

HeLa Genome Data Access Working Group

Report to the
Advisory Committee to the Director
December 9, 2022

Garth Graham, M.D., M.P.H.
Director and Global Head of Healthcare and
Public Health at Google/YouTube

Lyric Jorgenson, Ph.D.
Acting Associate Director for Science Policy
Acting Director of the Office of Science Policy
National Institutes of Health

The HeLa Genome Data Use Agreement

Per the agreement between NIH and the Lacks family, NIH is requesting that *all researchers*:

- Apply for access to HeLa whole genome sequence in the database of Genotype and Phenotype (dbGaP)
- Abide by terms outlined in the HeLa Genome Data Use Agreement, such as:
 - Data can only be used for biomedical research only; this does not include the study of population origins or ancestry
 - Requestors are not to make contact with the Lacks family
 - Requestors are to disclose any commercial plans
 - Requestors are to include an acknowledgment in publications and presentations
- Deposit future whole genome sequence data into dbGaP

HeLa Genome Data Access Working Group Roster

Garth Graham, M.D., M.P.H. (Co-Chair)

Director and Global Head of Healthcare and Public Health at
Google/YouTube

Lyric Jorgenson, Ph.D. (Co-Chair)

Acting Associate Director for Science Policy
Acting Director of the Office of Science Policy
National Institutes of Health

Russ B. Altman, M.D., Ph.D.

Professor, Bioengineering, Genetics, & Medicine
Director, Biomedical Informatics Training Program
Stanford University

Ruth Faden, Ph.D., M.P.H.

Philip Franklin Wagley Professor in Biomedical Ethics
Director, Johns Hopkins Berman Institute of Bioethics
Bloomberg School of Public Health
Johns Hopkins University

David Lacks, Jr.

Representative, Henrietta Lacks Family

Jeri Lacks-Whye

Representative, Henrietta Lacks Family

Richard M. Myers, Ph.D.

President, Director and Faculty Investigator
HudsonAlpha Institute for Biotechnology

Veronica Robinson

Representative, Henrietta Lacks Family

Working Group Evaluation Criteria

- Is the proposed research focused on health, medical, or biomedical research objectives?
 - Is the proposed research related to determining the ancestry or population origins of HeLa cells?
- Are there any plans to develop intellectual property?
Specifically:
 - Does the requestor anticipate or foresee IP or developing commercial products or services from the proposed research?
 - Has the requestor agreed to notify NIH if their plans for IP or commercial products change?
- Are there any plans to publish or present findings?

Status of Data Access Requests Since 2014

Number of Requests	Status
95	Evaluated by the HeLa Genome Data Access Working Group
88	Approved by NIH Director
1	Disapproved by NIH Director
5	Disapproved by NIH staff (requestors did not respond to requests for clarifications regarding publication plans, IP, and/or the non-technical summary)
Number of New Requests	Status
1	Being reported to ACD today

Working Group Findings: Evaluation of Access Requests

Since the last ACD meeting, the Working Group found 1 request to be consistent with the HeLa Genome Data Use Agreement

Project Title	Requestor's Affiliation	Project Overview	Working Group Findings
Assessing splice variants of RNA binding proteins	University of Kansas Medical Center	<ul style="list-style-type: none">• RNA-binding proteins (RBPs) participate in the processes that turn on or off the expression of genes in a cell important for biological processes. The requester is investigating one such biological process, inflammation, and how the location of where RBPs bind influences cellular inflammation.• Using HeLa cells, the requester identified unique locations where RBPs bind to mediate inflammation. The requester seeks access to the HeLa Cell Genome Sequencing studies to identify the precise location of where the RBPs bind to understand how the location may work together with the RBPs to control inflammation gene expression.	CONSISTENT WITH DATA USE AGREEMENT

ACD Discussion, Recommendation and Votes