> (no documents found)
- AcademyHealth <u>http://www.academyhealth.org/index.html</u> (no documents found)
- The Advisory Board Company <u>http://www.advisoryboardcompany.com/</u> (no documents found – member-only site)
- American Enterprise Institute (AEI) <u>http://www.aei.org/</u> (no documents found)
- Battelle http://www.battelle.org/ (no documents found)
- Brookings Institution <u>http://www.brook.edu/dybdocroot/</u> (no documents found)
- Cato Institute <u>http://cato.org/</u> (no documents found)
- Center for Budget and Policy Priorities (CBPP) <u>http://www.cbpp.org/</u> (no documents found)
- Center for Health Affairs (Project HOPE) <u>http://www.projecthope.org/CHA/</u> (no documents found)
- Center for Health Care Strategies (CHCS) <u>http://www.chcs.org/</u> (no documents found)
- Center for Study of Health Systems Change (CSHSC) <u>http://www.hschange.com/</u> (no documents found)
- Employee Benefits Research Institute (EBRI)

http://www.ebri.org/ (no documents found)

- Heritage Foundation <u>http://www.hschange.com/</u> (no documents found)
- Institute of Medicine (IOM) <u>http://www.iom.edu/</u> (no documents found)
- Lewin Group <u>http://www.Quintiles.com/Specialty_Consulting/The_Lewin_Group/default.htm</u> (no documents found)
- Mathematica Policy Research (MPR) http://www.mathematica-mpr.com/HEALTH.HTM (no documents found)
- National Bureau of Economic Research (NBER) <u>http://www.nber.org/</u> (no documents found)
- National Health Policy Forum <u>http://www.nhpf.org/</u> (no documents found)
- RAND Health <u>http://www.rand.org/health/archive/endoflifecare/lynn.100203.pdf</u> <u>http://www.rand.org/publications/RGSD/RGSD171/RGSD171.ch2.pdf</u>
- Research Triangle Institute (RTI) http://www.rti.org/abstract.cfm?pubid=462
- Urban Institute http://www.urban.org/ (no documents found)

Major Health Policy Foundations. For major health policy foundations, we searched the following sites:

- California Healthcare Foundation http://www.chcf.org/ (no documents found)
- Commonwealth Fund http://www.cmwf.org/ (no documents found)
- Robert Wood Johnson Foundation http://www.rwjf.org/index.jsp (no documents found)
- Henry J. Kaiser Family Foundation http://www.kff.org/medicare/upload/13365_1.pdf
- United Hospital Fund http://www.uhfnyc.org/ (no documents found)