NIH Kills Deal to Upgrade Heart Data

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BOSTON—What was heralded as a new model of public-private collaboration in medical research suffered a surprise reversal last week. A controversial plan to use private capital to upgrade a valuable public database collapsed amid concerns that it would cede too much control to a for-profit company. Boston University (BU), which runs the venerable Framingham Heart Study, and the National Institutes of Health (NIH), which funds the 52-year-old effort, instead will try to put together a nonprofit consortium in the coming year to modernize the massive database.

The decision, announced in a 26 December joint letter to the study participants, deals a mortal blow to Framingham Genomic Medicine Inc. of Framingham, Massachusetts, which was raising money to organize, digitize, and analyze the Framingham data. The company planned to repackage and sell data to the pharmaceutical industry (Science, 30 June 2000, p. 2301). The NIH decision also is a disappointment to BU, which was instrumental in forming the company. But the participants knew it would be risky: "There just wasn't a precedent for doing this," says Aram Chobanian, dean of BU's medical school.

The study has monitored the health of more than 10,000 people in the small town of Framingham during the last half-century, and it offers a treasure trove of data for researchers. But much of it is stored in boxes or file cabinets. NIH has been reluctant to put up the millions of dollars needed to update and upgrade the database, so BU hit upon the idea of getting a private company to do it instead. Its proposal, announced to the Framingham participants in April, raised tough ethical issues, ranging from questions about how outside scientists would get access to the revamped data to whether personal medical data collected with public money should be sold to private companies.

Ultimately, negotiations between BU and the National Heart, Lung, and Blood Institute foundered on how to balance scientific access to the data with the company's proprietary interests. "BU was under some pressure from the company to reach an agreement which gave them close to exclusive access to the data," says Claude Lenfant, the institute director. "We could not go along with that." He says that the institute was willing to make concessions, such as giving the company exclusive rights to data for the first 2 years, but this proved insufficient. Company officials could not be reached for comment. "The rationale was good, but the methodology was not," says Jay Lander, a Framingham attorney and vice chair of Friends of Framingham Heart Study, which represents participants.

Now, the challenge is to find a new way to pay for the database. Lenfant envisions a cooperative agreement among companies, nonprofits, and other interested groups. He said he intends to draft a plan this year, after BU's contract to conduct the study is renewed in the next couple of months. But he insists that the raw data should be available to everyone, and that only refined data should be private property. Chobanian agrees that that approach is now the way to go. "It's a slower and less effective way," he adds, "but probably better in the long term."
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