Research recruitment through cancer registries: Stakeholder perspectives

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Abstract: Heralded by the passage of the Health Insurance Portability and Accountability Act (HIPAA), the pendulum is swinging toward increasing regulation and scrutiny of research involving human participants. At the same time, the potential to learn more about cancer and other common diseases through epidemiologic, genetic, and other kinds of research has never been so great. Because cancer registries provide a population-based roster of newly diagnosed cancer cases, they can be an invaluable and efficient resource for identifying and recruiting participants for research studies. Policies for research recruitment are not uniform across registries, however, and there are insufficient data about the ethical and scientific acceptability of various approaches to research recruitment. How individual states are interpreting HIPAA with respect to registry recruitment protocols and the subsequent impact on research recruitment are similarly unknown.

This study examines, from several stakeholder perspectives, the scientific and ethical issues arising in the use of cancer registries to recruit participants for observational epidemiologic research. Specifically, it addresses the following research questions: (1) What are U.S. central cancer registries' policies and procedures for contacting patients for research purposes? (2) What are patients' levels of awareness and preferences about research recruitment through cancer registries? (3) How do physicians respond when investigators inquire about contacting patients identified through the cancer registry?

A major challenge in any research recruitment strategy is to provide appropriate privacy protections while promoting sufficient recruitment to achieve scientific goals. Although HIPAA itself does not preempt state laws and regulations that mandate disease reporting or govern release of information from cancer registries, it has long been recognized that patients have a right to have personal medical information kept private. At the same time, in the hands of researchers, such information can produce invaluable benefit. Elucidating the perspectives of registries, patients, and physicians with regard to research recruitment is intended to aid in the development of balanced recruitment approaches that protect patient privacy as well as encourage beneficial research. Investigators are another key stakeholder and understanding their experiences and perspectives is an important area for future research.

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