

# The Henrietta Lacks legacy grows

Henry T. Greely & Mildred K. Cho

On 7 August 2013, the US National Institutes of Health (NIH) announced that it had reached an agreement with the descendants of Henrietta Lacks concerning NIH-funded uses of the HeLa cell line [1], which, over the past 60 years has been featured in tens of thousands of experiments all over the world, and even in outer space.

The origin of these cells, although never a secret, did not become well known until the 2010 publication of Rebecca Skloot's book *The Immortal Life of Henrietta Lacks*. As was the practice of the time, Henrietta Lacks was not asked for permission to use samples of her tumour for research. For several decades, her family knew nothing about the HeLa cell line or its genetic tie to Henrietta Lacks—and to themselves. Henrietta Lacks's contribution was little recognized and her family received no benefits from the widespread use of the cell line.

On 11 March 2013, a team of researchers from The European Molecular Biology Laboratory (EMBL), led by Lars Steinmetz, published an article about the genomic characteristics of the one strain of the HeLa cell line [2]. Following current practice, they posted the whole genome sequence online, intending for it to serve as a resource to help other researchers; they did not intend or expect to set off an ethical controversy.

But they did. Articles in the scientific press raised questions about publishing the genome sequence of the HeLa cell line [3], because although it had mutated enormously over the past 60 years, the data did provide some genomic information about Henrietta Lacks and, probabilistically, about her living descendants. As a result, Rebecca Skloot, on behalf of the Lacks family, raised concerns about their privacy.

In the meantime, although the EMBL team had followed existing laws and regulations in its use of the HeLa samples, it responded to the controversy. The authors wrote to the Lacks family through Rebecca Skloot, apologizing for any distress the publication had caused, removed the sequence data from the internet, and offered to work with the family to find ways to make this potentially scientifically valuable information available while protecting the family's interests and acknowledging Henrietta

Lacks's crucial role. At Steinmetz's request, we conducted a bench-side ethics consult and provided some advice to the team as it strove to deal with this situation.

The 7 August agreement between the NIH and the Lacks family resulted from discussions between Francis Collins and family members. It requires that any HeLa genomic information from NIH-associated studies be deposited in NIH's 'database of genotypes and phenotypes' (dbGaP). A HeLa Genome Data Access Working Group made up of three scientists, two members of the Lacks family and one bioethicist will review requests to use the data, making recommendations to the Advisory Committee to the Director, and ultimately to the NIH Director. All publications that have used the data must include a specific acknowledgement of Henrietta Lacks and her family.

This compromise is a reasonable resolution to an unusually extreme example of the increasing conflict between researchers' need for broad availability of data (and samples) and legitimate privacy and autonomy interests of the people who are the sources of biological research materials and data. Unlike most research in recent decades, until this agreement, no one ever gave any permission for Henrietta Lacks' tumour cells to be used for research. And the source of the HeLa cells is not only identifiable, but famous.

However, the agreement is not completely enforceable. The Director of the NIH only has power over the NIH and the work it funds. We hope researchers not funded by NIH will abide by the agreement, both out of respect for the Lacks family and to help build trust among millions of other research subjects, but this cannot be guaranteed.

A bigger issue is the many other human samples and data sets that are broadly accessible to researchers and sometimes the public. Some come with no consent, some have some consent, but few have actual and honest informed consent to be used for any purpose by any researchers or for data to be publicly available online. And although most are stripped of individual identifiers, that is cold comfort in an era of common breaches of data confidentiality and the use of other data sets to re-identify 'anonymized' data and samples [4].

We cannot set up new administrative committees for every set of human data or biological samples. What we can do—and must do—is to make sure that, going forward, donors have knowingly made clear how they can, and cannot, be used. In addition, we must acknowledge that genomic information is no longer truly anonymous. These changes will require new understandings between researchers and research participants. The HeLa agreement provides a way to resolve that dilemma in an exceptional case; we now need to manage that conflict in common cases.

One last note. Steinmetz and the EMBL group apologized to the Lacks family and took down the genomic data whilst a resolution could be explored. Jay Shendure and his group agreed to hold up publication of their similar paper [5] for the same end. The NIH seriously reached out to the family to make an agreement happen. And the Lacks family agreed. We think these acts—of consideration, patience and understanding, acknowledging and respecting the important role of research donors and participants—show an understanding of the underlying interests that researchers and research participants share. That all sides could find common ground in this most extraordinary case is perhaps the best result, and lesson, of the controversy.

#### CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

#### REFERENCES

1. Hudson KL, Collins FS (2013) *Nature* **500**: 141–142
2. Landry JL *et al* (2013) *G3 (Bethesda)* **3**: 1213–1224
3. Calloway E (2013) *Nature* [Epub ahead of print] doi:10.1038/nature.2013.12609
4. Rodriguez LL *et al* (2013) *Science* **339**: 275–276
5. Adey A *et al* (2013) *Nature* **500**: 207–211

**Henry T. Greely is the Director, Centre for Law and the Biosciences, Stanford University, Stanford, California, USA. Mildred K. Cho is Professor of Paediatrics, Division of Medical Genetics at the Stanford Centre for Biomedical Ethics, Stanford University School of Medicine, Stanford, California, USA. E-mail: micho@stanford.edu**

EMBO reports (2013) **14**, 849; published online 13 September 2013; doi:10.1038/embo.2013.148