EMERGING ISSUES IN GLOBAL AIDS POLICY: PRESERVING PRIVACY

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I. WILL HIPAA’S PRIVACY AND SECURITY RULES ADEQUATELY PROTECT AIDS/HIV PATIENTS? A COMPARISON OF U.S. AND EUROPEAN DATA PROTECTION LAWS

In this Twenty-second Annual International Health Law Symposium, we are focusing on AIDS/HIV patients worldwide—where we have been, and what can be done to improve the condition of these individuals and their families. Healthcare is at the top of many AIDS/HIV patients’ concerns. Proper care is vital; no mistakes are permitted—it is a life or death issue. Anything relating to their medical condition or their treatment is very precious and particularly sensitive. Central to their healthcare is the information kept in medical files—symptoms, lab results, reactions to drugs, trials, and failures with treatment. This information must be comprehensive, detailed, complete, accurate and always available to ensure proper adapted care. Improper, erroneous or missing information could cause misdiagnosis or inadequate treatment. Any modification or removal of information from the medical records could have dramatic and severe consequences. Assuring and ensuring the availability and integrity of the information requires adequate privacy and security measures.

The medical files of AIDS/HIV patients also contain the diagnosis—the AIDS/HIV status. This information is news over which, legitimately, AIDS/HIV patients want to maintain total control. They need, and want, to be able to share the information with whom they want, and when they want. Any unwanted access to, or disclosure of, their medical records could trigger rejection from their family and friends, loss of employment or clients, loss of income, discrimination, quarantine and the like. AIDS/HIV patients need to ensure that their medical information will receive adequate privacy and security protection.

It is critical, therefore, that personally identifiable health information (PHI) of AIDS/HIV patients receive the utmost attention and care. Healthcare providers, insurance companies, and others must ensure that this information is not disclosed, accessed, used or modified by third parties except for the small number of physicians, nurses, and payors who need the information to perform their respective healthcare related functions.

Recent efforts to enact privacy and security laws and regulations that protect healthcare information are helping shape an environment that is more sensitive to patients needs.1 However, much remains to be done to achieve a satisfactory level of protection. European data protection laws, for example, appear to

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1. See e.g. Lawrence O. Gostin, James G. Hodge, Jr. & Lauren Marks, The Nationalization of Health Information Privacy Protections, 37 Tort & Ins. L.J. 1113 (2002).
I will analyze selected U.S. data protection laws that apply to the protection of the privacy and security of AIDS/HIV patients’ medical information, and compare them to similar laws in the European Union. It concludes that while there has been much progress in the recent years, U.S. laws provide patients—including AIDS/HIV patients—with less protection and personal rights than that which are available to individuals under the equivalent EU laws.