

# HeLa Genome Data Access Working Group

## Report to the Advisory Committee to the Director

June 9, 2023

### **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

## **Lytic 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

<b>Number of Requests</b>	<b>Status</b>
<b>96</b>	Evaluated by the HeLa Genome Data Access Working Group
<b>89</b>	Approved by NIH Director
<b>1</b>	Disapproved by NIH Director
<b>5</b>	Disapproved by NIH staff (requestors did not respond to requests for clarifications regarding publication plans, IP, and/or the non-technical summary)
<b>Number of New Requests</b>	<b>Status</b>
<b>1</b>	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
Analysis of DNA sequence and methylation in cancer-derived DNA	University of Edinburgh, Edinburgh, United Kingdom	<ul style="list-style-type: none"><li>The investigator requests access to the HeLa Cell Genome Sequencing Studies to use as a reference to map genome sequences to cancer cell sequence data and participant cancer cell data. The mapping or comparing the HeLa Cell Genome Sequencing Studies to cancer cell sequence data and participant cancer cell data, will allow the investigator to detect and analyze DNA changes, like methylation.</li></ul>	CONSISTENT WITH DATA USE AGREEMENT

## ACD Discussion, Recommendation and Votes