The New York Times

Should You Worry About Being the Next Henrietta Lacks?

By Robert Klitzman, M.D.

April 21, 2017

Yesterday I had my yearly blood draw, my wrist and tube labels all bar coded with unique IDs. I first sat in a large laboratory waiting room with 25 others, waiting to be pricked. But I wondered if we should consider the fate of our blood. Would researchers use our specimens in other ways, without telling us? Would marketers or drug companies get the information? Could any of us become the next Henrietta Lacks?

Ms. Lacks, an African-American woman from Baltimore, was only 31 when she died of an unusually aggressive form of cervical cancer in 1951. Her doctor removed some of her cancer cells before her death and discovered they could reproduce on their own in petri dishes, making them "immortal." Since then, researchers have produced over 20 tons of those cells — called "HeLa cells" after her name — facilitating the development of new drugs and vaccines, aiding many millions of patients and earning biotech and pharmaceutical companies hundreds of millions of dollars in profits.

Yet Ms. Lacks never granted consent to use her cells, and her family shared in none of the profits.

A best-selling book published in 2010, followed by **a movie** that premieres Saturday on HBO starring Oprah Winfrey, has brought these events to wider attention among patients, doctors and policy makers.

One of the most common questions I have been asked as a bioethicist is: Should we worry about this kind of thing happening today?

The answer is complicated. With the advent of new and inexpensive genome sequencing in recent years, numerous companies, institutions and countries are establishing enormous biobanks, making this an issue of growing concern. In several years, your doctor and many others may have access to your entire genome.

Several things happened to Ms. Lacks: Her cells were taken without her consent for clinical reasons, and then used for research, and shared with countless other scientists. Her genes, and thus those shared by her family members, were published, in association with her name.

Since then, policies protecting research participants have addressed some of these issues. Some reforms grew out of revelations in the early 1970s about the Tuskegee Syphilis Study, in which poor African-American men with syphilis were followed by government researchers for 40 years, beginning in the early 1930s, but were neither told about penicillin nor offered it when it became available as a cure. Among the changes were new regulations that strengthen institutional review boards that oversee studies of human participants to ensure that the research is ethical.

However, these regulations still allow data, stripped of identifying details such as names and birth dates, to be given to other investigators without specific patient consent. Information from patients at multiple hospitals can then be pooled to assist in the development of new treatments.

Partly as a result of public outrage over Ms. Lacks, President Obama in 2015 proposed regulations requiring researchers to obtain consent from patients for future use of specimens collected for clinical purposes. Scientists currently examine millions of samples collected without such permission. Yet tracking such consent would be hard. Many companies and institutions thus argued that this requirement would stifle much research, and the administration dropped the proposal.

Increasingly, partly because of Ms. Lacks, many informed consent forms now state that patients won't receive any profits that their samples may yield. You can then decide if you want to participate in these studies or not.

Medical journal publishers have now established standards to protect patients' privacy in publishing genomes. Yet electronic health records make our personal medical information increasingly available to others. The DNA of each of us is unique, and if associated with just a few facts about us — such as our age and ZIP code — could uncover our identity using publicly available data. Unfortunately, genetic discrimination continues: Life and disability insurance companies can legally require genetic testing from individuals applying for insurance, and then deny coverage or raise premiums. So, you should remain careful about sharing your genetic information.

If you are asked to enter a research study, you may be given a 40-page consent form to read and sign, filled with complex scientific information that most patients don't understand. Researchers should simplify these forms to be comprehensible; but you should also feel free to ask questions, and ask if you can take the form home with you to show and discuss with family members or others. Many patients feel afraid or ashamed to ask, but they shouldn't be.

As doctors, patients and family members, we all should try to increase our understanding of science and underlying ethical tensions here — concerning how best to balance patients' privacy versus advances in science. Ideally, we can both protect patients and aid research.

I'm happy to have my blood help others. Most people in that waiting room would probably be, too. But to ensure that none of us becomes the next Henrietta Lacks, we should all proceed with care. Researchers, pharmaceutical companies, policy makers and others should also take stronger steps to protect the valuable gifts that patients, with enormous generosity, often contribute unknowingly: parts of their very bodies. Ms. Lacks's legacy endures not only in petri dishes, but in all of our lives.

Robert Klitzman, M.D., is a professor of psychiatry and the director of the Bioethics Masters & Online Course and Certificate Programs at Columbia University, and the author, most recently, of "The Ethics Police?: The Struggle to Make Human Research Safe."