



CLEAR challenge: Translating research into practice

Rules governing the use of health information are “horribly out of date,” according to Fred H. Cate, Indiana University law professor and one of four co-directors of the recently launched Center for Law, Ethics and Applied Research in Health Information (CLEAR).

With tools available to collect and transmit health information at warp speed, the world “is almost drowning in data,” says Cate (above right). Yet most laws predate current technology and were enacted at a time when personal health information “flowed between a doctor, a patient and nobody else.”

Supported by a \$4 million Lilly Endowment grant, CLEAR focuses on the practical uses of health data. The issues that Cate and his colleagues will study are complex but their goals are straightforward. They will work to ensure the accuracy, availability, confidentiality and ethical application

of health information. Likely beneficiaries of their efforts include legislators, who need to understand the implications of privacy rules that are too restrictive or too permissive; patients, who experience better outcomes when their doctors have access to the right data at the right time; and researchers, who rely on health data to guide them as they develop new products and treatments.

“Our interest is not simply in producing scholarly papers for publication,” says Eric M. Meslin (left), a bioethicist, CLEAR co-director and former executive director of the National Bioethics Advisory



Eric Meslin (left), director of the IU Center for Bioethics at the IU School of Medicine, and **Fred Cate, director of the IU Center for Applied Cybersecurity Research and distinguished professor at the IU Maurer School of Law**, are two of the four-member CLEAR team. They will sort through the myriad issues surrounding the practical uses of health data.

Commission. Recruited to Indiana University in 2001 with funding from the Endowment's \$155 million INGEN grants, he maintains that "the way valuable health data are collected, stored, studied and used will be among the most important challenges for the life sciences industry. We want to put our efforts behind translating knowledge into practice and testing how these issues will be applied in real time here in Indiana. The work of CLEAR is vital to the life sciences research efforts in Indiana and throughout the nation."

To discourage CLEAR researchers from pursuing projects that may lack relevance – a "natural tendency" in the academic world, says Cate – the center has assembled an off-campus stakeholders committee: patient representatives and government officials, employees of health-care institutions and information technology companies. "They won't make decisions," explains Cate, "but they'll tell us if

other researchers are working on the same issue, if a project isn't of sufficient interest, or if they have ideas that we haven't considered."

Both Cate and Meslin believe that CLEAR's interdisciplinary approach to research sets it apart from centers at other universities. The four co-directors bring different points of view and a range of skills to the table. Cate directs the IU Center for Applied Cybersecurity Research; Meslin directs the IU Center for Bioethics; Kay Connelly is a professor in the IU School of Informatics and Computing; and Stanley Crosley is founder of the International Pharmaceutical Privacy Consortium. Part of the leadership team is based in Bloomington and part is on the IUPUI campus in Indianapolis.

"In many ways this is a virtual institute because there isn't a building that says 'CLEAR' on it," says Meslin. "Our view is more about getting the work done than about bricks and mortar. We don't see geography as an impediment."

When they aren't meeting face to face, the directors are on the phone or trading e-mails. An early priority has been to identify two or three issues that they will research collaboratively. Considering the criteria for selection, they agreed that the projects should have the potential to:

- benefit patients, providers and the public
- break new ground and not duplicate prior work
- attract the participation of additional partners
- draw on more than one area of CLEAR's expertise

"The process is well under way," says Cate, who has helped narrow the field of possible projects to a dozen. He describes them all as "complex and intrinsically interdisciplinary," attributes that make them strong candidates for scrutiny. "Lawyers alone can't solve them; ethicists alone can't solve them. It's only at the intersection of law and ethics and medicine and technology that we're really going to make a difference."