

**Examination of the Extent Prescription Drug Information  
Is Sold, Traded or Exchanged**

**By**

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## **Introduction**

Patient and prescriber information found on a prescription for a drug product is a valuable commodity for many organizations involved in the manufacturing, marketing and distribution of pharmaceuticals. There are prescription drug data consolidating companies, research consulting companies, prescription data vendor companies such as SDI, and Wolters Kluwer, brand and generic pharmaceutical manufacturers, pharmaceutical marketing companies, government agencies, and academic researchers just to name a few which have a need for the data and purchase the data.

With computerized pharmacy claims record systems, enormous databases of prescription drug information can be collected and consolidated and integrated with other health care records and consumer marketing information (e.g. coupons, surveys, buying clubs) to form massive electronic data information sources which can easily be accessed, analyzed, segmented or merged with other data bases making these very valuable information sources. Even without integrating the prescription drug information with other health information, the information contained in the prescription drug database is an extremely valuable commodity. In fact, many health care information companies, marketing firms, drug manufacturers, state and federal agencies and academic institutions purchase either segments of the data or they purchase informational reports generated from these databases. The analytical reports written using the data can cost thousands of dollars and to purchase the prescription data can cost hundreds of thousands of dollars.

It is important to recognize that personal patient identifiable information such as patient name, address, diagnosis, etc. is protected information by the Health Insurance Portability and Accountability Act of 1999 and is not to be released unless approved by the patient. The protection and confidentiality of patient information is a legal and ethical requirement for all U.S. health care practitioners and health care institutions including pharmacists and pharmacies. Patients must give their written approval before such information is released.

Obviously, in providing high quality health care services to patients, some personal, medical and prescription drug information needs to be exchanged between providers, institutions and payers but for the most part patient health care information is to remain confidential and not to be released.

As mentioned, if the personal identifiable patient information is to be released, patients must sign a waiver and give permission to release the information. One exception to this is when the information is critical to public health care officials or law enforcement officials such as for the monitoring of epidemics, infectious diseases or hazardous situations in which there is a potential for physical harm.

The overall purpose of this study was to examine the extent different types of health care organizations, providers and institutions provide, sell, trade, barter or exchange prescription drug and prescriber information to include patient and prescriber identifiable information from

either the written or electronic prescription record, the pharmacy's patient record system or from a third-party prescription drug claim.

## **Rationale of the Study**

There have been many anecdotal reports of confidential patient identifiable information being released and shared with outside parties. These reports have been brought to the attention of Texas Senator Leticia Van De Putte and Senator Van De Putte submitted legislation in 2009, Senate Bill 646, to mandate a study to collect information on the issue. The legislation was passed and signed by the Texas governor in 2009. A copy of the senate Bill 646 can be found in Appendix A.

Texas Senate Bill 646 directed the Texas State Board of Pharmacy "to conduct a study on the license, transfer, use and sale of prescription information records containing patient-identifiable and practitioner-identifiable information by pharmacy benefit managers, insurers, electronic transmission intermediaries, pharmacies and other similar entities for the purpose of advertising, marketing or promoting pharmaceutical products." The Texas State Board of Pharmacy contacted the Center for Pharmacoeconomic Studies at the College of Pharmacy, University of Texas to conduct the study. Thus, this study was conducted jointly with and under the guidance of the Texas State Board of Pharmacy.

## **Objectives**

The objectives of this project were as follows.

1. Collect information from pharmacy benefit firms, insurers, electronic intermediaries, and chain pharmacies to determine to what extent they sell, trade or exchange prescription drug information;
2. Determine from the sellers of prescription drug information the purchasers of the information;
3. Determine "fields" of information from prescription data bases being sold or exchanged;
4. Determine if patient identifiable information is being sold;
5. Determine if and how firms obtain patient permission to release personal identifiable information.

## **Methodology**

This study used a non-experimental design employing a self-report administered questionnaire to collect the needed information. Participants completed the questionnaire and returned it to the researcher. Organizations were warned in the cover letter that if they did not participate the organization was subject to a penalty of \$5,000 per day by the State of Texas for each violation. The legislation states:

"an entity. . . that fails to provide to the board the information requested by the board for the study conducted under this section before the 90<sup>th</sup> day after the date the board request the information is liable to this state for a civil

penalty not to exceed \$5,000 for each violation. Each day violation continues constitutes a separate violation.”

Questionnaires were mailed to pharmacy benefit firms, insurance firms, prescription drug claim intermediary companies, and chain drug stores. The mailings were sent by UPS one-day mail and for non-responders telephone calls were made and emails were sent. Companies or organizations in which the name of the person was known as the authority and had the responsibility of selling or distributing prescription drug information were sent and asked to complete the questionnaire. For those firms in which the identity of the “responsible” person is unknown, the questionnaire was mailed or emailed to the organization’s legal department. A self-address return envelope was provided for mailing the completed instrument back to the researcher.

#### *Mailing and Cover Letter*

A cover letter accompanying the data collection instrument used Texas State Board of Pharmacy letterhead. The cover letter explained the purpose, information needed for completing the instrument, contact people if there are questions, deadlines and penalties for noncompliance. The cover letter had two signatures. The first was from the Executive Director of the Texas State Board of Pharmacy, Gay Dodson. The second signature was from the principle investigator, Marv Shepherd Ph.D., Director Center for Pharmacoeconomic Studies, College of Pharmacy, University of Texas. The majority of the completed instruments were returned via a stamped enclosed envelope to the principle investigator. Four were returned via email to the principle investigator.

#### *Institutional Review Board*

The study proposal was submitted to the University of Texas Institutional Review Board for review and approval. However, since the study was a legislative mandate, the study was excluded from Institutional Review Board review and thus formally withdrawn.

#### *Questionnaire*

The questionnaire was constructed by the principle investigator under the guidance of the Texas State Board of Pharmacy. The questionnaire can be found in Appendix B. The questionnaire was divided into four sections: 1.) Respondent Organization Contact Information, 2.) Types of Information Sold or Transferred, 3.) Other Descriptive Information, 4.) Purchasers and Cost of the Information.

### **Results**

After the initial mailing of 15 cover letters and instruments, a total of 13 organizations responded as of August 24, 2010. One firm was dropped from the survey due to the weak market coverage in Texas and another telephoned the researcher and indicated that they did not have access to prescription drug information to sell, trade or exchange.

*Does your organization sell, trade or exchange prescription drug information?*

The lead item on the questionnaire was: “Does your organization sell, trade, or exchange prescription drug information which originates from a prescription for drug therapy or a prescription claim form? There were only two choices: “Yes” or “No.”

Out of 13 responses, three organizations indicated “no;” one of the organizations had access to the prescription drug information but did not sell, barter or exchange prescription drug information. It was against company policy to release such data. The other two did not have access to the patient prescription information. Respondents who answered “no” were not required to finish the questionnaire. They were instructed to mail the questionnaire back to the researcher. Two of these firms were wholesalers and last one was a health care plan/provider.

Ten firms indicated “yes,” they sold, traded or bartered prescription drug information. However, two firms which answered “yes” failed to complete many items on the questionnaire. Instead they wrote paragraphs describing what they did. Throughout this report these firms are denoted as Firm A and Firm B. Firm B was acquired by Firm A in 2010. Both Firm A and Firm B had the following statement under this item on the questionnaire.

... Does not sell, trade, or exchange prescription drug information for purposes of advertising, marketing or promoting pharmaceutical products. As described further below, any exchange of prescription drug information by ... is conducted in accordance with applicable laws including HIPPA and HITECH.

This statement is obfuscates the issue because the both respondents answered “yes” they did sell, exchange or barter prescription drug information, but the written response indicates just the opposite, plus answers to remaining questions on the questionnaire indicate that both firms did sell, barter or exchange prescription drug information.

Please note that despite the limited number of completed questionnaires and the fact that Firm A and Firm B provided “sketchy” and confusing information, there information gleaned from the returned instruments was very revealing and insightful; the responses do raise further questions.

*Type of prescription drug information sold, bartered or exchanged*

If the respondent indicated “Yes” their firm sold, traded or exchanged prescription information, they were asked to indicate the types of prescription information they provided. Respondents were given a list of prescription drug information items and were asked to check-off all those information items they provided with their data sets. Table 1 presents the prescription drug information list and the number of firms who indicated “Yes” or “No” that they provided the information. Firm A and Firm B did not provide a response to the list of information items.

Rather these firms wrote a paragraph describing what was done. Responses from Firm A and B follow Table 1.

**Table 1: Types and Frequency of Prescription Drug Information Provided<sup>a</sup>**

<b>Information Type</b>	<b>YES</b>	<b>NO</b>
Drug Information	8	
Drug Name	8	
Drug Strength	8	
Drug NDC Number	8	
Drug Quantity Dispensed	8	
Date of the Prescription	8	
<b>Cost Information</b>		
Dispensing Fee	5	3
Copay/Coinsurance	7	1
Drug Ingredient Cost	6	2
Average Wholesale Price	6	2
Usual Customary Charge	5	3
Third party plan-Name/Number	8	
<b>Prescriber Information</b>		
Prescriber Name	8	
Prescriber Address	7	1
Prescriber Provider Number	8	
<b>Pharmacy Information</b>		
Pharmacy Provider Number	8	
Zip Code	8	
Pharmacist Provider Number	2	5

<sup>a</sup> Two firms did not complete the items.

Firm A's response to this question was as follows:

Note that with respect to PROVIDING the information listed below, Firm A may provide many of the types of information listed below, in connections with our pharmacy benefit management services (e.g. prescription claims adjudication services) that we provide on behalf of our clients. For example, we provide anonymized, de-identified drug and cost information (e.g. copay/coinsurance) to pharmaceutical manufacturers in order to support invoices we submit to those manufacturers for rebates they pay based upon utilization of their drug products under various health plan sponsor clients. At all times when providing any types of information below, Firm B does so in accordance with all applicable laws, including federal and state privacy laws (e.g. HIPAA / HITECH), so that no individually identifiable health information is provided except as permitted by law.

Note that, with respect to SELLING any types of information listed below, Firm A does not currently sell any such data to third parties; we may do so in the future, but again, subject to all

applicable laws, including federal and state privacy laws. Firm A would not sell any type of information listed below for advertising, marketing or promotional purposes.

Firm B provided the following response:

Note that with respect to PROVIDING the information listed below, Firm B may provide many of the types of information listed below, in connection with both Firm B's pharmacy benefit management ("PBM") services provided on behalf of its clients, as well as Firm B's mail order pharmacy services provided to members/patients of those clients. For example, as a PBM that adjudicates prescription drug claims from other retail pharmacies, Firm B provides members' copay/coinsurance information (and other similar "Prescription Drug Cost Information" as identified below) at the point-of-sale to the retail pharmacy provider. As another example, through Firm B's rebate arrangements with pharmaceutical manufacturers, Firm B provides certain authorized third party payer information (including as listed below) to pharmaceutical manufacturers in order to support invoices that Firm B submits to those manufacturers for rebates. As a further example, Firm B, as a mail order pharmacy provides certain "Prescriber information" (as identified below) to its health plan clients as relates to prescriptions written by such prescribers for dispensing to those clients' covered members. At all times when providing any types of information below, Firm B does so in accordance with all applicable laws, including federal and state privacy laws (e.g. HIPAA / HITECH), so that no individually identifiable health information is provided except as permitted by law.

Note that, with respect to SELLING any of the types of information listed below, Firm B did sell aggregated, anonymized and de-identified (in accordance with HIPAA) claims data to certain third party data aggregators (e.g. IMS, Wolters Kluwer) prior to acquisition of Firm B by Firm A. Firm B no longer conducts such sales. Firm B also sells certain "drug Information" (as listed below) and "Prescriber information" (as listed below) to pharmaceutical manufacturers, but only as permitted by applicable laws. That is, Firm B does not sell any individual identifiable health information (i.e., PHI as defined under HIPAA), nor any other information that would violate federal or state privacy laws. Firm B also does not sell any of the types of information listed below for advertising, marketing or promotional purposes.

Another firm answered the above questions but added the following:

Information may be provided depending on the source of the data, recipient, applicable state regulations and other relevant requirements. Information in this response contains the proprietary, confidential trade secret information of... and is provided pursuant to the terms of S.B. 646 Section 562.057(c). Data provided by... to third parties is HIPAA compliant.

The results show that many of the surveyed organization do provide, sell, or exchange patient prescription drug information. Eight firms indicated that provide on the information related to the prescription drug (drug name, quantity, number of days supply, drug strength, etc.). The majority of the firms also provide the financial information such as dispensing fee, copayments, drug ingredient cost average wholesale price, usual customary chare and third party plan name. All of the responding firms provide the prescriber's name and provider number. And all the

firms provide the pharmacy’s name and zip code number. Only two firms provide the pharmacists provider number.

*Patient demographic information provided*

The next item on the questionnaire asked about patient information. The question asked: “Do you provide patient demographic information when you sell or provide prescription drug information?” There were three answer choices: “Yes,” “Sometimes,” or “No.” A total of six firms answered “Yes,” they do sell or provide patient demographic information and four firms indicated “sometimes.” Firm A and Firm B provided a “Yes” response.

If respondents answered “Yes” or “Sometimes,” they were given a list of demographic information items and to check-off those patient specific items their organization provided. Table 2 presents the list of the patient specific information items and the number of “Yes” and “No” responses.

A total of eight firms completed this question. Firms A and Firm B indicated “Yes,” they did not provide responses to the items but instead they provided a paragraph explaining what they do. Their explanations follow Table 2 along with explanations from other respondents.

**Table 2: Demographic Characteristic and Frequency of Firms Providing<sup>a</sup> the Information**

Patient Demographic Characteristic	Yes	No
Age of Patient	7	1
Gender of Patient	8	0
Name of Patient	4	4
Patient Address	4	4
Patient’s Zip Code	7	1
Patient’s city/state	3	5
Diagnosis	3	5

<sup>a</sup> Two organizations failed to respond.

The response provided by Firm A is as follows:

We may provide from time to time some demographic characteristic information below; but, to the extent we do, we do so in accordance with all applicable laws including federal and state privacy laws, and including as appropriate, any necessary de-identification of the information pursuant to 45 C.F.R. § 164.512(b).

The response provided by Firm B is as follows:

Firm B may provide from time to time some demographic characteristic information below; but, to the extent Firm B does, it does so only in accordance with all applicable laws, including federal and state privacy laws, and including as appropriate, any necessary de-identification of the information pursuant to 45 C.F.R. § 164.512(b) and aggregation of the demographic information.

In addition, one firm had checked Name of Patient, Patient's Address, Patient's Zip Code, Patient City/State and Diagnosis and had written the following statement.

Information provided...only pursuant to HIPAA compliant authorization. Information in this response contains the proprietary, confidential trade secret information of... and is provided pursuant to S.B. 646 Section 562.057(c). Data provided by... to third parties is HIPAA compliant.

Another firm had checked items: name of patient, patient address, patient zip code and added the following statement:

Name, address & zip code information are encrypted to prevent identification of the patient.

The follow-up question was in regard to how these organizations obtain the patient's permission to provide patient specific information. The question was: "If your organization provides patient specific or protected information, please describe the method(s) used to obtain patient consent to release the information. Seven organizations responded to the item. One organization failed to respond. The responses were as follows.

Response 1: We provide no PHI.

Response 2: Only de-identified patient information is provided. All data transfers are encrypted and secure.

Response 3: The pharmacy benefit manager only sells, trades or exchanges prescription drug information which originates from a prescription for drug therapy or a prescription claim form that has been de-identified under HIPPA privacy standards.

Response 4: Firm X strictly adheres to applicable federal and state laws regarding the confidentiality of protected health information and medical information. Therefore, Firm X uses and discloses protected health information only in accordance with the health Insurance Portability and Accountability Act of 1996, as amended (HIPAA) and any applicable state law. Patient consent is therefore obtained by providing each patient "Notice of Privacy Practices" as required by HIPAA and obtaining the patient's signed consent to use and disclosure of protected health information stated in the Notice of Privacy Practices. The patient's consent allows Firm X

pharmacies to use and disclose individually-identifiable health information in accordance with HIPAA and state privacy laws for purposes of treatment, payment and health care operations.

There are circumstances when individually-identifiable health information is provided to a business associate as provided by HIPAA regulations. In those cases, the purpose for disclosure of such information is for the aforementioned treatment, payment or health care operations of the pharmacy and the pharmacy receives no compensation for providing the information to the business associate. For example, Firm X provides another company Y with such information. Company Y takes the information and includes it in a national database of patient prescription history so that in the event of a natural disaster, such as a hurricane that we've experienced in the recent past, pharmacists will still have the prescription records so that patient treatment remains uninterrupted. Since company Y is a business associate of ours, company Y is contractually bound by restrictions on use and disclosure of such information mandated by HIPAA and applicable state law.

With respect to Drug Data Vendor companies such as IMS, SDI, etc., no individual identifiable information or protected health information is provided to those entities. Any information provided has been de-identified in accordance with HIPAA regulations and is therefore by definition not "protected health information."

Response 5: We only provide a patient's PHI for those manufacturers whose drug is required to go through a HUB/Patient Reimbursement Support Center. Both prescribers and patients must enroll and sign a release in order to gain access to the drug. This signed release is included as part of the enrollment form and is forwarded to dispensing specialty pharmacy along with the prescription. This information is scanned into our system and becomes part of the patient's permanent record. The HUB/Patient Reimbursement Support Center is responsible for re-enrolling patients/rectifying prescribers and obtaining new release signatures on an annual basis as outlined in their FDA-approved REMS program. For other drugs that do not have this requirement, the Specialty Pharmacy will only provide a patient's birth year. No other patient PHI is provided.

Response 6: Our organization provides patient "protected health information" (as defined under HIPAA) only as permitted under applicable laws, including as appropriate, pursuant to a patient's written valid authorization that we obtain in accordance with 45 C.F.R. § 164.508.

Response 7: Firm B provides patient "protected health information" (or "PHI," as defined under HIPAA) only as permitted under applicable laws, including appropriate, pursuant to a patient's written valid authorization obtained in accordance with 45 C.F.R. § 164.508. Without such authorization, Firm B only provides PHI for treatment, payment or health care operations purposes that are permitted under HIPAA.

Response 8: Third party requesting data obtains a HIPAA compliant authorization pursuant to business associate agreements with us, or third party provides us with a copy of a HIPAA compliant authorization for our review prior to release of the data, consistent with HIPAA requirements.

The results do show that patient information is being provided but based on the explanations the firms indicate that they follow HIPAA requirements. Some of the patient information being

released is somewhat surprising. For example, four of the firms indicated that they provide the patient's name and address and three indicated that they provide diagnosis.

### *Other Descriptive Information*

A variety of questions were asked in regard to prescription volume, contract research organizations and number of purchasers. The first item in the section was: "Please estimate the yearly volume (number of prescriptions) your organization processed last year (2009)." The following is the listing of the number of prescriptions reported by the ten firms.

- 476,000
- 10,900,000 (Texas only volume)
- 20,000,000
- 25,000,000
- 40,900,000
- 52,000,000
- 237,000,000
- 323,000,000
- 615,000,000
- 690,000,000

Respondents were asked: "Does your firm provide prescription drug data to research firms which analyze the data and provide a report or tables/graphs back to your firm?" A total of five respondents reported "Yes" and five indicated "No." For those firms that indicated "Yes," the respondents were asked: "What happens to the data once the report is written?" Two respondents failed to answer the question. Three responses provided an answer, but two did not address the question. The responses were as follows.

1. Reports are not archived. Raw encrypted data is retained indefinitely.
2. Used of business analysis.
3. The outside firm licenses the data.

### *Purchasers and Cost of the Information*

Respondents were asked to estimate the number of organizations which had purchased prescription drug information from their organization in the past year. The number of organizations ranged from two purchasers of information to a high of 60 purchasers. The breakdown of the number of purchasers is as follows: one organization indicated two purchasers, two organizations indicated that they sold data three purchasers and two indicated four purchasers, one firm reported ten purchasers, one organization reported selling drug information to 25 purchasers, one reported selling the information to 58 different purchasers and one respondent indicated that their organization had sold drug information to 60 different purchasers.

In a follow-up question, respondents were asked to indicate the types of organizations (e.g. brand name manufacturer, drug data vendor, drug marketing firm, etc.) their firm sells or provides prescription drug information. Table 3 presents the listing of the types of organizations presented on the questionnaire and the frequencies reported by the nine firms.

**Table 3: Responses to: We are interested in knowing the types of firms your organization sells or provides prescription drug information to.<sup>a</sup>**

Type of Organization	Yes	No
Prescription Drug Data Vendor (e.g. SDI, Wolters Kluwer)	9	0
Brand Name Drug Manufacturer	5	4
Generic Drug Manufacturer	3	6
Pharmaceutical Wholesaler	2	7
Pharmaceutical Benefit Manager	4	5
Health Care Insurance Company	4	5
Academic Institutions (Universities/College)	1	8
Research Consulting Organizations	0	9
Marketing/Advertising Firms	2	7
Other <sup>b</sup>	3	6

<sup>a</sup> One respondent failed to answer the question.

<sup>b</sup> Others listed were government agencies, Sure Scripts, Destination Rx. Another firm listed insurance verification and health plan sponsors.

### *Charge for prescription drug information*

In another follow-up question, respondents were asked: “On average how much does your organization charge per prescription/drug claim?” Only four respondents provided a response. The four responses were: \$0.006 per claim, \$2.00 per claim, \$0.0069 per claim. One respondent indicated: “...typical data exchange is pursuant to a barter agreement to obtain data services.”

From these charges, the prescription volume reported and the number of purchasers, it can be seen that many of these firms are generating a millions of dollars of revenue annually from selling prescription drug information.

### **Limitations**

As with all research studies, this study does have limitations. The first is the problem that some firms did not fully complete the survey instrument, some provided confusing information or provided responses that did not address the question. Some respondents provided only “sketchy” information. Some respondents preferred to write “umbrella statements” instead of providing specific information. One possible reason is that some of the questionnaire items may not have been clear or may not have been interpreted by the respondent as intended by the researcher. This is the first attempt at conducting a study with this focus, so there were no other instruments available to use as a template. Another possibility is that perhaps the questionnaire items were

interpreted correctly, but the respondent's objective was not to provide the specific information asked for.

Despite the limitations, the results do provide useful and insightful information as to the extent patient prescription drug and prescriber information is being sold or exchanged.

## **Summary**

The results do show that prescription information is being provided, sold, traded or exchanged. However, in doing so the organizations insist that they follow HIPAA guidelines when they do provide the prescription drug information.

To reiterate, the purpose of this study was to investigate the extent different types of health care organizations, providers and institutions provide, sell, trade, barter or exchange prescription drug information including patient and prescriber identifiable information from the written or electronic prescription record, the pharmacy's patient record system or from a third-party prescription drug claim. A survey was sent to 15 companies which were believed involved in this activity and responses were received from 13 firms. However, three of these firms indicated that they did not sell, exchange, or barter prescription drug or patient information. Thus, a total of ten responses were analyzed. However, two of these ten responding firms failed to answer some questions and only provided "sketchy" and confusing answers to the questions.

The results show that the responding firms do sell, barter or exchange prescription drug and patient information to outside organizations. This is very evident with one firm indicating that they had 60 purchasers of the patient prescription drug information in 2009. It must be pointed out that many respondents were very careful to indicate that they do provide the information in accordance with all applicable laws, including federal and state privacy laws (e.g. HIPAA/HITECH).

The results showed that patient identifiable information, such as patient name and address, is being sold or exchanged by four responding firms. In a follow-up question, which was: "If your organization provides patient specific or protected information, please describe the method(s) used to obtain patient consent?" The vast majority of the respondents indicated the information is de-identified or encrypted which is confusing. Only one respondent provided a response which addressed the question. Their response was the patient must sign a release statement before the information is provided. They also indicated that the release is part of the enrollment form for the provider services.

In addition, all the firms except one indicated that they provide the patient's age and all the firms provide the gender of patients. Seven firms indicated that they report the patient's zip code, four firms reported that provide the patient's name and address in some instances. Three firms provide the patient's diagnosis.

In regard to prescriber information, all eight firms provided the prescriber's name. Only one firm indicated that they did not provide the prescriber's address. All eight firms indicated that they

provide the pharmacy's identification, and two indicated that they provide the pharmacist's provider number.

The evidence of selling prescription information was reinforced by the number of reported purchasers of the data. One firm indicated that in 2009 they had sold prescription and prescriber information to 60 different buyers. Purchase price varied but it appears that the rate is around \$0.006 per prescription claim. This rate may seem low, but when you realize there are a hundreds of millions of prescription claims annually from some firms (chain pharmacy store operations, health care plans or large mail order firms), the potential revenue generated is enormous, especially when you combine this with the number of purchasers of the information.

In examining the types of firms these organization sell, barter or exchange their prescription and patient data to, all firms indicate that they provide the information to prescription drug data vendors such as SDI and Wolters Kluwer. Five firms indicated that they provide the information to brand name drug manufacturers and three firms indicated that they provide information to generic drug manufacturers. Four indicated they had supplied prescription drug information to pharmacy benefit organizations and health care insurance companies. Only two firms indicated that provided information to marketing or advertising organizations and only one firm said they provided information to academic institutions. No firm indicated that they provided prescription drug information to research consulting groups.

To reiterate, the study results show that many firms are selling patient prescription and prescriber information, including patient protected information although all the firms indicated that they do HIPAA and other federal and state regulations. The extent of providing patient information varies by organization; some organization refuse to provide or sell the information while others to make it a revenue generating business.

## Appendix A

### Senate Bill 646

S.B. No. 646

AN ACT

relating to a study regarding the confidentiality of prescription information; providing a civil penalty.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF TEXAS:

SECTION 1. Subchapter B, Chapter 562, Occupations Code, is amended by adding Section 562.057 to read as follows:

Sec. 562.057. COMMERCIAL USE STUDY; CIVIL PENALTY.

(a) The board shall conduct a study on the license, transfer, use, and sale of prescription information records containing patient-identifiable and practitioner-identifiable information by pharmacy benefit managers, insurers, electronic transmission intermediaries, pharmacies, and other similar entities for the purpose of advertising, marketing, or promoting pharmaceutical products.

(b) Not later than August 1, 2010, the board shall submit to the governor, the lieutenant governor, the speaker of the house of representatives, and the appropriate standing committees of the legislature a report regarding the results of the study conducted under Subsection (a), together with any recommendation for legislation.

(c) The report under this section must consist of aggregate information and may not identify by name any entity that provided information to the board. Information provided by an entity that is a trade secret is subject to Section 552.110, Government Code.

(d) An entity described by Subsection (a), other than a pharmacy, that fails to provide to the board the information requested by the board for the study conducted under this section before the 90th day after the date the board requests the information is liable to this state for a civil penalty not to exceed \$5,000 for each violation. Each day a violation continues constitutes a separate violation.

(e) The amount of the penalty shall be based on:

- (1) the seriousness of the violation;
- (2) the history of previous violations;
- (3) the amount necessary to deter a future violation; and
- (4) any other matter that justice may require.

(f) The board or the attorney general may sue to collect a civil penalty under this section. In the suit the state may recover the reasonable expenses incurred in obtaining the penalty, including investigation and court costs, reasonable attorney 's fees, witness fees, and other expenses.

(g) A pharmacy that fails to provide to the board the information requested by the board for the study conducted under this section before the 90th day after the date the board requests the information is subject to appropriate administrative sanctions imposed by the board.



## Appendix B

### Questionnaire

#### Section A

##### Respondent, Employer and Contact Information

In case we need to get in touch with you please answer the following questions. Thanks

1. What is your name, position and name of your employer?

Name: \_\_\_\_\_

Position: \_\_\_\_\_

Name of your employer: \_\_\_\_\_

2. Please provide a contact telephone number and email address where you can be reached in case a question arises.

Telephone \_\_\_\_\_

Email address \_\_\_\_\_

#### Section B

##### Types of Information Sold or Provided

**The following questions pertain to the type(s) of prescription drug information your organization sells, barter or offers to other parties. For the purpose of this survey prescription drug information is defined as information from either the patient's drug therapy prescription or the prescription drug claim form.**

3. Does your organization sell, trade or exchange prescription drug information which originates from a prescription for drug therapy or a prescription drug claim form?

\_\_\_\_\_ Yes---**If Yes proceed to Question # 4.**

\_\_\_\_\_ No----**If No, you have completed the questionnaire please return it using the enclosed envelop.**

4. We are interesting in knowing the types of prescription drug information you are providing or selling. From the following list, please check the adjacent blanks to those types of information you normally provide when selling or providing information from a prescription? Check all that apply.

**Drug Information**

- \_\_\_\_\_ Drug Name
- \_\_\_\_\_ Drug Strength
- \_\_\_\_\_ Drug NDC Number
- \_\_\_\_\_ Drug Quantity Dispensed
- \_\_\_\_\_ Date of the Prescription

**Prescription Drug Cost Information**

- \_\_\_\_\_ Dispensing fee
- \_\_\_\_\_ Copay/Coinsurance (patient’s copayment or fee)
- \_\_\_\_\_ Drug Ingredient Cost (what the insurance or pharmacy benefit manager paid for the product)
- \_\_\_\_\_ Average Wholesale Price
- \_\_\_\_\_ Usual and Customary Charge
- \_\_\_\_\_ Third Party Payer Name or Number
- \_\_\_\_\_ Third Party Payer Plan (ie. BIN Number)

**Prescriber information**

- \_\_\_\_\_ Prescriber name
- \_\_\_\_\_ Prescriber address
- \_\_\_\_\_ Prescriber identification number

**Pharmacy provider Information**

- \_\_\_\_\_ Pharmacy identification number/address
- \_\_\_\_\_ Pharmacy’s Zip Code
- \_\_\_\_\_ Pharmacist identification

4. Do you sell or provide patient demographic information when you sell or provide prescription drug information?

\_\_\_\_\_ No---**Please proceed to question # 5**

\_\_\_\_\_ Sometimes

\_\_\_\_\_ Yes

} **If sometimes or yes, please answer questions 4a and 4b.**

4a. If you answered sometimes or yes, from the following list of demographic characteristics, please mark those items which your organization provides with the prescription information.

- \_\_\_\_\_ Age of patient
- \_\_\_\_\_ Gender of patient
- \_\_\_\_\_ Name of Patient
- \_\_\_\_\_ Patient Address
- \_\_\_\_\_ Patient’s zip code
- \_\_\_\_\_ Patient’s city/state
- \_\_\_\_\_ Diagnosis

4b. If your organization provides patient specific or protected information, please describe the method(s) used to obtain patient consent.

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**Other Descriptive Information**

5. Please estimate the yearly volume (number of prescriptions) your organization processed last year?

\_\_\_\_\_ Number of Prescriptions in 2009

6. Does your firm provide prescription drug data to research firms which analyses the data and provides a report or tables/graphs back to your firm?

\_\_\_\_\_ Yes-----If yes, what happens to the data once the report is written by the outside firm?\_\_\_\_\_

\_\_\_\_\_ No \_\_\_\_\_

7. Within your organization, what is the title of the organizational unit(s) or department in charge of selling, trading or exchanging prescription drug information?

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8. Please estimate the number of drug information purchasers you have had of your data in 2009?

\_\_\_\_\_ Number of prescription drug purchasers

**Purchasers and Cost of the Information**

9. We are interested in knowing the types of firms your organization sells or provides prescription drug information to. Please mark all that apply.

\_\_\_\_\_ Prescription Drug Data Vendor Companies such as IMS, Veraspan, etc.

\_\_\_\_\_ Brand Name Drug Manufacturers

\_\_\_\_\_ Generic Drug Product Manufacturers

\_\_\_\_\_ Pharmaceutical Wholesalers

\_\_\_\_\_Pharmaceutical Benefit Managers

\_\_\_\_\_Health Care Insurance Companies

\_\_\_\_\_Academic Institutions (Universities and Colleges)

\_\_\_\_\_Research Consulting Organizations

\_\_\_\_\_Marketing or Advertising Organizations

\_\_\_\_\_Other, please explain\_\_\_\_\_

10. On average how much do you charge per prescription/drug claim does your organization charge for prescription drug information?

\_\_\_\_\_ Charge per prescription or claim

**Thank you completing the survey instrument. Please place the completed questionnaire in the mail using the enclosed enveloped.**