



CPDR

California **Parkinson's** Disease Registry

Frequently Asked Questions

Health Insurance Portability & Accountability (HIPAA)

1. What is the HIPAA Privacy Rule?

In 1996 the U.S. Congress passed a law requiring, among other things, uniform federal privacy protections for individually identifiable health information. This law is called the Health Insurance Portability and Accountability Act of 1996, or "HIPAA." The U.S. Department of Health and Human Services issued final regulations implementing the privacy provisions of HIPAA. These regulations are called the "Privacy Rule." Copies of the HIPAA Privacy Rule, as well as helpful explanatory materials, may be found at the HHS Office of Civil Rights website: <http://www.hhs.gov/ocr/hipaa>.

2. Is it a violation of HIPAA for a covered entity to report information about cases of Parkinson's disease to CPDR?

No. Reporting information about cases of Parkinson's disease in accordance with the requirements of the CDPH authorizing statute and regulations is permitted by HIPAA. The Privacy Rule contains a specific provision authorizing covered entities to disclose protected health information as required by law. See 45 CFR sec. 164.512(a)(1). (Note: Covered entities include health plans, health care clearinghouses and health care providers who conduct certain financial and administrative transactions electronically. These electronic transactions are those for which standards have been adopted by the Secretary under HIPAA, such as electronic billing and fund transfers. More information on covered entities can be found at the HHS website: http://www.hhs.gov/ocr/privacy/hipaa/faq/covered_entities/)

3. Does HIPAA require covered entities to obtain written authorization from the individual before reporting protected health information to CPDR?

No. The provision of the Privacy Rule authorizing disclosure of protected health information as required by law is an exception to the requirement for written authorization. See 45 CFR sec. 164.512(a)(1).

4. Are covered entities required to determine whether the information about cases of Parkinson's disease reported to CPDR is the "minimum necessary" information required to be disclosed?

No. The Privacy Rule does include a general requirement that covered entities make reasonable efforts to limit the disclosure of protected health information to the minimum necessary to accomplish the intended purpose of the disclosure. See 45 CFR sec. 164.502(b)(1). However, there is a specific exception to this requirement for disclosers that are required by law, such as the reporting of information about cases of Parkinson's disease to the CPDR pursuant to California law and regulations. See 45 CFR sec. 164.502(b)(2)(v).

Find more information at:
www.cdph.ca.gov/parkinsons

Email us at:
CPDRhelp@cdph.ca.gov



5. Does HIPAA apply to the use or disclosure of information about Parkinson’s disease cases after it has been reported to CPDR?

No. The Privacy Rule applies to disclosure of protected health information by covered entities as required by law. It does not apply to subsequent use or disclosure by the recipient. However, CPDR authorizing legislation includes strict limits on use and disclosure of reported information. Those requirements include obtaining a federally designated Institutional Review Board approval, and contractual agreements to maintain confidentiality and privacy of the data and to not disclose confidential information beyond the confines of the specific research project. See California Health & Safety Code sec. 103870.1. When a researcher contacts a patient, they are required to inform the patient of how they obtained the patient’s name, that the patient is under no obligation to participate in the study, that their participation or non-participation will not be reported to anyone, and that they may request that no one contact them again. Occasionally a patient will object to having their name released without prior consent, and CPDR has methods to restrict those names from future contacts. But many patients are happy to participate in special studies in order that we may learn more about diseases to better prevent and treat them. CPDR was created to serve as a resource for research about Parkinson’s disease. The CDPH has a long history of collecting confidential data and using it for research that saves lives.

6. Are covered entities required to provide individuals upon request with an accounting of any protected health information that the entity has disclosed about them to the CPDR?

Yes. The Privacy Rule requires covered entities to provide an accounting of disclosures of protected health information. See 45 CFR sec. 164.528.

7. Does HIPAA require covered entities to obtain written authorization from the individual before reporting protected health information to CPDR?

No. The provision of the Privacy Rule authorizing disclosure of protected health information as required by law is an exception to the requirement for written authorization. See 45 CFR sec. 164.512(a)(1).