

September 24, 2001

Dear NAACCR Colleagues:

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) became law April 14, 2001. While most organizations have two years – until April 14, 2003 – to comply, questions regarding how this new law impacts cancer reporting have arisen.

On behalf of its membership, NAACCR has developed materials to assist Central cancer registries and cancer reporting entities in assuring compliance with HIPAA regulations. These include a letter from the NAACCR legal counsel and an in-depth, academic interpretation of the impact of this legislation on cancer incidence reporting to central cancer registries.

To summarize, HIPAA has very little impact on cancer reporting to central cancer registries. Specifically, HIPAA provides for the continuation of reporting identifiable data for reportable diseases to public health entities for the purpose of public health surveillance. Additionally, HIPAA does not obstruct any state law that supports or mandates the reporting of disease or injury for public health purposes. Written informed consent from each cancer patient reported to public health entities is not required under HIPAA; rather hospitals must document that reporting has occurred. This can be done simply for all cancer cases since reporting is mandatory for all cases.

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In an effort to help you respond to questions from hospital cancer registries and other cancer reporting entities, we have compiled a packet of information for your use. This packet contains:

- (1) An academic interpretation of HIPAA legislation as it relates to the reporting of cancer incidence;
- (2) A letter from NAACCR legal counsel;
- (3) A sample letter that you could send to hospitals that explains, in brief, the impact of HIPAA on cancer reporting, and
- (4) A question and answer document (reviewed by legal counsel) that provides answers to frequently asked questions regarding this issue.

We hope these materials increase your understanding of the HIPAA requirements with regard to cancer incidence reporting. Please direct additional questions or comments to the undersigned at ddeapen@hsc.usc.edu or to Dr. Rachel Jean-Baptiste at the NAACCR Executive Office at rjeanbap@naaccr.org.

Sincerely,

A handwritten signature in black ink that reads "Dennis Deapen". The signature is written in a cursive, flowing style.

Dennis Deapen, DrPH
Chair
NAACCR Data Confidentiality Committee

Enclosures:

1. Academic letter interpreting HIPAA
2. Legal letter interpreting HIPAA
3. Model letter from central registry to reporting facility regarding HIPAA
4. FAQ's and answers regarding HIPAA and cancer reporting