NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES

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FREQUENTLY ASKED QUESTIONS AND ANSWERS ABOUT HIPAA REGARDING CANCER REPORTING

1. When does HIPAA become effective?

The regulations were approved by President Bush on April 12, 2001. The official effective date of the regulations is April 14, 2001. Covered entities, including hospitals and physicians, have two (2) years to comply (by April 14, 2003), except for small health plans which have until April 14, 2004 to comply.

2. What is a 'Public Health Authority' under HIPAA?

Under HIPAA, a 'Public Health Authority' refers to "an agency or authority of the United States, a State or territory, a political subdivision of a State or territory, or an Indian tribe, or a person or entity acting under a grant of authority from or contract with such public agency, including the employees or agents of such public agency or its contractors or persons or entities to whom it has granted authority, that is responsible for public health matters as part of its official mandate."[1] "...Such agencies are authorized by law to collect or receive such information for the purposes of preventing or controlling disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions."[2] ***Central cancer registries and hospital cancer registries if required to report cancer cases*** are considered public health authorities because their duties are mandated by state laws.

[1] C.F.R. 164.501
[2] C.F.R. 164.512

3. What is a 'Covered Entity' under HIPAA?

A 'Covered Entity' is a health care plan, a healthcare clearinghouse, or a health care provider who transmits any health information in electronic form for financial and administrative transactions. A 'health care provider' is "a provider of medical or health services, and any other person who furnishes, bills or is paid for health care in the normal course of business."[1]

[1] C.F.R. 160.103

Sponsoring Organizations: *American Cancer Society – American College of Surgeons – American Joint Committee on Cancer*
Health Canada – Centers for Disease Control and Prevention –National Cancer Institute – National Cancer Reaistrars Association – Statistics Canada

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4. What if a patient does not want follow–up information to be collected?

State-mandated cancer reporting typically does not require patient informed consent nor can individuals elect to be removed from reporting. In a state which allows the collection of follow–up cancer data for public health purposes, it can be collected regardless of consent from a patient.

5. Will private practice physicians be permitted to continue to provide follow-up information to hospital cancer registries without patient consent?

Yes. Although private practice physicians are *health providers*, and thus covered under the provisions of the HIPAA privacy regulations,[2] there are several reasons why they can continue to provide follow-up information to hospital cancer registries without patient consent. First, the hospital cancer registry is likely to be viewed as a public health authority[1] because it is an entity acting under a grant of authority from or contract with a State, tribal, or local public health agency to provide for public health surveillance.[1]

The HIPAA regulations specify that covered entities may use or disclose protected health information without the written consent or authorization of the individual …" under specific circumstances. These include disclosures for public health activities and purposes to public health authorities authorized by law to collect or receive such information for the purpose of preventing or controlling disease or conduct public health surveillance.[3]

As public health authorities, hospital cancer registries are exempt from the HIPAA regulations and may continue to seek public health data from providers the same as before the HIPAA regulations were finalized. DHHS did not attempt to interfere with state and local public health matters such as cancer surveillance through the implementation of these regulations.

Second, even if some hospital cancer registries are not public health authorities (because they are not associated with a state or local public health agency to work on public health matters), physicians may still have to provide follo-up information. HIPAA regulation Sec. 162-512(a) specifically states that:

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> A covered entity may use or disclose protected health information to the extent that such use or disclosure is required by law and the use or disclosure complies with and is limited to the relevant requirements of such law.

Thus, where a hospital cancer registry is required by state or local law to collect cancer data, physicians must follow the follow-up requirements of the registry to the exclusion of HIPAA privacy protections.

Finally, the consent requirements for disclosures under the HIPAA regulations does not limit the types of disclosures allowed. Provided a patient consents to the use or disclosure of his or her health data to a hospital cancer registry as part of a broader consent language, regularly sharing data between physicians and hospital cancer registries is permissible. In future cases, patient consents may specifically reference the sharing of data with all hospital cancer registries. For existing cases, written patient consent may also suffice for the purposes of authorizing these exchanges.

[1] 45 C.F.R. 164.501
[2] 45 C.F.R. 160.103
[3] 45 C.F.R. 164.512

6. How does HIPAA impact the data collection of non–reportable/benign diseases (i.e. benign brain, CIN III, Co-morbid conditions)?

HIPAA does not obstruct any state law that supports or mandates the reporting of such cases.

7. Are private practice physicians still required to report new cancer cases?

Yes, in compliance with state reporting regulations. The central cancer registry has a reportable list that identifies which cancers are reportable, and all reportable cancers should be reported, as required by state law.

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8. Is there specific legal documentation that supports the requirement to release cancer patient information to any agency?

Individual state laws and regulations document cancer reporting requirements. Central registries should be able to provide copies of their state's law(s) and regulation(s) upon request.

9. What, if any, are the consequences of not cooperating with state cancer registry requests for new cancer case information?

HIPAA does not obstruct any state law that supports or mandates the reporting of diseases or injury for public health purposes. Penalties for failing to comply with state reporting are specified in the state law and often consist of significant fines.

10. Doesn't HIPAA nullify the state law for reporting cancer cases to central cancer registries?

No. Public health reporting under the authority of state law is specifically exempted from HIPAA rules.

11. Once HIPAA is in place, will pathology labs be able to continue to send new cancer case information to the state cancer registry?

Yes. Public health reporting under the authority of state law is specifically exempted from HIPAA rules

12. Since HIPAA is federal, will it override the state laws?

No. HIPAA does not obstruct any state law that supports or mandates the reporting of diseases or injury for public health purposes.

13. If the government–authorized public health entity is not located in the same state as the covered entity, is it still ok under HIPAA to provide the data?

Yes. In fact, the definition of a 'public health entity' was broadened in the section "Uses and Disclosures for Public Health Activities", which states specifically "…We broaden the scope of allowable disclosures …by allowing covered entities to disclose protected health information not only to U.S. public health authorities but also, at the direction of a public health authority, to an official of a foreign government agency that is acting in collaboration with a public health authority."[1,2]

[1] F.R. p. 82525
[2] 45 C.F.R. 164.512