Sharing and Using Immunization Registry Data

With most states now having an operable registry to record patient immunizations, one question that often arises is who may use or access the data stored in the registry. Although the information included in a registry varies by state, generally data will include the patient's name (first, middle and last); date of birth; gender; address, including zip code; mother's maiden name; mother's or other responsible party's name (first, middle and last, including maiden name); and vaccine administration date, type, lot number, and manufacturer.

The sharing and use of information kept in a state's vaccine registry (typically called an immunization information system (IIS)) is governed by state law. In general, personally identifiable data stored in a vaccine registry is confidential and may not be disclosed through public records requests. However, because immunization registry data is useful to many different entities for a variety of purposes, many states do permit specified individuals, businesses, and agencies to access immunization registry data. Health care providers use registry data to determine what vaccinations a patient has had and what vaccinations are needed. Schools, daycare centers, and camps use registry data to ensure that students have the proper vaccinations before entering these facilities. Health insurers may want to access registry data to verify services or to provide alerts to their insureds that vaccinations are due or missing. Researchers use vaccine registries as data sources for health care and public health-related research. And public health agencies, which typically administer a state's IIS, use the data for many different activities, such as monitoring vaccine coverage rates and keeping track of the use and supply of publically-funded vaccines.

The extent to which a third party has access to registry data also varies by state based on who is requesting the data and how the data will be used. In some states, access to a registry database may be limited to looking up specific patient names to verify immunization status rather than having access to the entire database. When used for research, registry data may be made available in aggregate form without providing any personally identifiable information to the researcher.

Once data in an immunization registry has been shared with a third-party, state law generally provides that patient information retrieved from the IIS remain confidential and not subject to further disclosure without patient consent. Many states impose penalties, ranging from fines to administrative and criminal sanctions, for improper disclosure and re-disclosure of vaccine registry data.

For more information on immunization information registries, see our Myth Busters here: http://www.healthinfolaw.org/article/myth-buster-health-care-providers-must-vaccination-registry and http://www.healthinfolaw.org/article/myth-buster-health-care-providers-must-obtain-parent-consent-under-hipaa-share-child-vaccina

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