TO: **Members of Ways & Means**
FROM: **Andrea Meyer, Legislative Director**
RE: **DHS Budget Rebalance & SB 355 (2010) Prescription Drug Monitoring Program**
DATE: **February 2010**

Upon passage of SB 355 (2009), the Department of Human Services (DHS) was tasked with preparing and implementing the Prescription Drug Monitoring Program (PDMP).

DHS is required to report to the 2010 legislature (Ways & Means) for final authorization. ACLU has reviewed the DHS Report (Draft 3.1)[1] and we have the following concerns as the legislature moves forward. We hope before any additional authorization is granted, these issues will be addressed.

1. DHS should stop all attempts to implement a notification system
DHS intends to use the PDMP for a purpose not authorized by law. DHS states that one of the four purposes of the PDMP is to:

> "Implement through automated system notification activities to assist primary care providers to screen patients whose prescription drug purchases have exceeded an extreme threshold" (page 7).

In other words, DHS plans to use the PDMP as a tool for the government to monitor Oregonians' prescription use and send unrequested notifications to providers if use exceeds a DHS determined threshold. SB 355 was intended to be a resource for providers if they choose to review a patient/customer's records, not a government resource for monitoring.

DHS states the law does not *prohibit* this use. However, the law is explicit about the very limited authorized uses of this database and this was not one.

In light of DHS statements that patient identification will be difficult and providers will be advised a PDMP record is based on a probabilistic match (meaning it may contain information about more than one individual), DHS should not be advancing use of a database that is not only *not* authorized but will exacerbate release of patient misidentification.

[1] This report states it is the final document prepared by DHS for legislative review in 2010 but we are under the impression there may be a revised report provided.

2. Providers Will Get Information on Non-Patients
DHS has reported that the database will misidentify patients:

> "Providers will be provided with a warning that linked records are based on probability, and therefore may not pertain to the patient in question. Information from the system is intended to help inform healthcare decisions and should not be used exclusively. . . Providers will be cautioned that records are matched using probabilistic linking methods and that they should not base treatment decisions solely on PDMP data" (pages 86 & 87).

DHS provides a record matching table to show how two records *"are probably the same consumer."* Except, DHS's example actually does *the opposite*.

Record 1 is: Robert Smith; DOB 1/21/1970; Address 123 Main; Physician: Dr. Williams
Record 2 is: Bob Smith; DOB 1/21/1970; Address 1223 SW Main; Physician: Dr. Jones

The expectation that private personal medical information of a non-patient will be released is contrary to good public policy.

3. Role of Pharmacy in Using PDMP
SB 355 allows pharmacies to access and obtain records on all customers. DHS is silent on the pharmacy/customer relationship and the risks to customers accessing medication through their pharmacy in a timely manner because of a probabilistic match or proactive notification by DHS.[2]

What happens when a pharmacist receives a PDMP report that raises concerns because it was a probabilistic match and contains inaccurate information on the actual patient seeking a prescription fill? A pharmacy may have no time or resources to contact DHS or the vendor and wait for clarification of any questions about a report. It's reasonable to expect that if the pharmacy has any questions or concerns, it may deny the customer the required medication (under SB 355 the only time pharmacist cannot refuse to fill based on the PDMP is if the system is down).

Another risk is that the pharmacies armed with information they do not know is inaccurate, may suspect a customer of criminal activity. SB 355 does not prevent the pharmacist (or provider) from contacting law enforcement.

4. Patient Access to Report
SB 355 authorizes patients to access a copy of their PDMP "report." However, DHS is planning only providing prescription information to patients and *not* information on which providers and pharmacies have requested access to a patient's report (Appendix G, Page 10).

[2] It appears that DHS may not intend to send automated notifications to pharmacies, but does not state either way.

With 20,000 authorized users and 10 million prescriptions to be databased a year, auditing who is using the system and assurances that it is being used appropriately is a significant issue. In fact, about 80% of data breaches (misuse) are by those authorized to access the system, which means the risks are very high with this database in light of the large number of authorized users.

The one proactive way patients can take steps to protect themselves is to obtain a copy of their report *that includes the names and dates of anyone who has sought or obtained a copy of that patient's report*.[3] Patient copies of their own records should include all these details.

DHS recognizes the risk to patient misidentification. With providers it's a probabilistic match that will contain non-patient information but with patients, DHS expresses significant concerns about matching problems. With patient access DHS intends to operate the system in a very different manner than with provider access.

> "Due to the lack of a unique identifier (i.e. social security number) collected by the PDMP system, a patient's records must be probabilistically linked where multiple similar records are present in the database (e.g. same name and DOB, different address between two records). *Patients will only be provided with records that exactly match the authenticated request identifying information (i.e. name, DOB, address) to prevent the potential disclosure of another patient's records*" (page 27).

Why is the concern about the very high risk of releasing personal patient medical information only at issue when patients request their own PDMP record, but not when a pharmacist or provider requests a report. For patients to understand any problems arising with their record, patients need to see what the provider and pharmacist are seeing.

5. Correcting Mistakes in the PDMP Database

SB 355 authorizes patients to request corrections to their PDMP records. DHS does not intend to allow for corrections to database errors. It states that it cannot change that information because it is proprietary pharmacy data which is considered the "gold standard" (definitive) source data of prescription dispensation records (page 12).

However, DHS also states in the same report "It is true that consumers may find errors in their pharmacy records and across Oregon consumers engage in efforts to correct their pharmacy record. *The Oregon Board of Pharmacy reports that consumer complaints about erroneous pharmacy records are a known problem*" (page 88).

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[3] Because SB 355 is written *so broadly* as to allow a pharmacist to obtain a report on *any* customer (and provider on *any* patient), the role of patient oversight is even more critical. **(Again, we urge that the law be constrained to "*about to* prescribe or sell schedule II, III or IV" as the sole trigger for authorizing a report and to remove pharmacy access to the database entirely.)**

It's hard to reconcile these apparent contradictions. It seems evident that the pharmacy records of patients in Oregon are not up to the "gold standard" and it's fair to assume that another database with ten million prescriptions a year based on name, DOB, address will only exacerbate this problem.

6. Patient Will Not Receive Meaningful Notification of the PDMP System

SB 355 requires patients to be notified prior to entry into the database program. Unfortunately, DHS plans notification through generic signage at the pharmacy, not through providers.

> "DHS will work with the Board of Pharmacy to include information about PDMP in Board of Pharmacy patient information *that is currently required to be displayed at pharmacies where patients can clearly see it prior to dispensation of a drug*" (page 20).

Relying on a pharmacy posting does not provide meaningful or timely notice under SB 355.

7. Patient Appeal Process: Knowing their Rights

SB 355 authorizes patients to appeal the content of their PDMP record if they identify a mistake. While DHS notes the rights of patients to appeal the content of their report as authorized from SB 355, DHS never discusses ensuring that patients *know* their rights. Having the right to challenge a record and a subsequent right to an administrative hearing are different from knowing about those rights.

Patients should be given a detailed explanation of their rights in writing on how to request a PDMP report, how to contest any information in the report and how to seek an administrative hearing. This should happen when they receive a prescription that will be entered into the PDMP database.

8. Patient's Access to Report Requires Notarization

SB 355 requires DHS to provide copies of patients' PDMP report at no cost. DHS is going to require an individual to submit a notarized request form *along with* a copy of photo identification for a patient to access a copy of their own PDMP report. While we appreciate the concern about ensuring protection of this data, adding the notary requirement provides a significant burden on the patient that does not seem necessary. If a person provides a form requesting his or her report *along with* a copy of his or her driver license (which also has address), there should be sufficient safeguards that the person who is requesting the report is the actual patient.

The notarization requirement for a patient to obtain a copy of their PDMP report should be removed.