An Overview of the NHGRI Office of Communications

The power of inclusive, fact-driven communications about genomics

Sarah Bates, Communications Director

September 2023

National Human Genome Research Institute

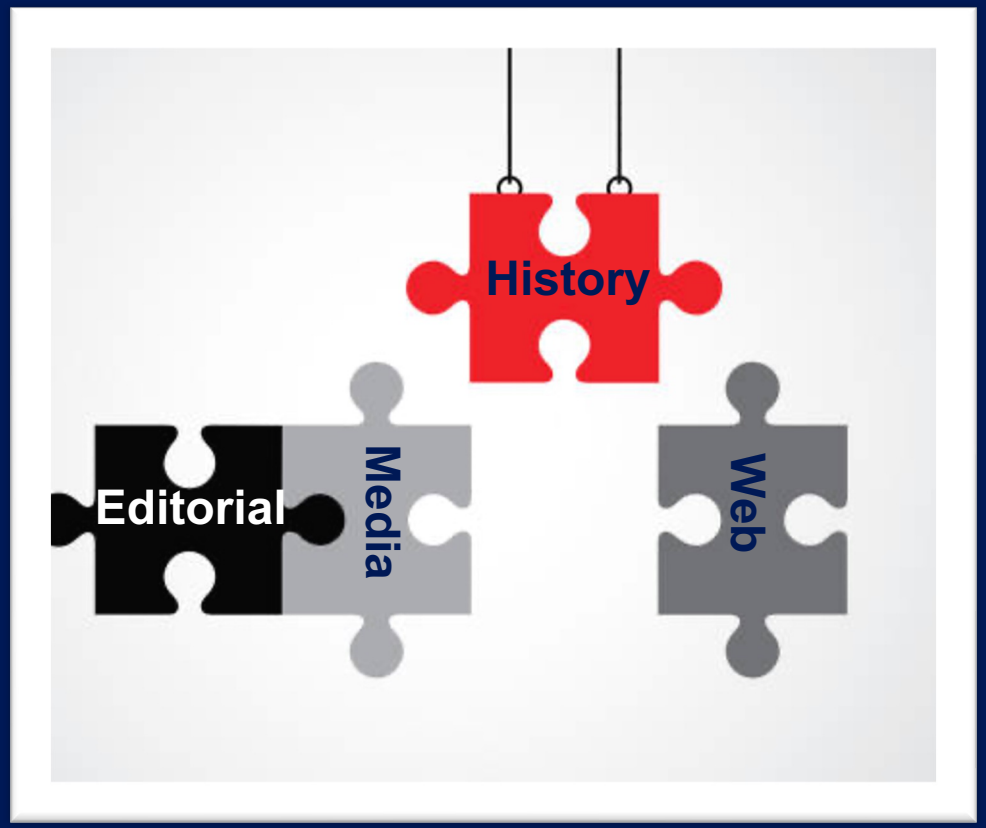
The Forefront of Genomics®

Guiding principles & values

- Communications is **integral to NHGRI strategy and operations**
- **Social, historical and ethical context** is critical
- **New tools and their changing uses** and audiences continue to alter the science communications landscape
- **Collaboration** between researchers and science communicators is vital

NIH NHGRI

Office of Communications



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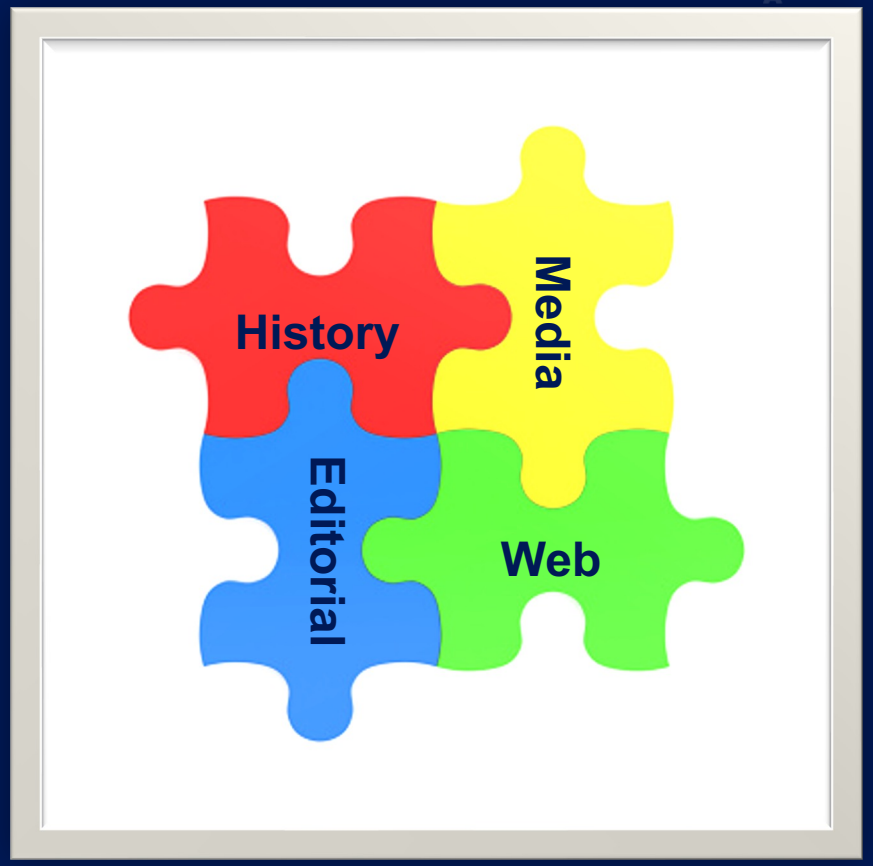

Now

NIH NHGRI

Outline

- Overview of the Office of Communications (15 mins)

  Sarah Bates, NHGRI

- History of Genomics Program (15 mins)

  Christopher Donohue, NHGRI

- Information Science Research Talk Based upon NHGRI Archive (15 mins)

  Spencer Hong & Thomas Stoeger, Northwestern

10 mins for Q&A

NHGRI Office of Communications

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Deputy Director

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Operations Coordinator

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Science Writer

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Alvaro Encinas
Videographer

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Zach Utz
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Nicola Sugden
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Midlevel Web Developer

Ellaha Sadat
Frontend Designer

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Lead Public Affairs Specialist

Jenn Montooth
Social Media Specialist

Mukul Nerurkar
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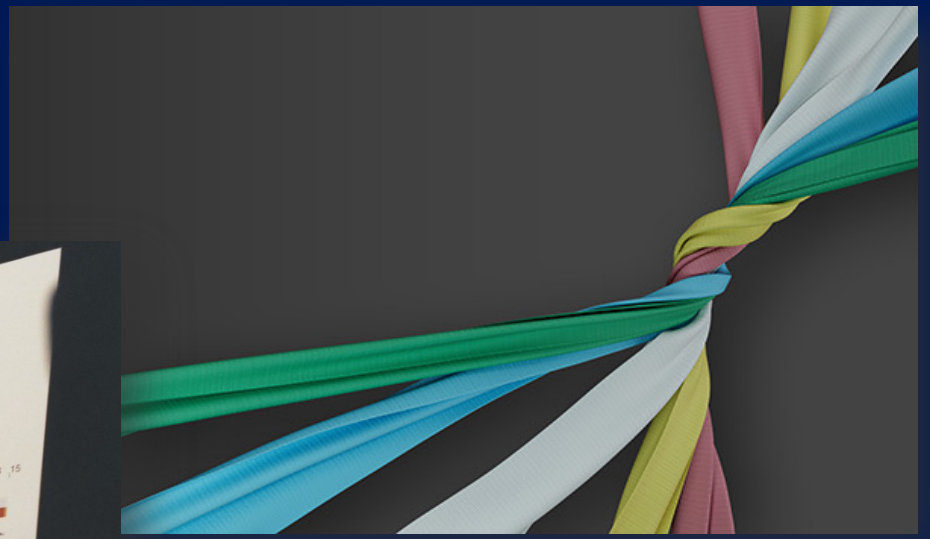
Now

The modern era of scicomm



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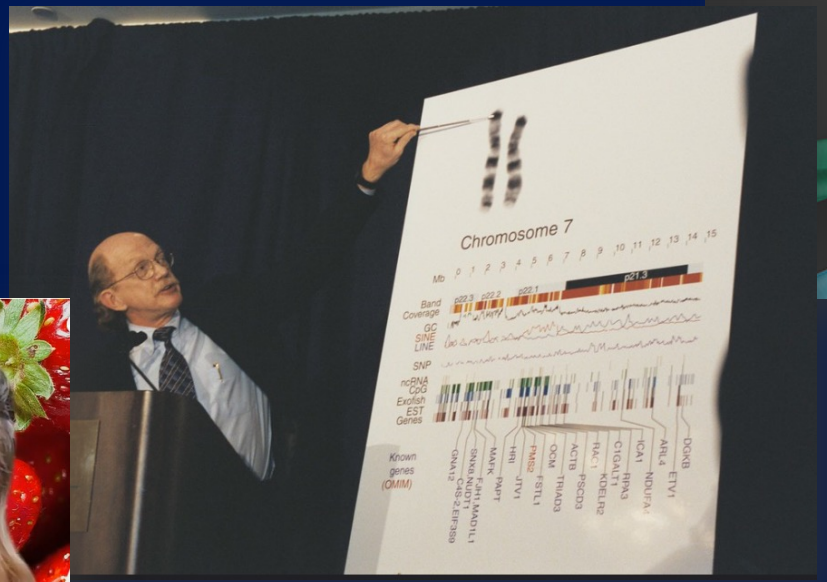

Interdisciplinary

Engaging

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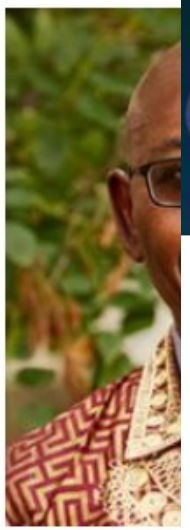

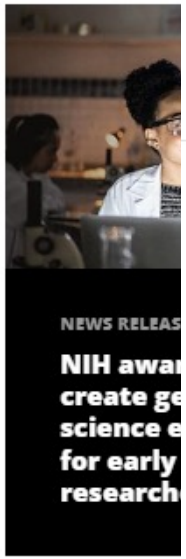

YouTube Search

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National Human Genome Research Institute

@genometv 40.7K subscribers 2.2K videos

Subscribed

NHGRI is the driving force for advancing geno...

genome.gov and 6 more links

HOME VIDEOS SHORTS LIVE PLAYLISTS

Why Y took so long

National Human Genome Research Institute • 632 views • 2 weeks ago

The Y chromosome is one of two human sex chromosomes, the other being the X chromosome. When researchers completed the first hum...

NHGRI's Oral History Collection ▶ Play all

NHGRI's Oral History Collection features discussions with influential figures in the field of genomics

Aneuploidy

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ABOUT GENOMICS | RESEARCH FUNDING | RESEARCH AT NHGRI | ABOUT HEALTH | CAREERS TRAINING | NEWS & EVENTS | ABOUT NHGRI

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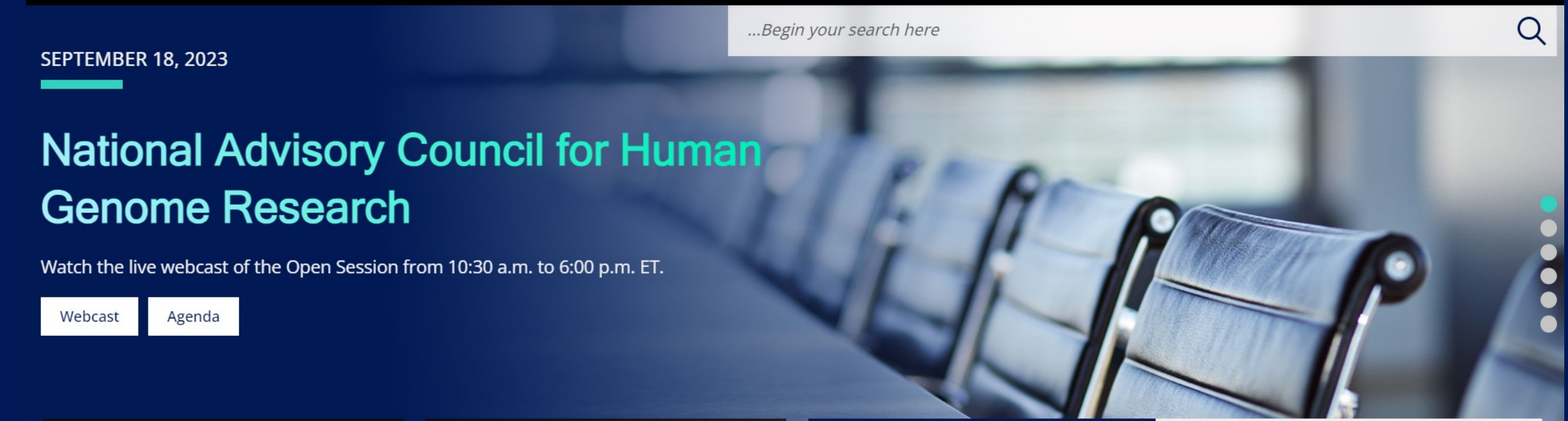
SEPTEMBER 18, 2023

National Advisory Council for Human Genome Research

Watch the live webcast of the Open Session from 10:30 a.m. to 6:00 p.m. ET.

Webcast | Agenda



NEWS RELEASE

NIH awards $50.3 million for "multi-omics" research on human health and disease

THE GENOMICS LANDSCAPE

Human Genome Project leaders release video of virtual reunion

ABOUT NHGRI

2020 NHGRI Strategic Vision

NIH NHGRI

GOVERNMENT SOCIAL MEDIA

The D.C. Science Writers Association DCSWA

DIRECTOR'S AWARDS 2022

In the Multimedia category, Prabarna Ganguly and Harriet Bailey earned top prize for their video "The Human Pangenome," published by the National Human Genome Research Institute. "Explaining DNA is never easy, so I was impressed by their mastery of blending animation and strong writing to effectively tell a story," said one judge.

Group Awards

History of Eugenics Symposium Team

For extraordinary contributions to understanding the history of eugenics and scientific racism and their complex legacies in the modern health sciences.

- Sarah Bates, *NHGRI*
- Ernesto Del Aguila III., *NHGRI*
- Christopher Donohue, *NHGRI*
- Alvaro Encinas, *NHGRI*
- Prabarna Ganguly, *NHGRI*
- Radwanullah Kakar, *NHGRI*
- Britny Kish, *NHGRI*
- Jennifer Montooth, *NHGRI*
- Mukul Nerurkar, *NHGRI*
- Devona Perrineau, *NHGRI*
- Ellaha Sadat, *NHGRI*
- Jerryl Somani, *NHGRI*
- Jill Thomas, *NHGRI*
- Zachary Utz, *NHGRI*
- Kris Wetterstrand, *NHGRI*

A new human "pangenome" reference

The NHGRI-funded Human Pangenome Reference Consortium has released a high-quality collection of human genome reference sequences, which together comprise a human "pangenome" reference. Encompassing genome sequences from 47 people of diverse ancestries (with the goal of increasing that number to 350 by mid-2024), the human pangenome reference captures significantly more population diversity than the previous reference sequence.

News

News Release: Scientists release a new human "pangenome" reference
May 10, 2023

From NHGRI Director: Remarks from the Human Pangenome Media Briefing
May 10, 2023

Media Advisory: NIH-funded Scientists to Discuss New Human "Pangenome" Reference
May 4, 2023

Human pangenome

Nature
Volume 617 Issue 7960, 11 May 2023

The cover shows the pangenome wrapping a globe and uses a sequence tube map rendering of a pangenome graph relating ten haplotypes within the highly variable HLA-A locus on chromosome 6 created by Adam Novak at the University of California, Santa Cruz.

Cover image: Darryl Leja/NHGRI

Read More

What is a reference genome sequence?

Why do we need a new human pangenome reference?

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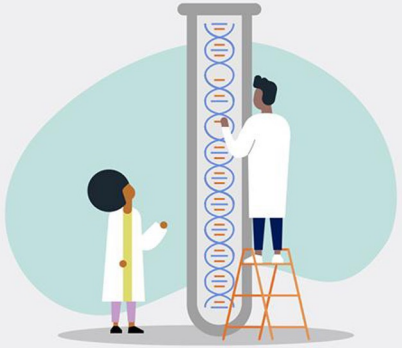
The original human genome reference sequence is outdated.

The original human genome reference sequence was generated by the Human Genome Project in 2003. While this reference sequence has been regularly updated as researchers fixed errors and filled in missing regions of the genome, it only reflected data generated from about 20 people. Most of that first human genome reference sequence was just from one person.

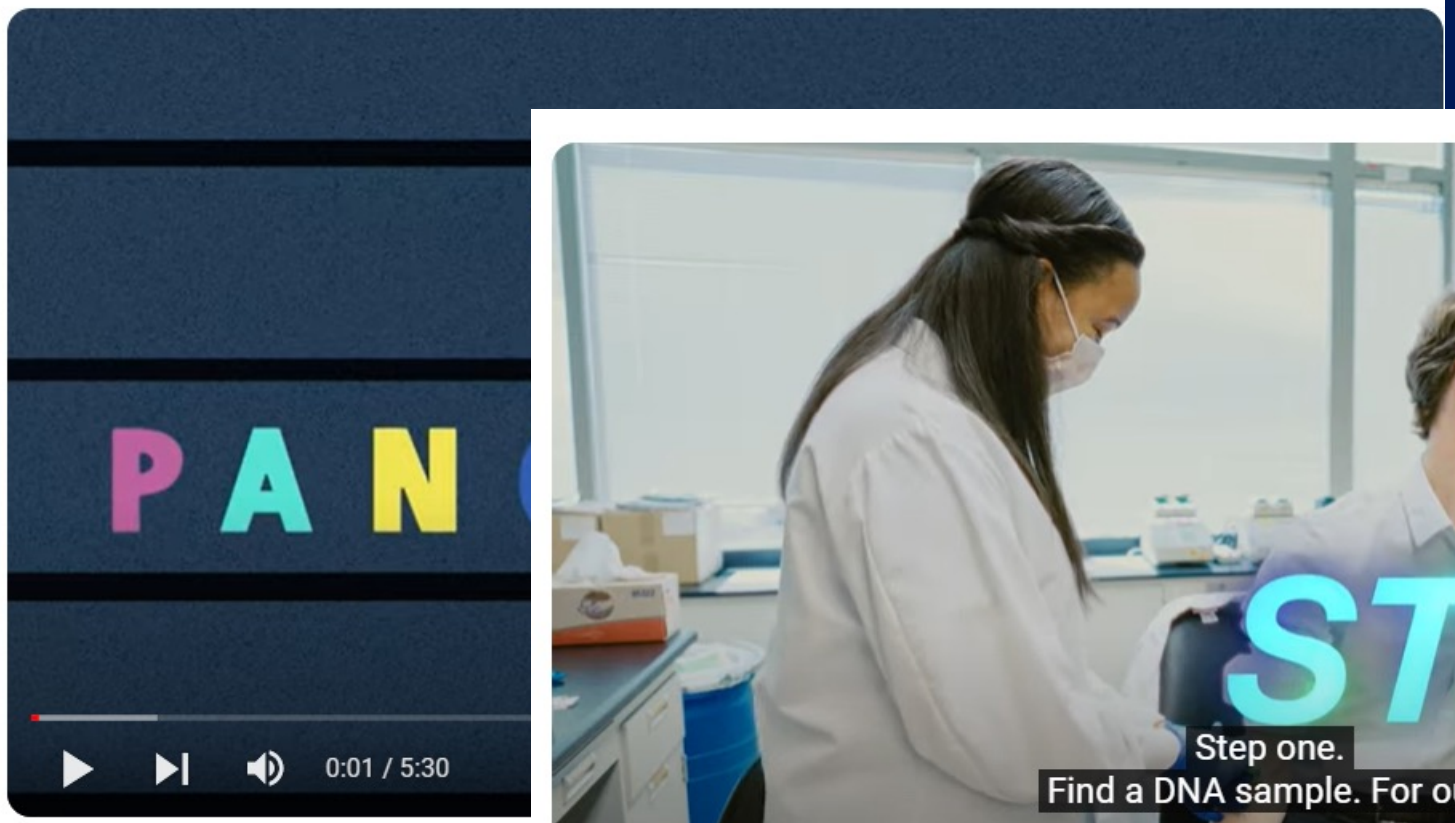
The previous human genome reference sequence has missing pieces (i.e., gaps).

The previous human genome reference sequence is only 92% complete, with an estimated 8% of the human genome missing because of gaps in the sequence. Recently, new types of DNA sequencing technologies have helped researchers read longer stretches of DNA at a time, allowing them to fill in missing sequences within those gaps, especially in areas that were repetitive and harder to read. The new human pangenome reference is more comprehensive and incorporates the missing 8% of the human genome sequence, adding over 100 million new bases.



A human pangenome reference better reflects human diversity.

The new human pangenome reference includes genomic data from 47 people who are collectively more globally diverse. Researchers expect that number to reach 350 people by 2024. A human pangenome reference that better reflects genomic variation across all human populations will help ensure that it is beneficial for



The Human Pangenome

National Huma...
40.7K subscribers

25K views 2 years ago
In 2003, biologists created the first ever
reference genome, was mostly made up

How to Sequence a Human Genome in 7 'Easy' Steps!

National Huma...
40.7K subscribers
Subscribed
179
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6.3K views 6 months ago NATIONAL HUMAN GENOME RESEARCH INSTITUTE (NHGRI)
Join NHGRI researchers at the NIH Intramural Sequencing Center (NISC) as they show you step-by-step how to extract human DNA, sequence it, and interpret the data -- with some fun DNA high jinks along the way.

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National Human Genome Research Institute
@genome_gov

Researchers from the @genome_gov-funded Human Pangenome Reference Consortium (@HumanPangenome) have completed a collection of new human reference genome sequences that much more accurately reflect global diversity! genome.gov/pangenome

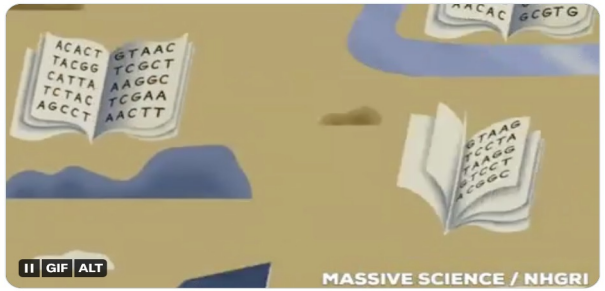
11:08 AM · May 10, 2023 · **114K** Views

View Tweet analytics

194 Retweets **26** Quotes **417** Likes **41** Bookmarks

National Human Genome Research Institute
@genome_gov

Scientists currently use one reference genome as a guide to study all humans, but one reference genome cannot possibly represent everyone! Now, researchers are working to create a "pangenome," a collection of complete genomes in which everyone's differences are represented.



11:36 AM · Jul 16, 2021

View Tweet analytics

40 Retweets **3** Quotes **110** Likes **7** Bookmarks

National Human Genome Research Ins... @genome... · Mar 16, 2022
I'M WONDERING WHEN WE WILL STOP SEEING OURSELVES AS HAVING JUST ONE COMPLETE GENOME BUT INSTEAD HAVING A COLLECTION OF GENOMES WHERE EVERYONE'S DIFFERENCES ARE REPRESENTED.

8 292 1,451

National Human Genome Research Institute
@genome_gov

Uh oh. Our opossum is back and he looks very upset. Luckily, researchers are working to create a "pangenome," a collection of complete genomes in which everyone's differences are represented! go.usa.gov/xz5N2.

11:03 AM · Mar 16, 2022

National Human Genome Research Ins... @genome... · May 11, 2022
HE SAID YOU CAN'T USE ONE REFERENCE GENOME TO STUDY EVERY DIVERSE POPULATION.

3 97 565

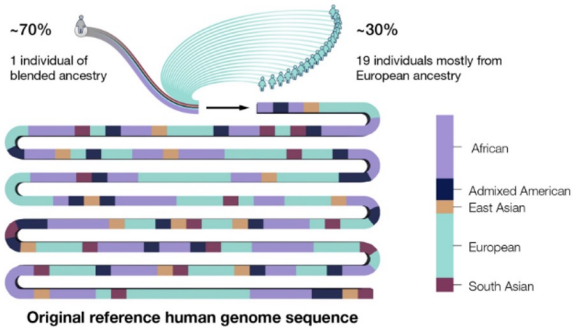
National Human Genome Research Institute
@genome_gov

You don't need spidey sense to know that one reference genome cannot represent every population! That's why researchers are working to create a "pangenome," a collection of complete genomes in which everyone's differences are represented. go.usa.gov/xeMzw

11:20 AM · May 11, 2022

Top Tweet earned 54.1K impressions

Why did we need to update the human genome reference sequence? When it was created during the Human Genome Project, around 70% of it came from only one person with blended ancestry, which includes African, European, Admixed American, East Asian and South Asian ancestry. pic.twitter.com/xkx9jXwXAW



1 122 375

Using one reference genome to study all humans isn't fetch at all. It cannot possibly represent everyone! That's why researchers are working to create a "pangenome," a collection of complete genomes in which everyone's differences are represented. go.usa.gov/xeMzw

11:53 AM · Dec 17, 2021

View Tweet analytics

130 Retweets **17** Quotes **542** Likes **14** Bookmarks

Top media Tweet earned 31.7K impressions

There's no wrong time or place to remind people that it's time to stop seeing ourselves as having one complete human genome reference! One genome sequence can't possibly represent everyone's diversity. pic.twitter.com/EQHgoB3zlP

4 71 294

NEWS WATCH NOW

SCIENCE NEWS

Scientists announce rough draft of human pangenome

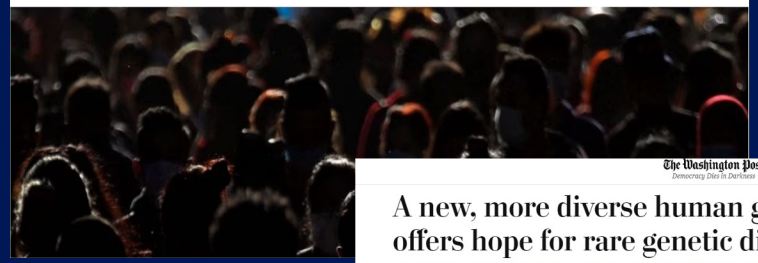
A collection of DNA that represents the genetic information from 47 individuals, the pangenome dramatically expands upon the original human genome reference.

Science

4 minute read · May 10, 2023 11:26 AM EDT · Last Updated 4 days ago

Human genome reboot better reflects global population

By Will Dunham



The Washington Post
Democracy Dies in Darkness

A new, more diverse human genome offers hope for rare genetic diseases

The first draft of the pangenome is based on the full genetic blueprints of 47 people from around the world

By Mark Johnson

May 10, 2023 at 11:00 a.m. EDT

Researchers say the new genetic map of humanity is more representatives of variety

By Pallab Ghosh

Science correspondent

Genetics Breakthrough: Promising new era of ethnic diversity-informed tests and treatments

Sky News
6.35M subscribers

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The New York Times

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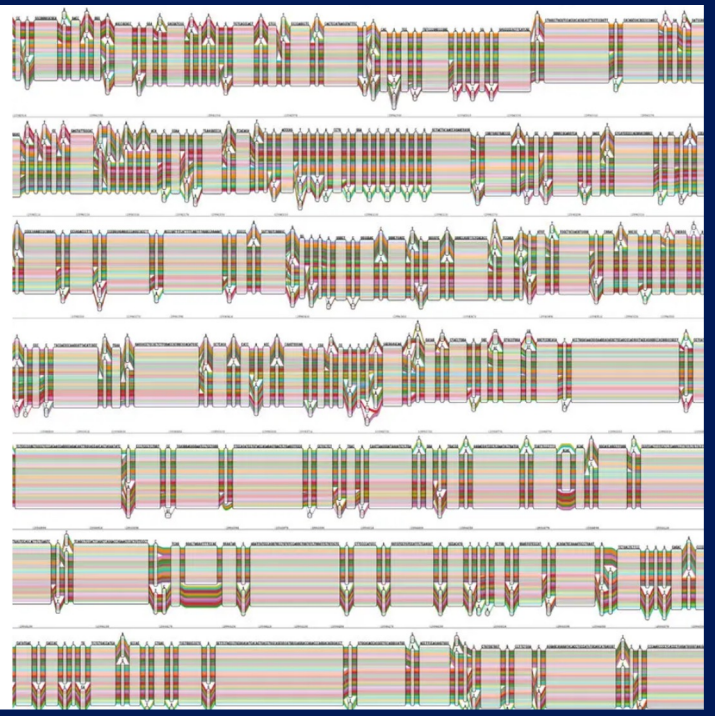
Scientists Unveil a More Diverse Human Genome

The "pangenome," which collated genetic sequences from 47 people of diverse ethnic backgrounds, could greatly expand the reach of personalized medicine.



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How we measure impact

- Monitoring tools: web, social, news
- Quantitative + qualitative measures

540K 1.4B

Top Articles

HEADLINES	OUTLET	REACH
DNA project gives scientists diverse genome for comparison	Yahoo News	136,475,913
Human genome reboot better reflects global population	Yahoo News	136,475,913
A new, more diverse human genome offers hope for rare genetic diseases	Yahoo News	136,475,913
A diverse human genome: "pangenoma"	MSN Salud US (es)	67,151,557
DNA \"reference guide\" expanded to reflect human diversity	MSN News Canada	67,151,557
DNA \"reference guide\" expanded to reflect human diversity	MSN Health & Fitness	64,480,000
World's first human PANGENOME is released	MSN Health & Fitness	64,480,000
Scientists have updated the human genome to make it more equitable and inclusive	MSN Health & Fitness	64,480,000
Ground-Breaking Genetics Library Finally Represents the Whole of Humanity	MSN Health & Fitness	64,480,000
Scientists Just Made a Massive Change to the Human Genome: The 'Pangenome'	MSN News	59,740,000
DNA project gives scientists diverse genome for comparison	MSN News	59,740,000
This Updated Human Genome Map Will Change Medicine Forever	MSN News	59,740,000
Collection of genome sequences hails new era in scientific research	MSN UK	59,520,000
Pangenome: DNA breakthrough could transform healthcare for people from diverse ethnic backgrounds	MSN UK	59,520,000
Scientists Unveil a More Diverse Human Genome	New York Times Online, The	38,168,535
Scientists release a new human "pangenome" reference	National Institutes of Health	35,266,063
Scientists have updated the human genome to make it more equitable and inclusive | CNN	CNN Online	33,909,950
Scientists have updated the human genome to make it more equitable and inclusive	CNN Online	33,909,950
Updated human DNA map captures diversity of life | CNN	CNN Online	33,909,950
Updated human DNA map captures diversity of life	CNN Online	33,909,950

UVPM (Unique Visitors Per Month): is measured at the outlet level and provides the number of visitors that outlet, as a whole, receives per month. Reach (true reach rather than potential reach/circulation) – Views, Unique Visitors, Repeat Visitors

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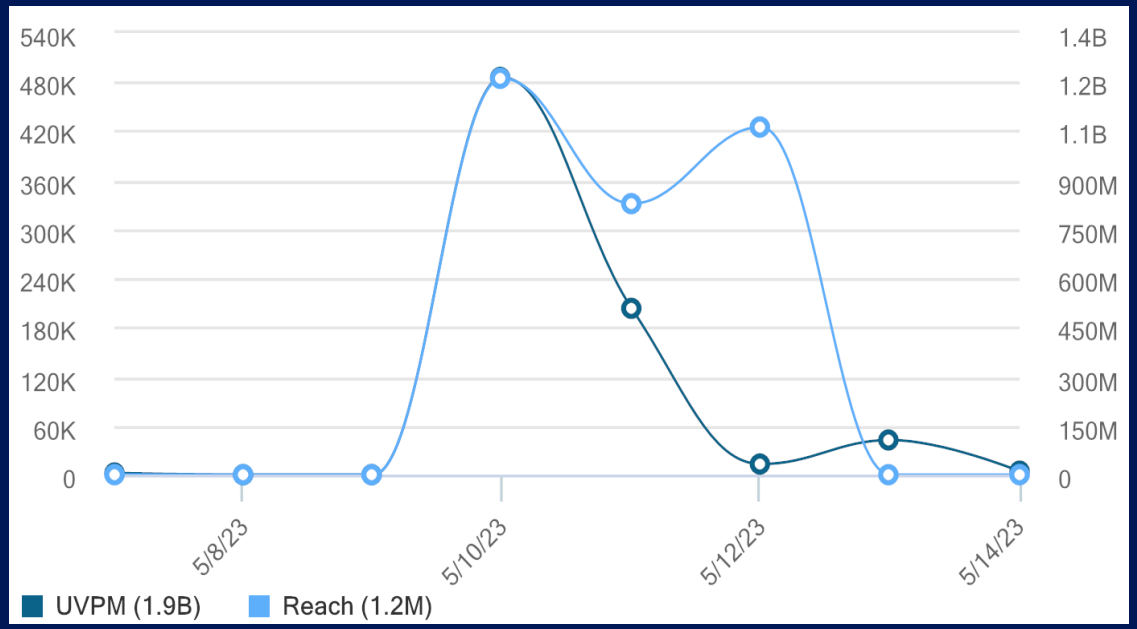
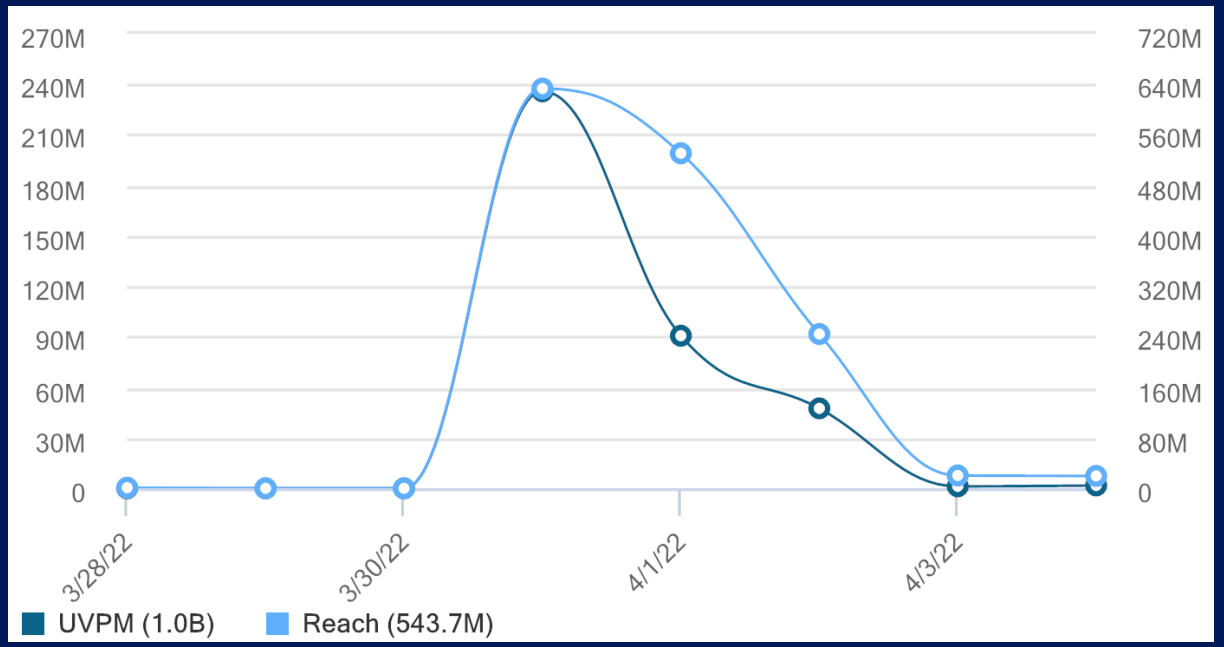
Measuring “reach”



Pangenome



T2T

National Human Genome Research Institute (NHGRI)
28,003 followers
1w •

Y chromosome being annoyingly proud of the many, many repetitive regions in i
DNA sequence.

All chromosomes have repetitive regions, but the Y chromosome has an unusual high percentage of repetitive DNA sequence (over 60% of the sequence!). This made it particularly difficult for scientists to study. Learn more about the Y chromosome: https://lnkd.in/e6k5FCwG

You and 511 others

12 comments • 26 reposts

Video: Why Y took so long

View video on YouTube. Credit: Ernesto Del Aguila III, NHGRI

The Y chromosome, along with the X chromosome, is often discussed for its role in sexual development. While these chromosomes play a central role, the factors involved in human sexual development are spread across the genome and very complex, giving rise to the array of human sex characteristics found among male, female and intersex individuals. These categories are not equivalent to gender, which is a social category. Additionally, recent work demonstrates that genes on the Y chromosome contribute to other aspects of human biology, such as cancer risk and severity.

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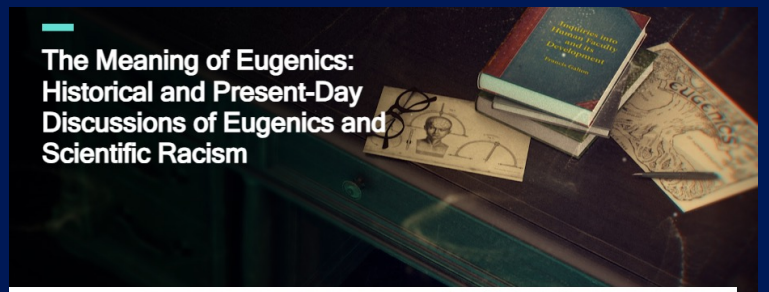
History of Genomics Program

NHGRI Historian Christopher Donohue

The story of the creation of the program



Event Details

Eugenics and scientific racism are widely misunderstood despite their long histories. Studying and sequencing the human genome were supposed to help eliminate common misconceptions about the biological differences between humans. After all, we are 99.9% the same according to our DNA.

And yet, why do these misconceptions continue to persist, resulting in modern day discrimination and bias? We look to the history of science and medicine to help explain.

Since its inception, the National Human Genome Research Institute (NHGRI) has funded forward-thinking research on the historical study of eugenics and other misuses of genetics and genetic information. This includes the broader social, ethical and legal implications (ELSI) of genomics through NHGRI's ELSI Research Program.

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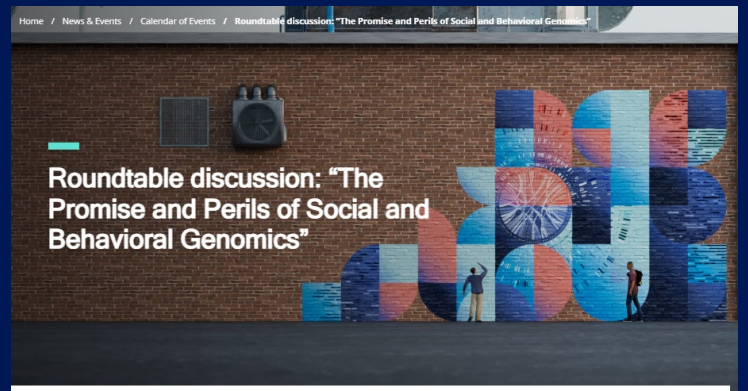
- Events ›



Event Details

The National Human Genome Research Institute (NHGRI) of the National Institutes of Health will host a virtual roundtable to discuss social and behavioral genetics and genomics, including their benefits, limitations and potential for misuse. Social genomics is a field of emerging research that suggests scientists can use genomic variation to understand complex social behavior. Panelists will discuss genetics and genomics studies that may be stigmatizing as well as strategies

Educational Resources

TIMELINE

Eugenics: Its Origin and Development (1883 - Present) ›

FACT SHEET

Eugenics and Scientific Racism ›

NHGRI's Oral History Collection

Erich Jarvis

Erich Jarvis, Ph.D., is a professor and head of the Laboratory of Neurogenetics of Language at the Rockefeller University. Dr. Jarvis' lab, which is part of the Howard Hughes Medical Institute, investigates the neurogenomics of complex traits such as vocal learning in animals, specifically in

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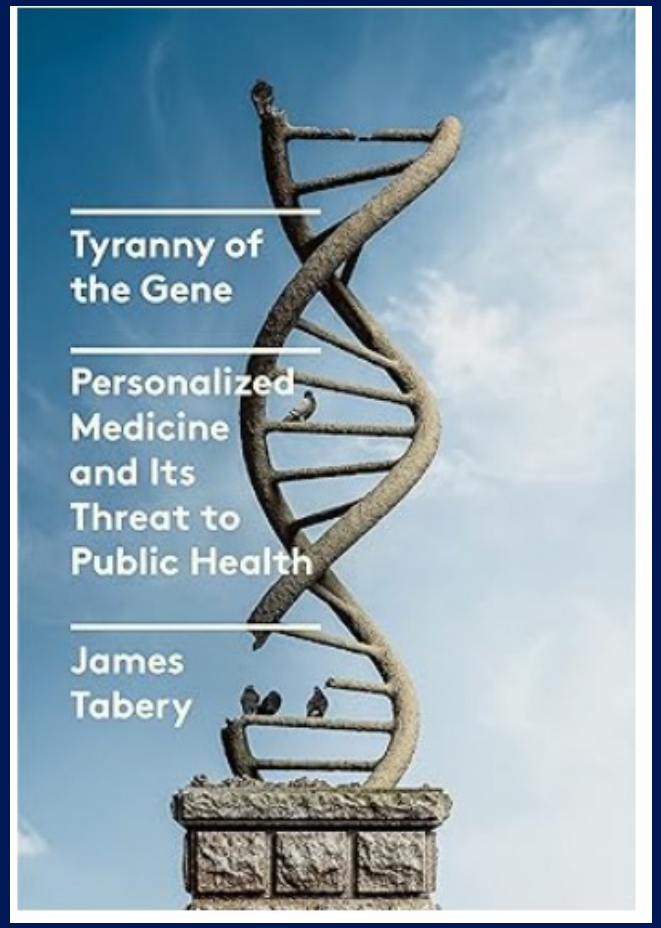
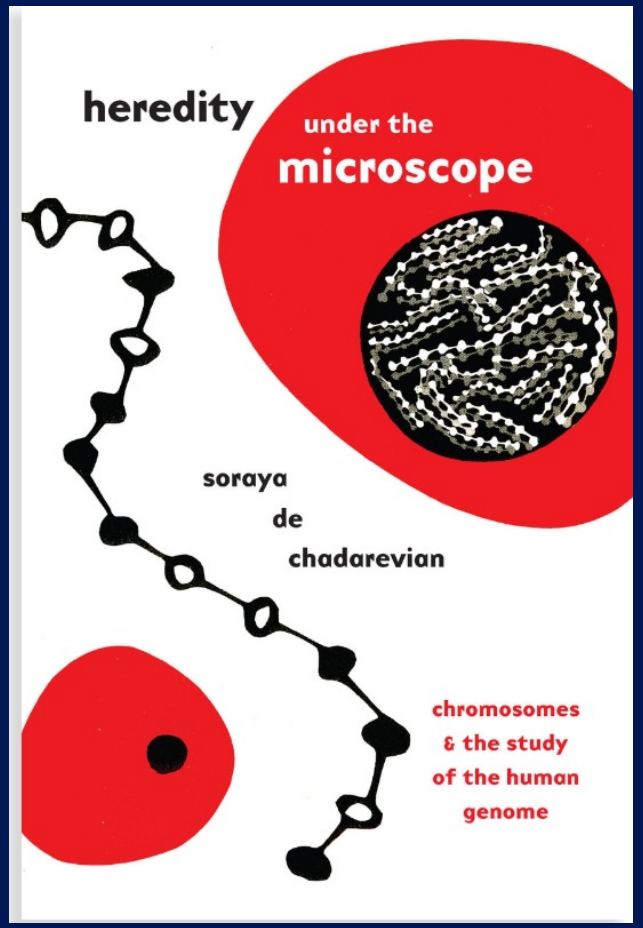
Examples of publications



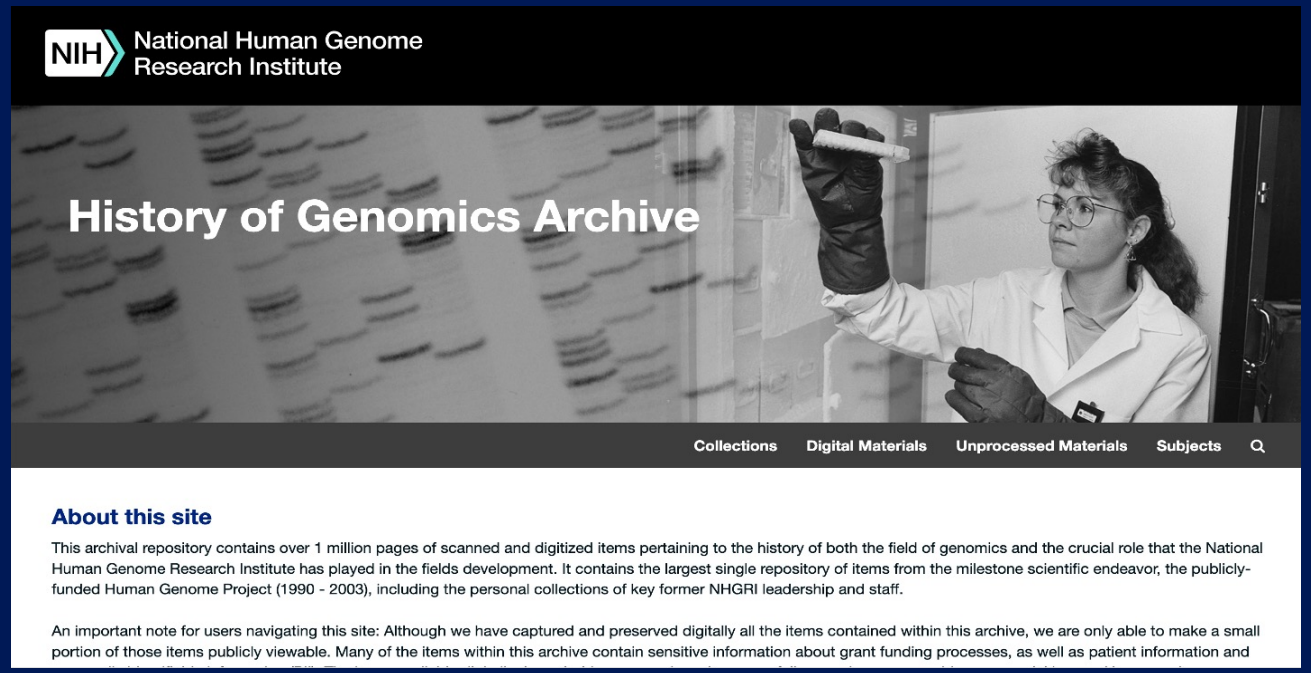


Archival Development and Analysis Guiding Principles

- Development and Implementation guided by FAIR (Findable, Accessible, Interoperable, and Reusable) Principles
- Further development of **Core Collection** and future datasets for scholarly community and other stakeholders
- Making more files and datasets available to public, scholarly community through ArchviesSpace
- Committed to asking (and answering) the big, complex questions about the HGP, the historical development of genomics, and how “team science” works

Archival initiative

ArchivesSpace



Research & analysis through SharePoint


The Forefront
of Genomics®