



**EP PerMed**  
European Partnership  
for **Personalised Medicine**

**ICPerMed**  
INTERNATIONAL CONSORTIUM

ICPerMed & EP PerMed Conference on Personalised Medicine Research  
**Day 2, 27 November 2025**

## SESSION 3

**Anna Laura Ross**

World Health Organization

**Advancing Human Genomics and  
Precision Medicine for Global Health**





# Advancing Human Genomics and Precision Medicine for Global Health

ICPerMed & EP PerMed  
Joint Conference  
26-27 November 2025, Prague

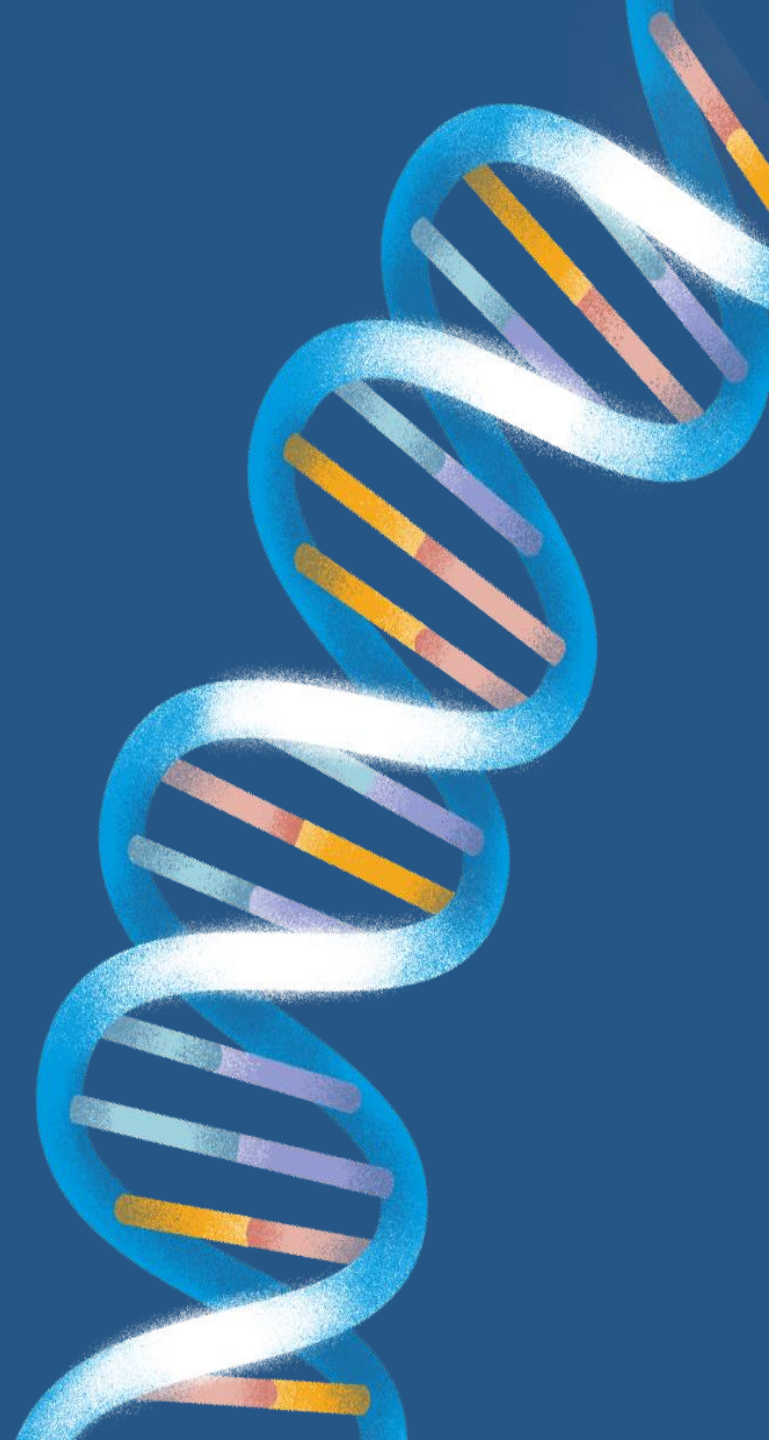
*Dr Anna Laura Ross, World Health Organization*





# Disclosure

My participation in this conference/webinar is solely in the capacity of a staff member of the World Health Organization. It does not constitute endorsement of, or association with, the organizers, the content presented by other participants, or any associated entities. The WHO emblem and name should not appear on any materials, including press releases, social media platforms, related to this meeting



# Genomics is revolutionizing global health

## Breakthroughs in Sequencing Technology

- Faster, cheaper, more accessible access than ever before

## Transforming Our Understanding of Health & Disease

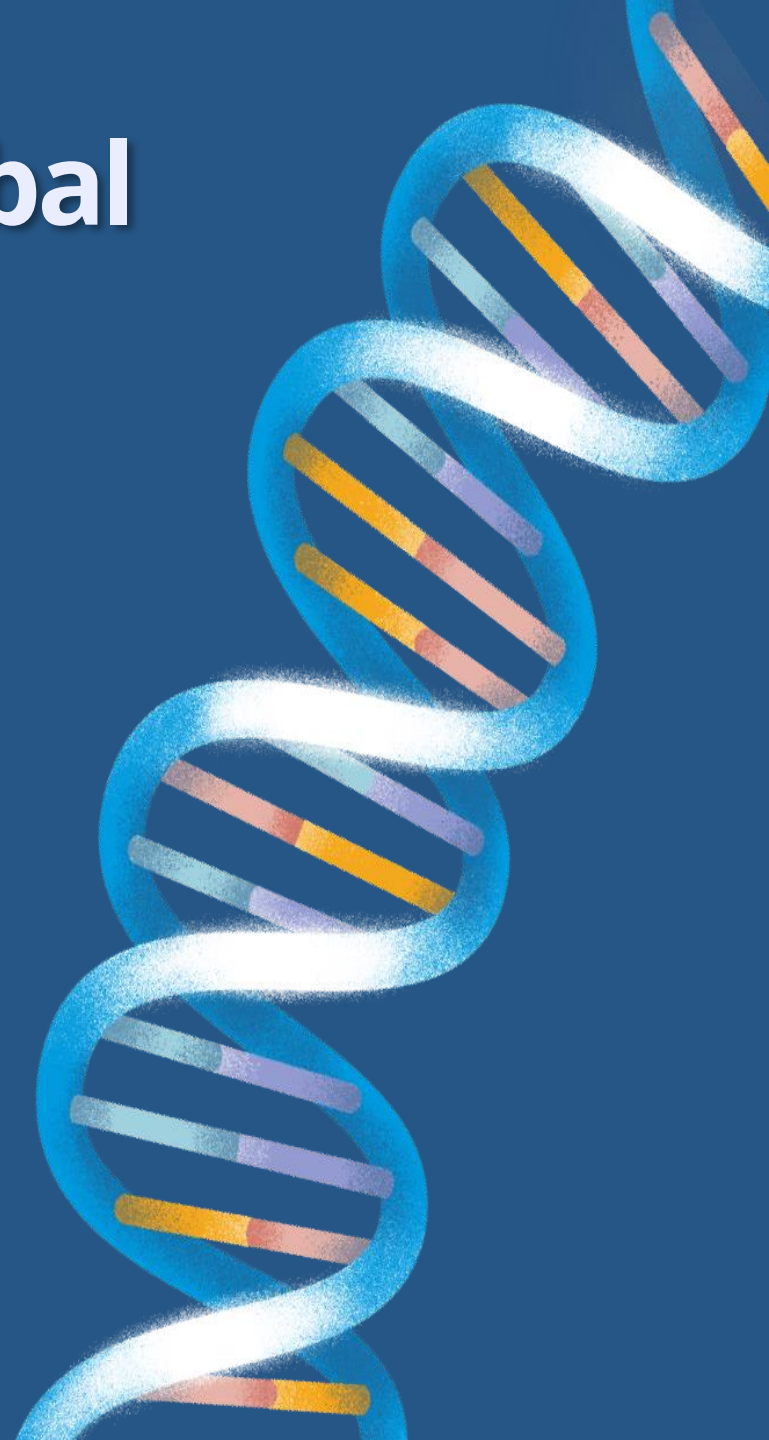
- Unraveling genetic variation and **disease mechanisms**.
- Advances in **cancer genomics, rare diseases, and infectious diseases**.

## Expanding Global Impact in Public Health

- Precision medicine, diagnostics, and outbreak response.

## A New Era of Equitable Health Solutions?

- The potential for genomics to drive **better health outcomes globally** is immense.
- But **who benefits from these advances?**



# Genomics as a foundation of precision medicine

- **Genomics technologies**, intended here as including transcriptomics, proteomics, epigenomics, metabolomics, and microbiomics, has enhanced the knowledge necessary for maximizing the applicability of genomics data for better health outcomes.
- **Moves beyond a one-size-fits-all approach**
- **Risk prediction and prevention**
- **Personalized and targeted treatments**
- **Pharmacogenomics**



# Genomics and PM for all? Addressing the gaps

**Unequal access to genomic technologies** – Research & applications remain concentrated in high-income countries.

**Limited implementation in LMICs** – Many health systems lack the infrastructure to benefit.

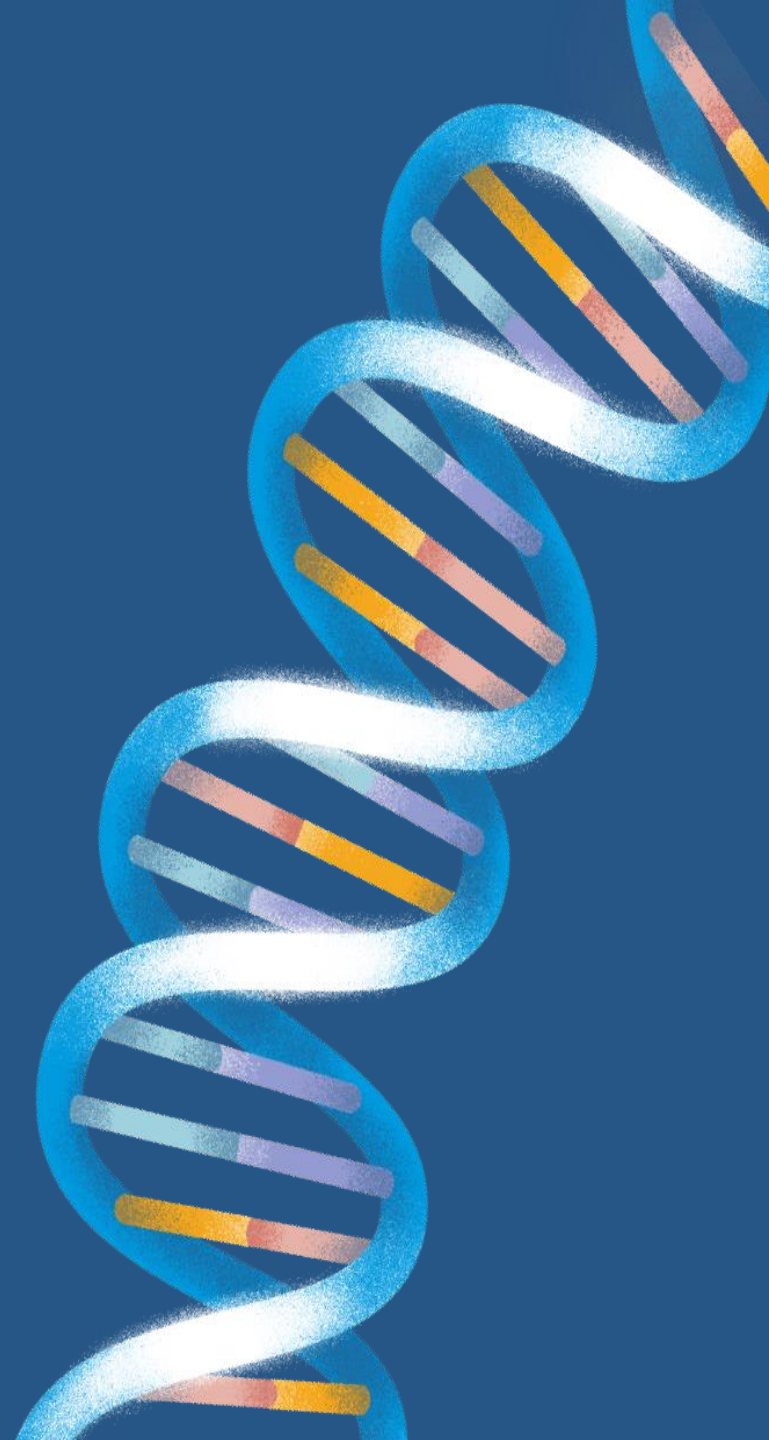
**Missed opportunities** – Genomics could address global health challenges, but gaps persist.

**The WHO Science Council: A Call to Action** – Recognized these challenges & issued key recommendations.



# WHO's mandate

- Promotes health and well-being worldwide
- Coordinates international health responses
- Sets global health standards
- Supports universal health coverage
- Provides technical assistance
- Monitors global health trends
- Advocates for vulnerable populations
- Promotes highest-quality research targeted at unmet needs





## Accelerating access to genomics for global health

Promotion, implementation, collaboration, and ethical, legal, and social issues

A report of the WHO Science Council



# WHO Science Council: A vision for genomics in global health

1. Promote the adoption or expanded use of genomics
2. Overcoming obstacles to implementation
3. Foster commitments to collaborative activities
4. Promote ethical, legal, and equitable use and responsible sharing of information





# Communication and advocacy

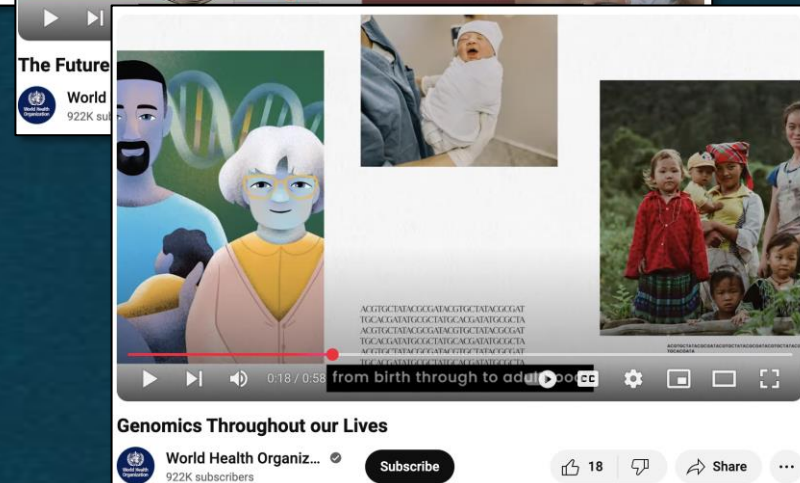
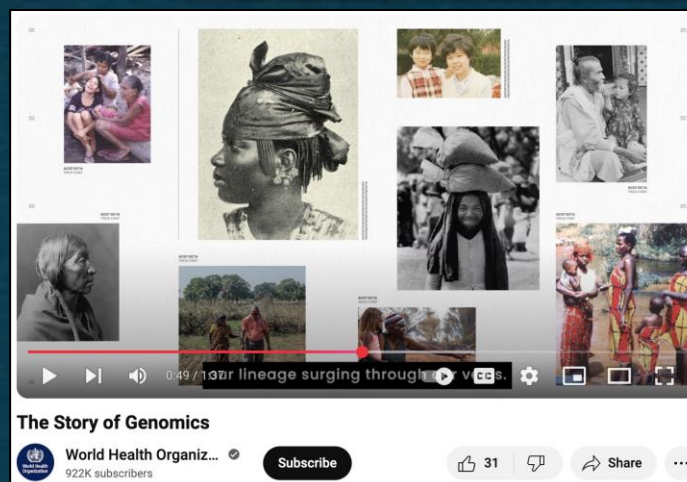
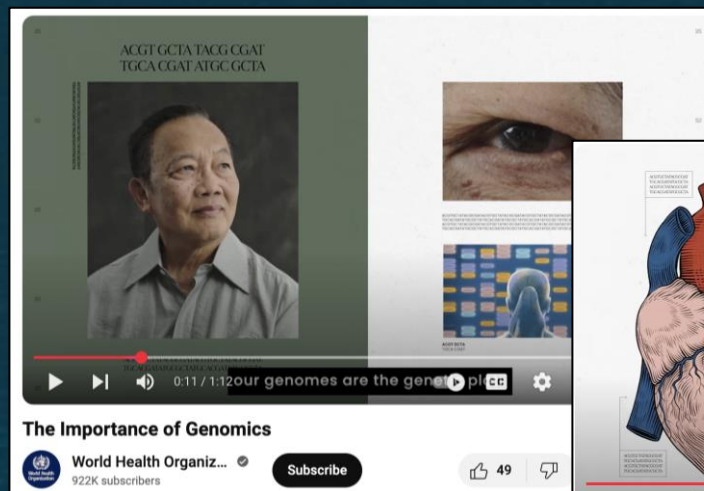


# Communication and advocacy

“Genomics can be explained through a simple metaphor: that each one of us is a unique book filled with pages that describe why we are the way we are.”

-

“The story of genomics is the story of our lives.”








# Communication and advocacy

The story of **genomics**

## How our differences benefit us all.


It helps us understand what makes us unique. Everything from our eye colour, to how our environment affects us, to our susceptibility to diseases.




Genomics is the study of the human genome. That's our complete set of genes, making us who we are.

It also shows us how we're similar. Patterns in our DNA can teach us about the health of people worldwide.

What we do with that knowledge is up to us. Genomics allows us to create medicines and prevent diseases. Incredible, don't you think?



Share the story  World Health Organization

The story of **genomics**


## A tale of advancing healthcare.

Genomics helps us understand our complete set of genes. It's the study of the human genome - all of our DNA, making us who we are.

Genomics can tell us more about diseases. How they develop, what genes are involved, and how to treat them.

Genomics allows us to create personalized treatments. By sequencing DNA, we can tailor treatments specific to our genetic makeup.

Imagine the possibilities. By understanding ourselves, we can advance healthcare all over the world.

Share the story  World Health Organization

The story of **genomics**

## Supporting health throughout our lives.


It identifies health issues at all stages of life. Understanding our DNA helps us treat and prevent diseases as we go through life.

What exactly is genomics? It's the study of the human genome - the full set of genes that define us as people.

It's used in newborn screening. Genomics can catch potential health issues early on.

And supports us as we grow older. Telling us how susceptible we are to certain diseases so we can prevent and treat them effectively.

Increasing access to enrich our lives. Cheaper innovations are ensuring all countries can benefit from genomics.

Share the story  World Health Organization

The story of **genomics**


## A world of healthcare possibilities.

Genomics helps us understand ourselves. It's the study of the human genome - our complete set of genes that makes us who we are.

It unlocks the potential of healthcare. Understanding our DNA is key to improving how we prevent, diagnose, and treat diseases.

The more information, the better. For everyone to benefit from the potential of genomics, we need data from populations from all over the world.

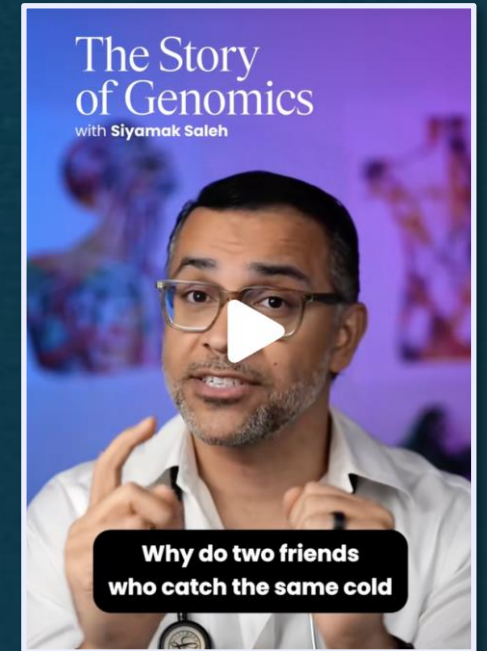
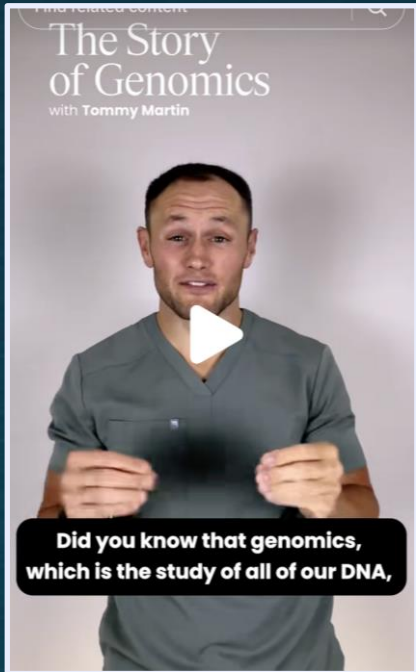
Increasing access to enrich our lives. Cheaper innovations are ensuring all countries can benefit from genomics.

Share the story  World Health Organization





# Communication and advocacy







# Communication and advocacy

Peer-reviewed publication for the scientific community



# nature medicine

## Correspondence

<https://doi.org/10.1038/s41591-024-03225-x>

## The WHO genomics program of work for equitable implementation of human genomics for global health

Check for updates

The publication of the first draft of the human genome sequence in 2001<sup>1</sup> was followed by the advent of high-throughput methodologies, which together have driven the expansion of genomic tools and technologies. These efforts have enabled the sequencing of millions of genomes and expedited the functional and clinical annotation of the human genome. The resulting discovery of thousands of gene–disease associations<sup>2</sup> and the characterization of human genetic variation at scale<sup>3</sup> has extended the application of genomics to enable diagnosis, prognosis and clinical management of disease, as well as risk prediction and implementation of preventive measures.

Despite the health benefits from these innovations and the potential to improve sectors related to agriculture, livestock and the economy (with indirect effects on health), the availability of genomic technologies remains inconsistent and often limited, particularly in low- and middle-income countries<sup>4,5</sup>. In part

Table 1 | The WHO genomics program of work

Topic	Details
Challenges	Poor awareness of the benefits of human genomics for individual and public health
	Lack of alignment and collaboration between human genomic stakeholders
	Limited financial and technological resources, and trained workforce
	Inconsistent equity, ethics and governance frameworks in human genomics
	Limited tools and frameworks to evaluate impact of interventions globally
Actions	Missing guidance to implement human genomics in research and clinical practice
	Communicate benefits and potential of genomics to different audiences
	Advocate for investing in genomics
	Map gaps, opportunities and priorities
	Guide genomic implementation based on good practices and local priorities
	Engage stakeholders across sectors and regions
	Promote a community of practice in genomics
	Support workforce education and training in genomics
	Guide human genome data access, use and sharing
	Guide equitable genomics research and practice
	Genomics stakeholders and expertise centers aligned and collaborating to accelerate the implementation of human genomics in research and clinical practice



# Communication and advocacy

Applied Health Economics and Health Policy (2025) 23:359–393  
<https://doi.org/10.1007/s40258-025-00949-w>

## SYSTEMATIC REVIEW



# The Cost Effectiveness of Genomic Medicine in Cancer Control: A Systematic Literature Review

Mackenzie Bourke<sup>1</sup>  · Aideen McInerney-Leo<sup>2</sup> · Julia Steinberg<sup>3</sup> · Tiffany Boughtwood<sup>4</sup> · Vivienne Milch<sup>5,6</sup> · Anna Laura Ross<sup>7</sup> · Elena Ambrosino<sup>7</sup> · Kim Dalziel<sup>8</sup> · Fanny Franchini<sup>9,10</sup> · Li Huang<sup>8</sup> · Riccarda Peters<sup>1</sup> · Francisco Santos Gonzalez<sup>1</sup> · Ilias Goranitis<sup>1,4</sup>

Accepted: 19 January 2025 / Published online: 29 March 2025  
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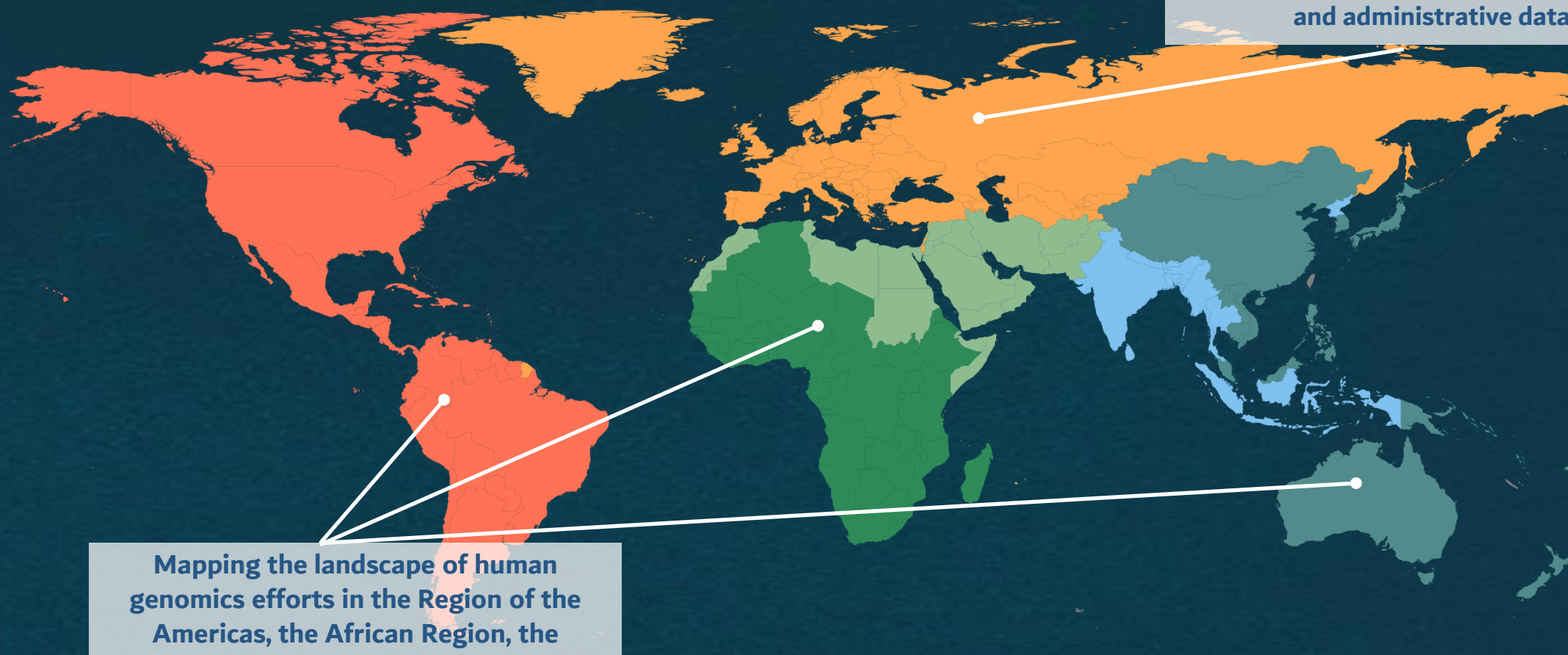


# Opportunities and challenges: insight from countries and regions



# Regional activities

Mapping the landscape of evidence generation and use in human genomics in the European Region: data sharing, ethical considerations, and the linkage of clinical and administrative data



Mapping the landscape of human genomics efforts in the Region of the Americas, the African Region, the Western Pacific region





## Regional activities: WPRO

“Experts noted the stark lack of diversity of Western Pacific populations in global genomic initiatives... They emphasized the need for **enhanced genomic literacy, early engagement and partnership with diverse populations**, and **proactive stakeholder involvement**.”

### EXPERT MEETING ON ACCELERATING ACCESS TO HUMAN GENOMICS FOR PUBLIC HEALTH



29–30 April 2024  
Manila, Philippines



# Regional activities:

## PAHO

“Member States will focus on strengthening human resources, infrastructure and equipment, national policies and guidelines, and funding mechanisms regionally, together with PAHO, for the creation of a **collaborative hub**.”

Human genomics for health  
Enhancing the impact of  
effective research

Report of the first regional  
meeting for the Americas

Brasília, 15–16 May 2024



# Regional activities: WPRO

WHO was requested to coordinate the completion of regional genomics toolkit, support countries in training genomics professionals, promote regional data-sharing, and facilitate collaboration across the Region.

## Meeting Report

### EXPERT WORKING GROUP MEETING ON ACCELERATING ACCESS TO HUMAN GENOMICS FOR ALL IN THE WESTERN PACIFIC



11–12 November 2024  
Kuala Lumpur, Malaysia





# Regional activities: EURO

WHO Regional office for Europe

## Regional virtual consultation on genomics and precision medicine

9:30 – 14:30 CET

29 April 2025





# Genomic Data Guidance



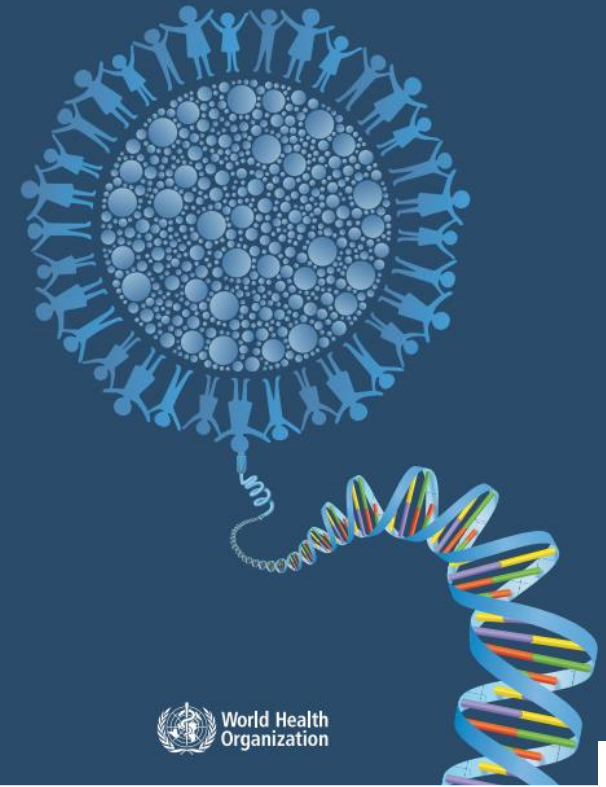


# Genomic Data Guidance

*"The potential of genomics to revolutionize health and disease understanding can only be realized if human genome data is collected, accessed, and shared responsibly and equitably," says **Dr. John Reeder**.*

*"This document outlines globally applicable principles designed to guide ethical, legal, and equitable use of human genome data, fostering public trust and protecting the rights of individuals and communities. It serves as a call to action, urging all stakeholders to adhere to these principles and ensure the benefits of genomic advancements are accessible to everyone."*

## Guidance for human genome data collection, access, use and sharing





# Developing the guidance

- A collaborative, interdisciplinary effort
- Contributions from:
  - **Bioethicists, geneticists, policymakers, legal experts**
  - **Patient representatives, experts from indigenous communities**
- Grounded in **equity, solidarity, and sustainability** principles.





# Developing the Guidance: an iterative process



1

Review of  
existing  
literature



2

Virtual  
consultation  
with experts



3

In-person  
workshop  
with experts



4

Public  
consultation





# Key Principles of the Guidance

1

**Affirming Individual & Community Rights** – Respecting informed decision-making for individuals and recognizing community impact.

2

**Social Justice** – Promoting equitable access to health benefits while preventing discrimination and bias.

3

**Solidarity** – Supporting fair distribution of genomic data benefits and reducing global inequities.

4

**Equitable Access & Benefit Sharing** – Ensuring diverse representation in genomic datasets while promoting fair use.

5

**Collaboration & Partnership** – Encouraging international and cross-sectoral cooperation for responsible data sharing.

6

**Stewardship of Human Genome Data** – Protecting data security, privacy, and ethical governance aligned with FAIR, CARE, and TRUST principles.

7

**Transparency** – Establishing clear, accessible policies on how genomic data is collected, used, and protected.

8

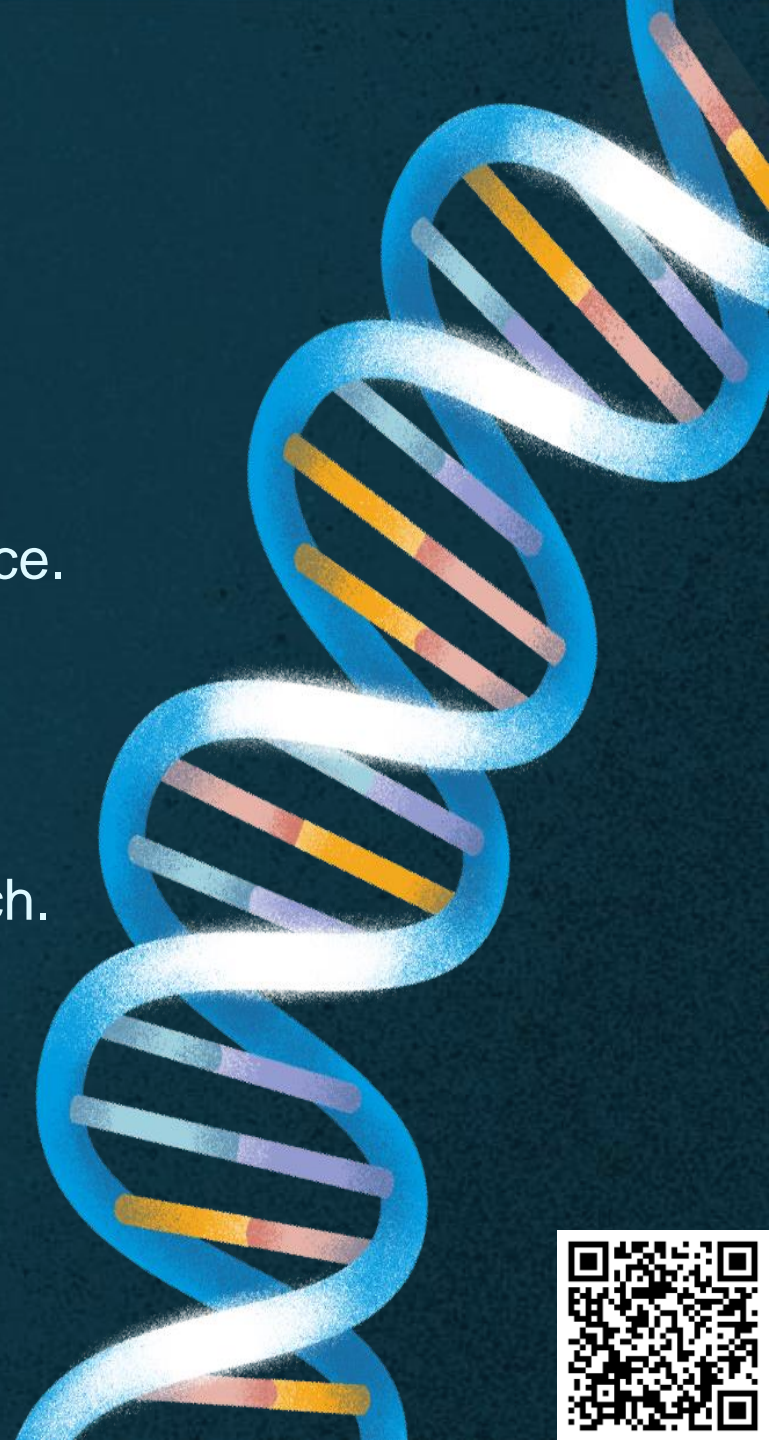
**Accountability** – Implementing oversight mechanisms to prevent misuse and ensure compliance with ethical and legal standards.



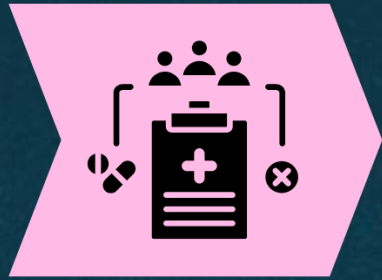


# What This Guidance Aims to Achieve

- Establish a **unified global framework** for genomic data governance.
- Guide **research institutions, policymakers, and health organizations** in ethical data handling.
- Encourage **fair benefit-sharing** and inclusivity in genomic research.
- Support **legal and policy frameworks** to ensure compliance with ethical standards.
- Encourage ongoing dialogue and adaptation as genomic science evolves



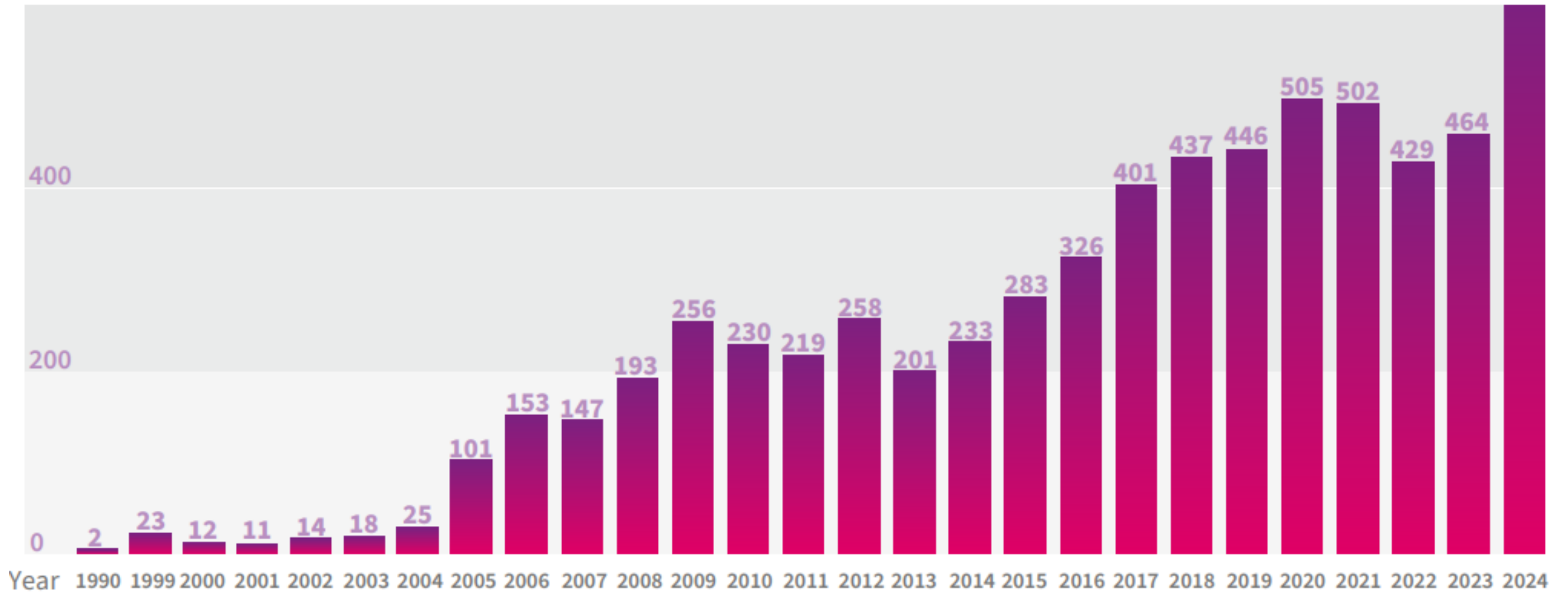




# Genomics in clinical research: a landscape analysis

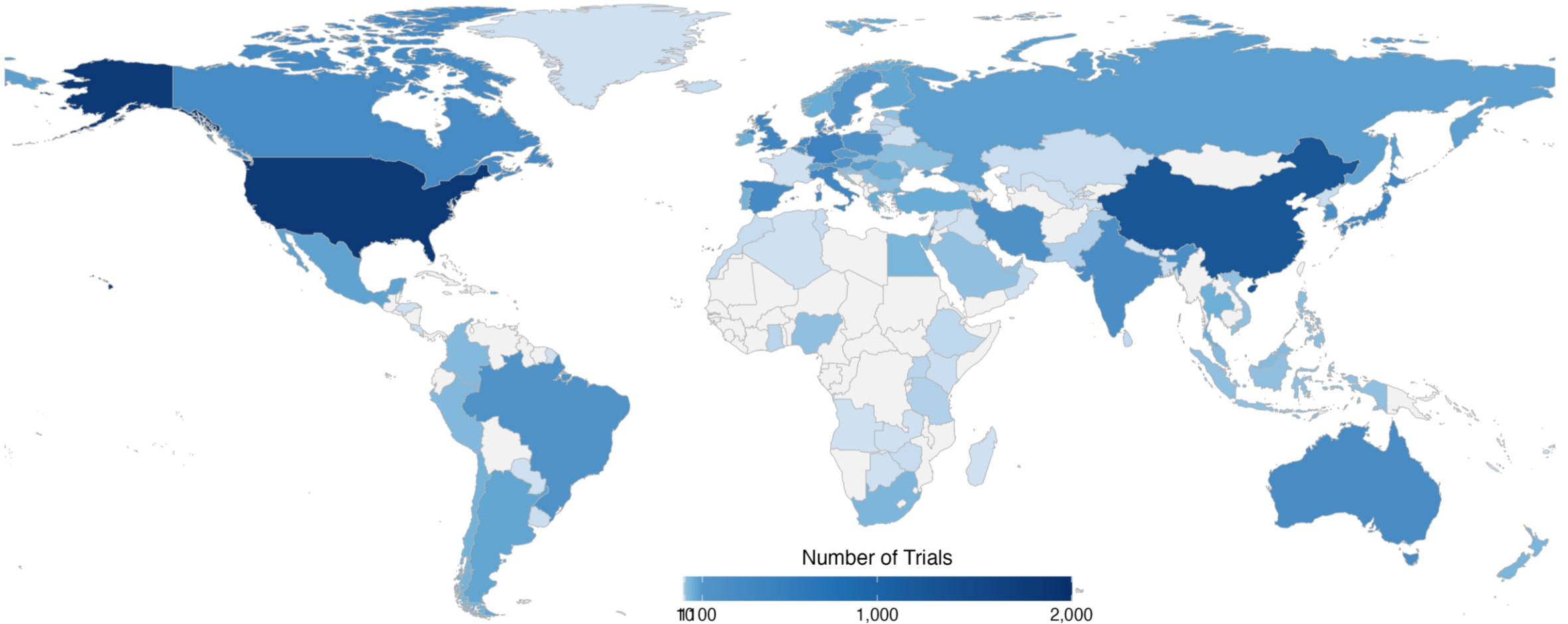


The number of clinical studies incorporating genomics has grown exponentially over the past two decades.



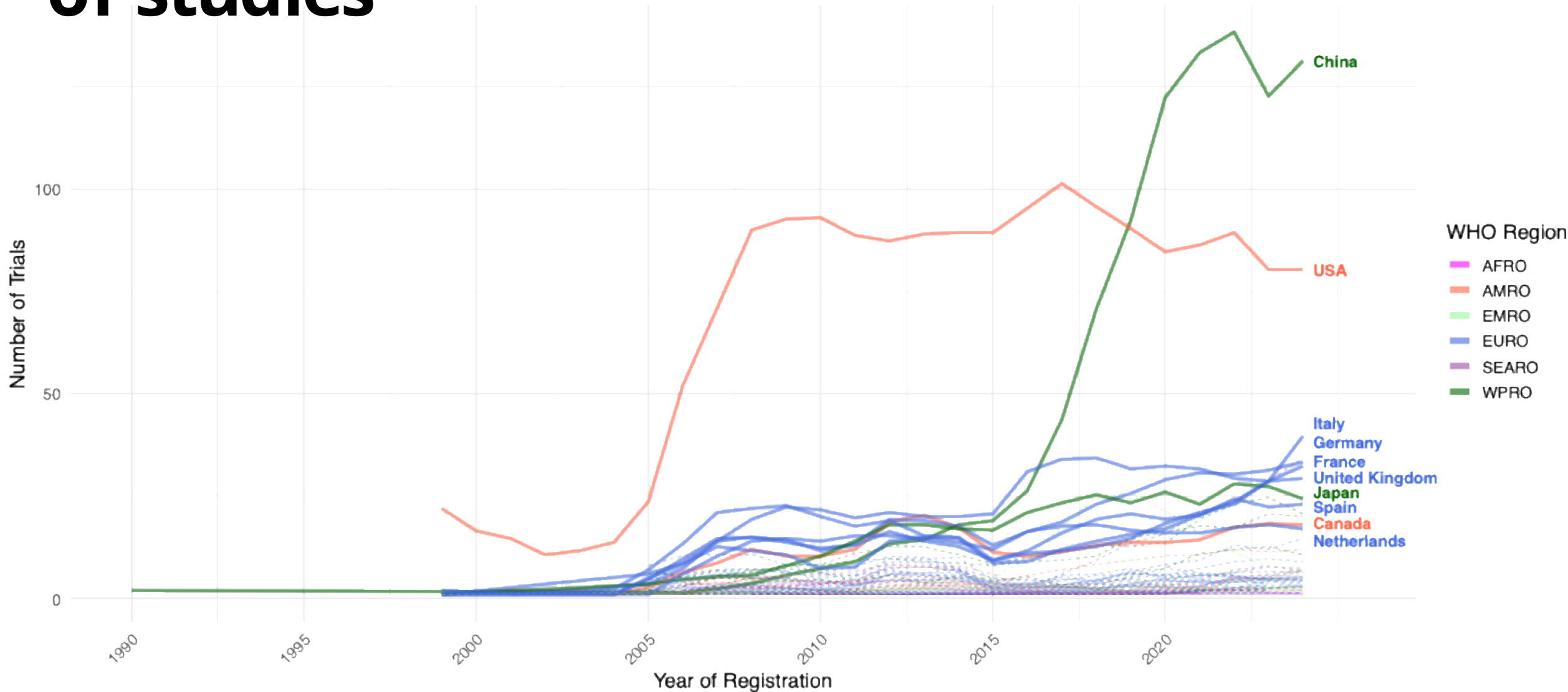


# Landscape analysis of clinical studies utilizing human genomic technologies: gaps and opportunities

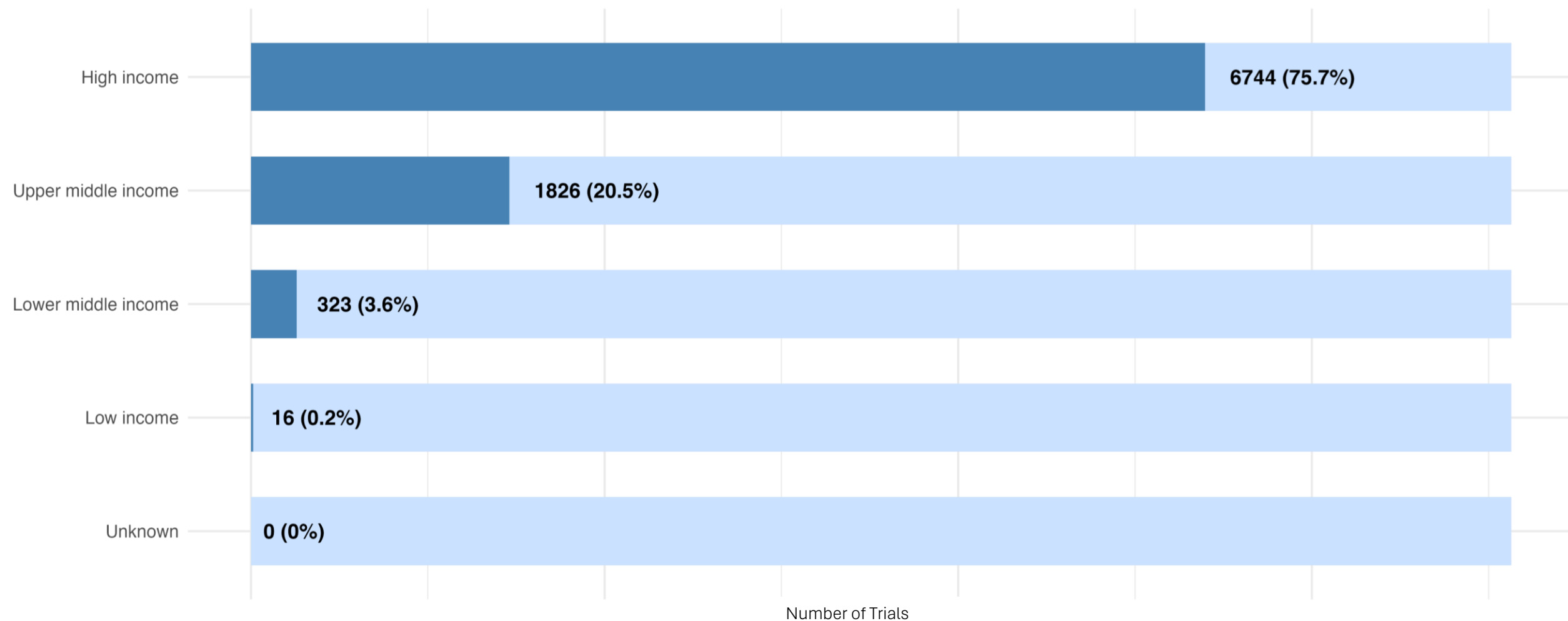




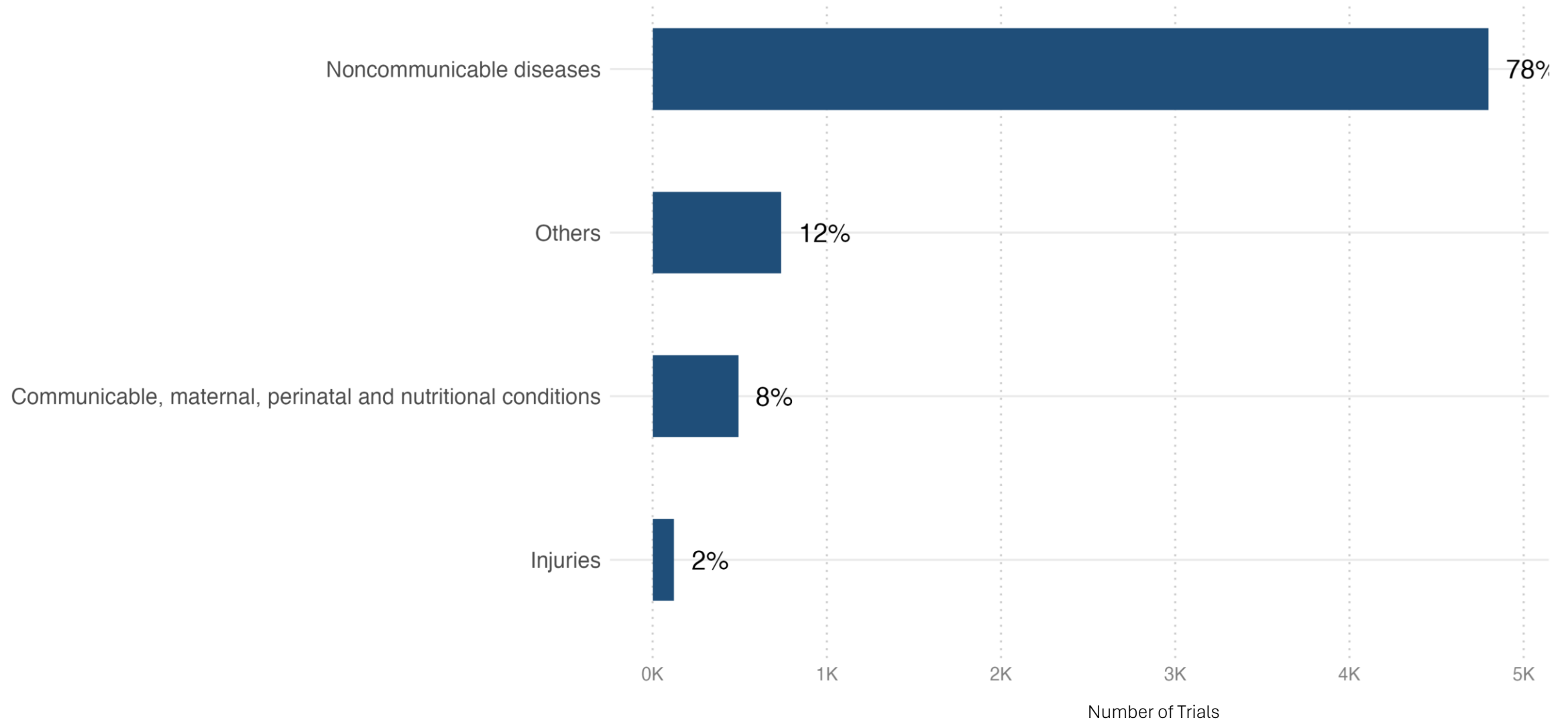
# Few countries responsible for the majority of studies



# Genomic clinical studies are dominated by high income countries

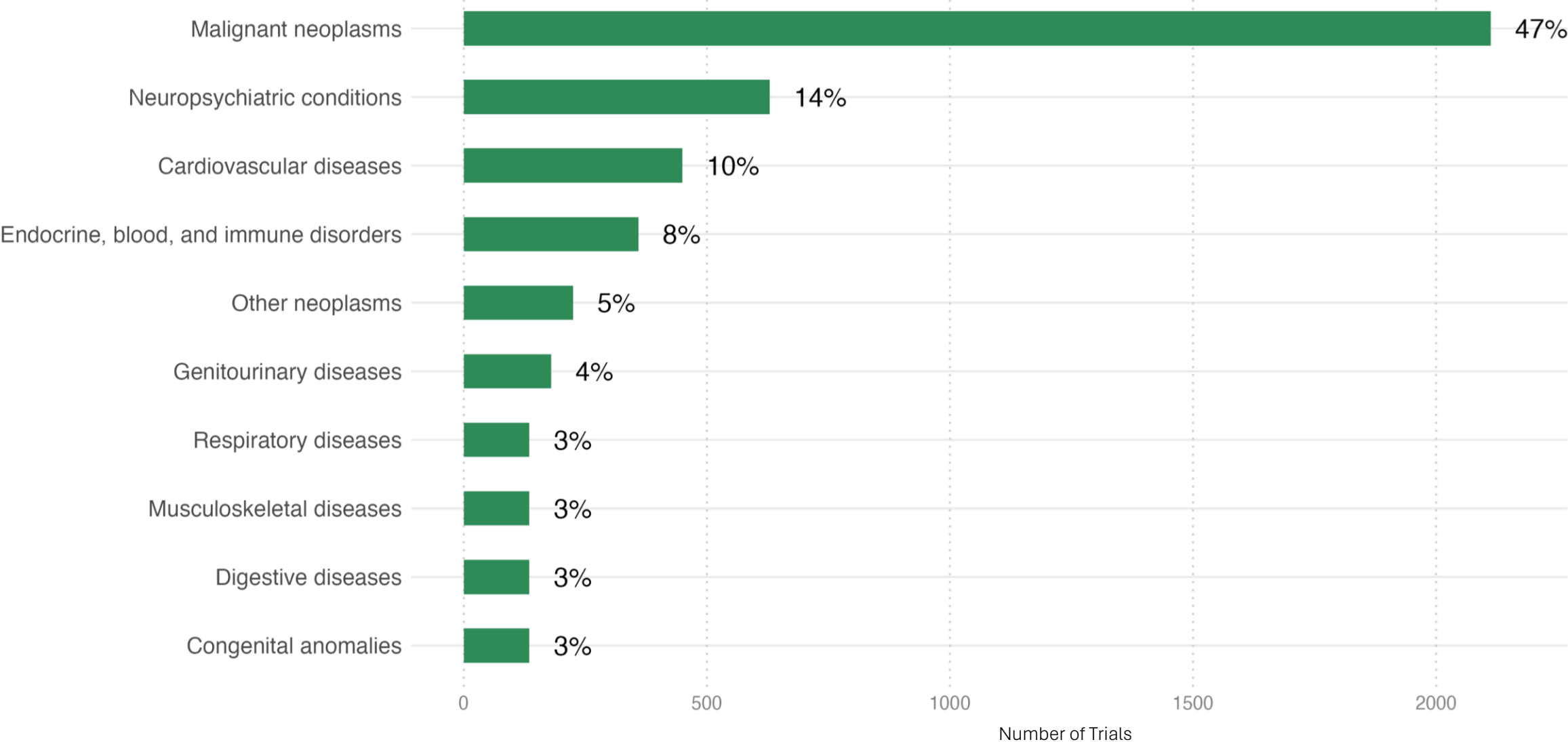


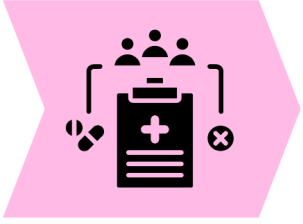
# What are the key focus areas of genomic studies?





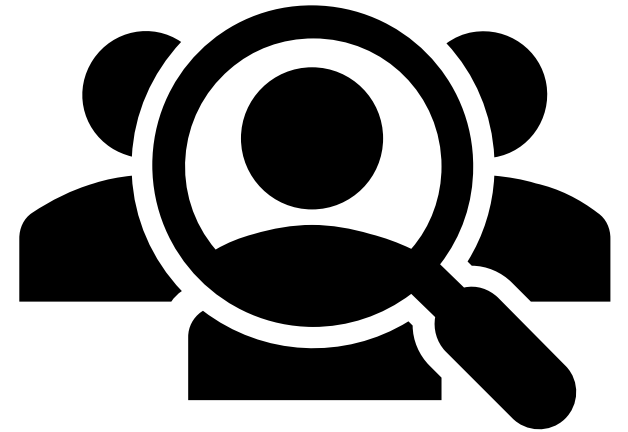
# Genomic studies are primarily focused on cancer research





## Key messages: genomics technologies to inform Precision Medicine

- Human genomic data use in clinical practice is accelerating
- Genomic and precision medicine research is geographically concentrated
- Genomic research is centered on non-communicable diseases, although infectious diseases represent an untapped potential
- Participation in genomics studies is uneven across the life course
- Efforts to improve equity and impact will require more inclusive, globally aligned research strategies





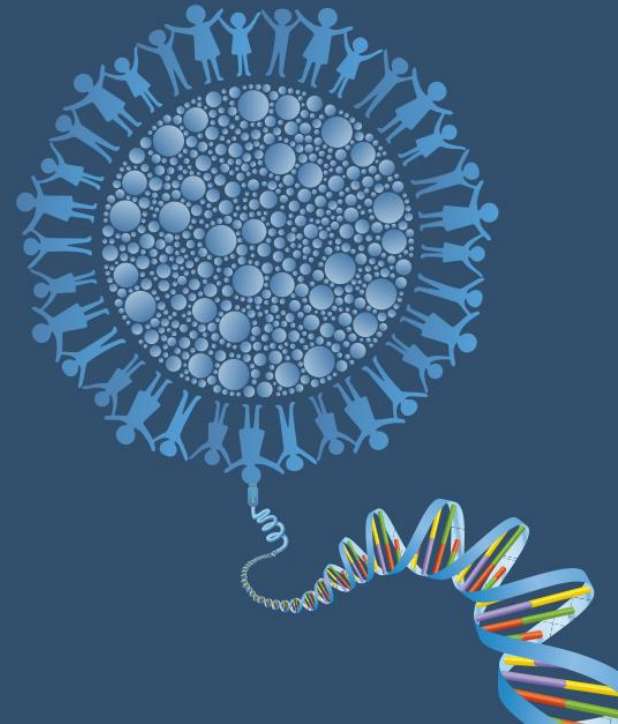


# Looking Ahead – integrating genomics and PM for global health

- Global roadmap with guiding principles, ethical and technical standards, and a roadmap for equitable, sustainable, and context-appropriate implementation\
- Develop a country maturity model for the integration of precision medicine interventions, grounded in a set of measurable indicators, with a view to supporting national capacity-building, prioritization of interventions, and progressive implementation
- Provide technical and normative support to Member States to integrate and prioritize PM interventions based on country-specific contexts
- Facilitate knowledge exchange, collaborations and partnerships

## Acknowledgements

- Patient representatives and civil society groups
- Global experts
- WHO Technical Advisory Group
- WHO Team: Elena Ambrosino, Sara Niedbalski, Sarah Charnaud, Katherine Littler
- Funders



# Thank you for your time and engagement

Connect with us: [genomics@who.int](mailto:genomics@who.int)

Learn more:

