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Center for Genomic Medicine Ethics & Policy

Genomics: Governance, Ethics, Policy, Practice – A Monthly Digest

March 2025 – Number 13

Genomics – spanning discovery, preclinical, clinical and translation to daily patient interventions – continues to evolve at an extraordinary pace. Advances in the scientific and technical dimensions of genomics overall are extensively communicated through the peer-reviewed journal literature and supporting grey literature.

Complementing this technical literature is a growing body of research, analysis and commentary addressing the governance, ethics, regulation, and policy dimensions of areas including genomic medicine. Much of this content is communicated through academic journals and grey literature. This digest intends to capture and curate the most substantive examples of this non-technical content.

Further, we intend this digest to provide a useful summary of key strategic and programmatic announcements from across genomics as issued by multilateral agencies, INGOs, governments/regulatory bodies, academic and research institutions, consortiums and collaborations, foundations, investors, and commercial organizations.

Given the complexity and velocity of the field, we are striving to make this digest comprehensive – but we acknowledge it is not exhaustive. We invite suggestions and ideas on how it can evolve to be more useful.

The digest is a program of the GE2P2 Global Foundation which is solely responsible for its content. Questions and comments should be directed to the Editor as below:

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Month in Review – *Milestones, Strategic Announcements, Analysis, Guidance*

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National Genomics Programs

The expanding global genomics landscape: Converging priorities from national genomics programs

Perspective

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American Journal of Human Genetics (2025), Published online March 10, 2025 Open access
https://doi.org/10.1016/j.ajhg.2025.02.008

Summary

The global landscape of health genomics is expanding rapidly, with an increasing number of national and international initiatives, many of which are targeted toward accelerating the clinical implementation of genomic technologies and services in the context of local health systems. This includes a range of entities with different levels of maturity, funding sources, and strategies that focus on research and clinical priorities to varying degrees. While there is no "one-size-fits-all" approach, analysis of national genomics programs helps to identify common priority areas, barriers, and enablers. Here, we synthesize the converging priorities of several national genomics programs to highlight the importance of progressing genomics research and clinical implementation on a national scale.

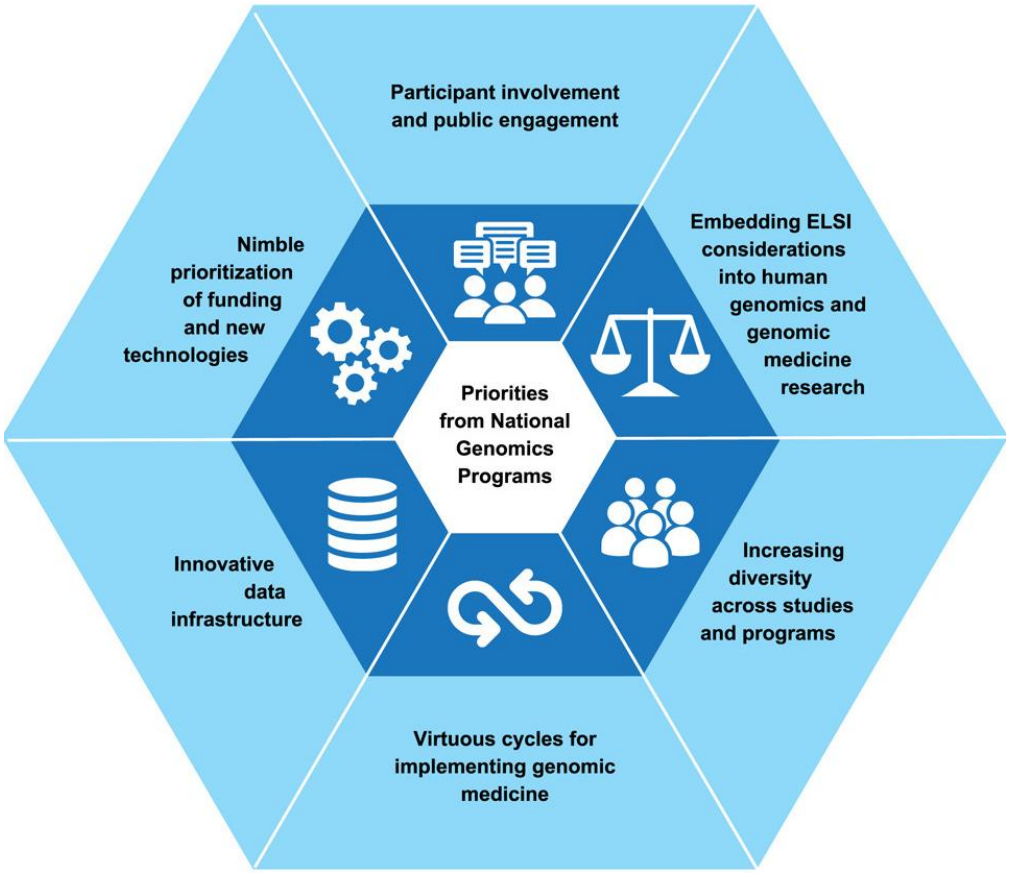
Introduction

Advances in genomic technologies are enabling unprecedented opportunities to transform the diagnosis, treatment, and management of many genetic conditions. The past two decades have seen the cost of DNA sequencing reduce by more than a million-fold, along with significant investments made toward integrating genomics into healthcare.[1,2] A growing number of national genomics programs are providing evidence to guide the system-wide changes required for the clinical implementation of genomics research.[2,3,4,5,6,7,8]

More than 96 major genomics programs have been launched to address barriers to genomic medicine implementation across many different countries.[9] Several large-scale national and international initiatives, including the All of Us Research Program in the United States, the European "1+ Million Genomes" Initiative, and China's Precision Medicine Initiative, are each aiming to sequence the genomes of 1,000,000 individuals to guide evidence-based precision medicine approaches (see web resources).[10,11]

National genomics initiatives often seek to leverage capabilities and address issues that are unique to their local healthcare system; hence, there is no "one-size-fits-all" approach when it comes to the implementation of genomic medicine. Published reviews and frameworks have identified a range of complex issues, such as workforce capability and capacity, the integration and interpretation of data, public acceptability, inconsistent reimbursement, and the development of data infrastructure with robust ethical and legal frameworks.[2,4,8,12] These reviews have also highlighted the critical role of national-level initiatives in driving the integration of genomics into healthcare. **As the field matures, national genomics programs are shifting focus from the diagnostic utility**

of genomics in rare diseases and cancer to sustainable and equitable clinical implementation.



In this perspective, we synthesize information related to seven active national human genomics programs: Genomics England; Genome Canada; the National Human Genome Research Institute (NHGRI); Precision Health Research, Singapore (PRECISE); the Danish National Genome Center (DNGC); the Qatar Genome Program (QGP); and Australian Genomics.

We have identified six priority areas shared by these programs: (1) participant involvement and public engagement; (2) embedding ethical, legal, and social implications (ELSI) considerations into human genomics and genomic medicine research; (3) increasing diversity across studies and programs; (4) virtuous cycles for implementing genomic medicine; (5) innovative data infrastructure; and (6) nimble prioritization of funding and new technologies. We highlight examples of how these priorities are being addressed to compare approaches and inform the design of new genomics programs (Table 1).[4,7,13] Continued investment in each of these inter-related priority areas is required to drive progress toward the broad implementation of genomic medicine globally...

… As national genomics programs mature, they increasingly look beyond their own national context to nurture collaborations and build expertise, with the aim of supporting equitable access to the benefits of genomic medicine internationally and ensuring that low- to middle-income countries and underrepresented populations are not left behind.[73] **Organizations such as the Global Alliance for Genomics and Health (GA4GH) and the Global Genomic Medicine Collaborative (G2MC) are important in building collaborative networks to advance the implementation of genomic medicine on a global scale.[74,75] Prioritizing opportunities to share expertise and lessons learned, such as through the "Tanawwo" network** (which means "diversity" in

Arabic) formed by the QGP under the Qatar Precision Health Institute (QPHI) with representation from 17 low- and middle-income countries (see web resources), is important to facilitate ongoing knowledge exchange and inform the design of genomics initiatives…

Editor's Note:
We include a very useful compilation by the authors of genomics programs as an appendix: Web Resources

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CRISPR in a "globally disjointed regulatory framework"

Managing Expectations for CRISPR in a Volatile World

Editorial Open Access
Rodolphe Barrangou, Editor-in-Chief, The CRISPR Journal
The CRISPR Journal, Volume 8, Issue 1 / February 2025 Published Online: 23 January 2025 https://doi.org/10.1089/crispr.2025.0006

The aftermath of the Casgevy regulatory approval in December 2023 by the U.S. Food and Drug Administration (FDA) was a moment of triumph for CRISPR pioneers and genome editing trailblazers.

Yet the volatile financial, regulatory, and geopolitical situation since then has curbed the enthusiasm of investors. That is concerning news not only for the genome editing community but also for patients, not to mention farmers, consumers, and others among the diverse collective of stakeholders.

Thankfully, however, **there are also reasons to be excited and confident about the promising clinical trial pipeline**. A series of readouts are anticipated throughout 2025.[1] There is continued progress on the therapeutic front with clinical trial program extension and approvals to initiate patient dosing, as recently announced by several CRISPR companies at the 2025 J.P. Morgan Annual Healthcare Conference, typically perceived as the tone setter for the year ahead.

Still, the uncertainty inherent to looming changes at several U.S. federal agencies supervising the medical and agricultural deployment of genome editing is a concern. The trepidation about future FDA, NIH, and CDC leadership and agendas might impact both therapeutic investments and the clinical pipeline execution timeline.

Likewise, the apprehension about the USDA and some recent court decisions regarding the existing regulations governing genetically engineering organisms (Northen District of California Case No. 21-cv-05695-JD related to 7 C. F. R. Part 340, the Sustainable, Ecological, Consistent, Uniform, Responsible, Efficient—SECURE—rule) **could detrimentally affect the commercial launch of genome-edited crops and livestock**, as well as send mixed signals to other jurisdictions in **a globally disjointed regulatory framework**.

Enthusiasm about genome editing remains unwavering within the scientific community, in industry, academia, governmental agencies and investors networks, with a sustained barrage of encouraging scientific studies…

We trust that science-informed decisions will continue to shape governmental policies and regulatory frameworks, and that the foundational principles that buttress translational research will hold steadfast…

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New Guidance – Heritable Intentional Genomic Alterations (IGA): Animals

We note the release of new FDA guidance [January 2025] for the agency's three-category approval approach for "heritable IGAs [Intentional Genomic Alterations] in animals" as below. This extends the FDA's May 2024 guidance on its risk-based approach to oversight also referenced below.

We also note and include an excerpt from the single example of a "Risk-Reviewed IGA" involving a heritable trait – short, slick haircoat in *Bos taurus* cattle – characterized as an adaption for this cattle to be better at withstanding hot weather in tropical or subtropical environments. This IGA "mimics genomic sequences found in conventionally raised cattle with a history of safe use in animal agriculture food production."

Finally, we are refreshing our understanding on the variable regulatory limits on such work across different jurisdictions and will report further in future editions.

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CVM GFI #187B Heritable Intentional Genomic Alterations in Animals: The Approval Process -January 2025

FDA GUIDANCE DOCUMENT - Center for Veterinary Medicine
Final Docket Number: FDA-2019-D-2648

Overview

This guidance explains how FDA's approval process applies in the context of IGAs in animals – intentional genomic alterations made using modern molecular technologies, and which may include random or targeted DNA sequence changes, including nucleotide insertions, substitutions, or deletions, or other technologies that introduce specific changes to the genome of the animal.

This FDA guidance is intended to clarify our requirements and recommendations for developers of IGAs in animals. In order to make FDA guidance regarding IGAs in animals clearer and more streamlined, and to allow for a process to update the more technical portions of our guidance, this guidance has two parts:

> **GFI #187A, "Heritable Intentional Genomic Alterations in Animals: Risk-Based Approach,"** articulates our risk-based approach to the oversight of heritable IGAs in animals. The guidance explains that FDA's approach is risk-based and ranges from: Category 1 products for which we do not expect developers to consult with us prior to marketing an animal containing an IGA; to Category 2 products for which we may not expect developers to submit an application for approval of the IGA if, after looking at data submitted about that product's risk, we find that we understand the product's risks for the specified intended use, any identified risks are appropriately mitigated, and we have no further questions for which we would need to see additional data to address; to Category 3 products for which FDA will review and, where the data supports it, approve a product using data requirements that are proportionate to the risk associated with the particular product; and
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> **GFI #187B, "Heritable Intentional Genomic Alterations in Animals: The Approval Process,"** provides technical guidance for those IGAs in animals that go through the approval process. This guidance is applicable once a sponsor is submitting an application for approval for IGAs described as Category 3 in GFI #187A.

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Intentional Genomic Alterations (IGAs) in Animals: Risk-Reviewed IGAs

[Excerpt]

… Below is a list of those IGAs in animals that, following a risk-based review, FDA has determined we do not expect submission of an application for approval. This is not a determination of "safety" under the Federal Food, Drug, and Cosmetic Act but is instead a determination that we understand the product's risks for the specified intended use and have concluded we have no safety concerns. If FDA becomes aware of new information about risk, it may revisit these decisions.

To increase transparency, FDA, with permission from the developer, intends to publish a summary of the types of data and information it evaluated and its conclusions for risk-reviewed products that are for food use or first of their kind on the market.

FDA – IGAs in Animals for Food Use

[Single example of a documented Risk Assessment Summary]

Risk Assessment Summary – V-006378 PRLR-SLICK cattle

Acceligen Inc (a Recombinetics Company), PRLR-SLICK cattle, SLICK alteration disrupting Bos taurus g.(NC_037347.1) fs(39099129-39099368) in exon 9 of PRLR gene in *Bos taurus*

1. Executive Summary

1. Product Definition

The intentional genomic alteration (IGA) in the prolactin receptor gene (called the *PRLR* gene) truncates (or shortens) the prolactin receptor protein (called the PRLR protein) in *Bos taurus* cattle and results in a short, slick haircoat. The cattle with the IGA are referred to as PRLR-SLICK cattle. The IGA is a heritable alteration that was introduced using a genome editing technique known as CRISPR in two "founder" beef calves. Because the IGA conferring the slick haircoat trait is heritable, it can be passed on to offspring, allowing the trait to be propagated through breeding into a line of PRLR-SLICK cattle.

The IGA is the equivalent to the naturally occurring slick mutations that occur in several breeds of conventionally raised cattle where they likely developed as an adaptation to being raised in tropical or subtropical environments. The slick mutations confer a short, "slick" haircoat, and cattle with the slick phenotype have been reported to be better at withstanding hot weather (Dikmen et al., 2008, 2014; Hammond et al., 1996, 1998; Littlejohn et al., 2014; Olsen et al., 2003).

2. Summary

Acceligen submitted genomic data and other information to FDA to demonstrate that the IGA contained in PRLR-SLICK cattle is the equivalent to naturally occurring mutations that occur in conventionally raised cattle with a history of safe use as a source of human food. These mutations result in the same short, slick haircoat seen in cattle with the IGA, and people have safely eaten food products derived from cattle with the slick haircoat for years.

Molecular characterization

Several different slick mutations developed via selective breeding over the years in multiple cattle breeds as they naturally adapted to sub-tropical and tropical environments. Even though the slick mutations identified to date vary in their specific genomic sequences, current literature suggests these mutations all result in functionally equivalent truncated PRLR proteins (within a defined range of amino acid residues) and confer the same slick phenotype.

PRLR-SLICK cattle have an IGA that mimics genomic sequences found in conventionally raised cattle with a history of safe use in animal agriculture food production…

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Q&A for Developers of Intentional Genomic Alterations in Animals

[Sample question from 17 questions on this webpage]

Q: Must I notify FDA that I am working with IGAs in animals?

A: In general, yes, particularly if you are working with a species traditionally consumed as food. Based on risk, there are some IGAs in animals for which the agency may exercise enforcement discretion and not expect submission of an approval application. For example, FDA is already exercising, and intends to continue to exercise, enforcement discretion for non-food species laboratory animals used for research. On a case-by-case basis, the agency may consider exercising enforcement discretion over other IGAs in animals where, after a review of data, we determine that we understand the product's risks for the intended use, any identified risks are appropriately mitigated, and we have no further questions for which we would need to see additional data to address.

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HGE – Animals

Gene Editing for Enhanced Swine Production: Current Advances and Prospects
Review Open Access
by Won Seok Ju, et al.
Animals 2025, 15(3), 422; Published: 3 February 2025 https://doi.org/10.3390/ani15030422
Simple Summary
Gene editing technologies are heralding a transformative shift in swine farming. This review explores recent advances in gene editing and its potential to enhance pig production. Beyond traditional breeding methods, cutting-edge technologies, such as CRISPR/Cas9, play a key role in improving traits such as disease resistance, growth rate, and feed efficiency. Gene editing focuses especially on addressing critical challenges, including disease resistance, while also exploring broader future applications. **This review not only provides an overview of the current state of gene editing but also examines its practical implications for swine production** and the challenges these technologies face moving forward.
Abstract
Traditional pig breeding has improved production traits but faces limitations in genetic diversity, disease resistance, and environmental adaptation. **Gene editing technologies, such as CRISPR/Cas9, base editing, and prime editing, enable precise genetic modifications, overcoming these limitations and expanding applications to biomedical research**. Here, we reviewed the advancements in gene editing technologies in pigs and explored pathways toward optimized swine genetics for a resilient and adaptive livestock industry. This review synthesizes recent research on gene editing tools applied to pigs, **focusing on CRISPR/Cas9 and its derivatives. It examines their impact on critical swine production traits and their role as human disease models.** Significant advancements have been made in targeting genes for disease resistance, such as those conferring immunity to porcine reproductive and respiratory syndrome viruses. Additionally, **gene-edited pigs are increasingly used as models for human diseases, demonstrating the technology's broader applications.** However, challenges such as off-target effects, ethical concerns, and varying regulatory frameworks remain. Gene editing holds substantial potential for sustainable and productive livestock production by enhancing key traits and supporting biomedical applications. Addressing technical and ethical challenges through integrated approaches will be essential to realize its full potential, ensuring a resilient, ethical, and productive livestock sector for future generations
[Article includes discussion of germline modification options, current work and challenges/limitations].

[Excerpt]
8. Conclusions
T**he advent of gene editing technologies represents a monumental advancement in swine production, offering unprecedented potential to improve animal health, productivity, and**

welfare. As discussed in this review, innovative tools such as the CRISPR/Cas9 system, base editing, and prime editing have established a transformative approach, enabling precise, heritable genetic modifications once deemed unattainable. These technologies have propelled the industry toward an era in which critical traits such as disease resilience, feed efficiency, and reproductive capability can be meticulously optimized, far surpassing the limitations of traditional breeding methods. Gene editing serves as a cornerstone for addressing the primary challenges of swine production, including the need for greater genetic diversity and the constraints posed by selective breeding.

However, challenges remain, including the need to mitigate off-target effects, address mosaicism, and achieve efficient gene delivery. While off-target effects are often cited as a challenge in gene editing, they have not proven to be a major issue in livestock applications, particularly with the advancements in newer technologies, such as improved CRISPR systems and precision delivery methods. These developments have significantly minimized unintended genetic changes, making off-target effects less of a concern in the context of livestock genetic editing.

Ethical and regulatory considerations, which vary widely across regions, necessitate transparent engagement to build public trust and foster broad acceptance. Integrating gene editing with high-throughput sequencing, big data analytics, and artificial intelligence promises unparalleled precision in genetic selection and management. **Achieving these benefits will require cohesive collaboration across research, industry, and regulatory bodies** to harmonize standards, promote innovation, and realize the full potential of gene editing as the cornerstone of a resilient, productive, and ethically responsible livestock sector for future generations.

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Genomics/Genomic Medicine/Surveillance – Africa

Renewed Commitment to Strengthen Public Health Surveillance and Address Disease Outbreaks in Africa

Africa CDC Addis Ababa, March 06, 2025 – The Africa Centres for Disease Control and Prevention (Africa CDC) and Illumina (NASDAQ: ILMN), a global leader in sequencing technology, strengthen their collaboration to advance the **Africa Pathogen Genomics Initiative (Africa PGI).**

The renewed commitment builds on existing efforts over the last 4 years to address COVID-19 and other infectious disease outbreaks, as well as tackle emerging public health threats and endemic diseases like tuberculosis, malaria, and cholera.

Together, both organizations are focused on broadening access to next-generation sequencing (NGS) tools and expertise and enhancing public health surveillance and laboratory networks across Africa.

"Africa CDC is pleased to continue its collaboration with Illumina and other partners to enhance Africa's capacity to detect and respond to emerging health threats. **Genomics is transforming disease surveillance, and this collaboration will help integrate next-generation sequencing into routine public health systems. Our goal remains clear – by the end of 2025, all 55 National Public Health Institutes (NPHIs) will have operational NGS capacity to better protect Africa's health."** said H.E. Dr. Jean Kaseya, Director-General, Africa CDC.

Since the inception of this collaboration in March 2021, Illumina has provided significant contributions, including next-generation sequencing (NGS) platforms, reagents, and training support. As a part of

this association, **additional sequencing instruments and reagents will be provided to around 25 countries…**

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Science and Society: Pathways to Equitable Access and Delivery of Genomics Medicine in Africa

REVIEW

Nchangwi Syntia Munung
Division of Human Genetics, Faculty of Health Sciences, University of Cape Town, Cape Town, South Africa

Current Genetic Medicine Reports, Volume 13, article number 1, (2025) Published: 24 February 2025

Purpose of Review

Recent advances in genetics are pushing the frontiers of health research in Africa. Notable developments include the release of the draft human pangenome reference, regulatory approval of gene editing therapies for sickle cell disease, and the announcements of major initiatives such as the Ghana Genome Project, the Personalized Medicine in North Africa Initiative, Nigeria's 100K Genome Project and South Africa's 110K Human Genomes Project. Additionally, gene-based therapies for HIV are on the horizon, with clinical trials planned in some African countries. Despite this progress, a pressing challenge remains: ensuring equitable access and delivery of genomics medicine worldwide, particularly in Africa and other low and middle income regions.

Summary and a Call to Action

Science diplomacy and academic-industry partnerships are key to achieving "Genomics for All." This requires collaboration between African governments, academic institutions, funding agencies, commercial biotechnology companies, civil society, and international health organizations. Together, these stakeholders must define and establish a sustainable framework to support genetic research in Africa, increase the availability of genetic data from African populations, and set-up translational genomics medicine initiatives tailored to the continent's unique healthcare needs. Science advocacy and diplomacy is also needed to establish mechanisms that prevent the hoarding of genetic resources, including genetic data and novel interventions, and guarantee equitable access to the scientific, medical and economic benefits of genomics for all nations. Achieving this vision may necessitate international treaties to promote equitable access to genomic innovations, responsible and ethical cross-border data sharing, and long-term strategies to address funding gaps in genomic research and its application in medicine and healthcare in Africa.

…Conclusion

Science diplomacy and equitable academic-industry partnerships will be instrumental in ensuring that genomic solutions for medicine and healthcare are accessible to populations across Africa. The WHO Science Council has committed to use its leadership role in global public health to advocate for broader availability of genomics medicine in member states [39]. However, achieving this vision requires unified and sustained efforts from African governments, academic institutions, funding agencies, philanthropists, commercial biotechnology companies, civil society, and international health organizations. These stakeholders must collaboratively define and implement a sustainable pathway to support genetic research in Africa; enhance the availability of genetic data from African populations; and promote translational genomics medicine initiatives tailored to the continent's healthcare priorities. Strong leadership, inclusive of diverse voices from the scientific community, will be essential to advance discussions around "Genomics for All" and science advocacy efforts must prioritise the development of mechanisms to prevent the hoarding of genetic resources, including genetic data and new interventions, and ensure that the scientific, medical, and economic benefits of genomics are equitably distributed among all nations. Drawing lessons from the COVID-19 pandemic,

African nations and the global community must work together to ensure that genomic resources and innovations are used responsibly, equitably, and for the collective benefit of humanity. This calls for international negotiations and treaties to govern access to genomic innovations; frameworks for responsible cross-border sharing of genomic data; equitable academic-industry partnerships; and long-term strategies to address funding gaps for both the conduct and translation of genomics research in Africa.

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Understanding cultural values, norms and beliefs that may impact participation in genome-editing related research: Perspectives of local communities in Botswana

Original Article *Open Access*

Setlhomo Koloi-Keaikitse, Mary Kasule, Irene Kwape, Dudu Jankie, Dimpho Ralefala, Dolly Mogomotsi Ntseane, Gaonyadiwe George Mokone

Developing World Bioethics, Volume 25, Issue 1 Pages: 1-79 March 2025 Pages: 24-34
First Published: 11 January 2024

Abstract

Gene-editing research is a complex science and foreign in most communities including Botswana. Adopting a qualitative deliberative framework with 109 participants from 7 selected ethnic communities in Botswana, we explored the perceptions of local communities on cultural values, norms, and beliefs that may motivate or deter likely participation in the use of gene-editing related research. What emerged as the ethnic community's motivators for research participation include the potential for gene-editing technologies to promote access to individualized medications, and the possibility of protecting family members from genetic related diseases. Deterrents for research participation include cultural values such as implications of lineage for chieftainship, trust, fear or anxiety, uncertainty, and sensitivity on the use of gene-editing. Findings of our study have implications for continuous engagement with local communities to explore potential ways of addressing cultural sensitivities that can further deter their participation in future gene-editing related research.

…

5 CONCLUSIONS

The implications of our findings are not only relevant for identifying aspects of gene-editing research that may motivate or deter communities from likely participation in such research but act as frameworks that can help future researchers prepare in advance for some of the challenges they may face as they interact with local communities in Botswana and other communities in their endeavor to conduct gene editing related research. Our findings also highlight that even when communities may value the use of gene-editing technologies for medical interventions, they also have some fears and anxieties, particularly the implications on how editing human genes may have on their cultural values, norms, practices, and belief systems.

The findings of this study are critical in helping to address some of the questions relating to what health systems may consider in terms of incorporating community values in guidance relating to national genome-editing clinical practices and policy frameworks. Findings also outline critical issues that must be addressed particularly the need for continuous engagement with communities for more open debates of attaining public and community consensus before proceeding with implementation of gene-editing for health interventions. It is, therefore, critical to be transparent about processes of engagement such that it becomes clear who is responsible for which policy choices about specific cultural values and principles and how these can be amended to fit the framework of genome-editing research. Such engagements can be used as a framework to foster collaborative debates and inputs, collectively address some anxieties and misconceptions surrounding future research on the use of gene editing technologies in addressing burden of diseases.

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"Asilomar at 50" – Civil Society Response

The "Spirit of Asilomar…" conference cited below has not posted any recordings or other documentation from the meeting and its website does not indicate what content will be posted, if any *[accessed 14 March 2025].*

We encountered the open statement below – endorsed by institutions from 23 countries – criticizing it as "a closed-door event of screened participants geared towards those who stand to gain" among other observations on the biotechnology sector. We include excerpts from this statement as a data point in the larger context of societal engagement and trust in the stewardship of emerging technologies overall.

We did not identify any response to this open statement by the conference organizers.

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"The Spirit of Asilomar and the Future of Biotechnology"
Meeting, 23-26 February 2025
Rice University, Science History Institute, Stanford University
This summit occurred on the 50th anniversary of the 1975 international meeting on recombinant DNA molecules at the historic Asilomar Conference Grounds in Pacific Grove, California.

The meetings themes and brief background discussion and goals are posted here:
- Pathogens Research & Biological Weapons
- Artificial Intelligence & Biotechnology
- Synthetic Cells
- Biotechnologies Beyond Conventional Containment
- Framing Biotechnology's Futures

[Excerpt from the Framing Biotechnology's Futures theme]
…The "Spirit of Asilomar" invites us to account for what or who has been missing from discussions to critique, and to say "here's another way to move forward." A fuller engagement with various stakeholders and communities invested in biotechnology's futures, and the frames that matter to each, can help all better recognize proxy battles versus points of fundamental disagreement. Understanding – and helping others to understand – the differing perspectives offered by various frames can create opportunities to shape the future of biotechnology – and our societies – in new ways…
[We did not identify any recordings or other documentation of the meeting on the conference website at 14 March 2025]

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An Open Statement from Civil Society (nonprofits) Addressing the '*Spirit of Asilomar and the future of Biotechnology*' conference and to mark the 50th anniversary of the 1975 Asilomar Conference
FINAL TEXT *[Undated; Editor's text bolding]*

We are at a point in human history when **technological developments, including genetic engineering, bioweapons, virological research, synthetic biology and other technologies, carry existential threats to health, the environment, the economy and human society**. Questions about how to regulate, restrict, or prohibit these technologies to reduce risk **require broad-based, open, transparent and honest debate involving all sectors of society.**

The 'Spirit of Asilomar' conference (Feb. 23-26, 2025) is billing itself as such an opportunity. But **we reject it as a meaningful path forward, a closed-door event of screened participants geared towards those who stand to gain.**

The original Asilomar conference of 1975 was a meeting mostly of molecular biologists. It was sparked in part by the possibility that their novel creations would cause society to regulate biotechnology. However, the 1975 meeting was antidemocratic. Held behind closed doors, its schedule was truncated, its invitees were unrepresentative, and the organisers unaccountable.

By disregarding or subverting every one of sociologist Robert Merton's famous scientific norms – universalism, disinterestedness, communism (1), and organised scepticism – Asilomar was not even scientific (Merton, 1942).

The output of Asilomar was more questionable still. Its discussions and the ensuing collective statement focused narrowly on the low-hanging fruit of laboratory containment (Berg et al. 1975). The all-important moral, ethical, technical, commercial, legal, and other concerns raised by biotechnology were virtually ignored. Science was never pristine; but the Asilomar conference could have been a building block for democratic (i.e. inclusive and transparent) decision-making for new technologies. Instead it became a launch-pad for the capture of biological science by unaccountable groups of scientist-entrepreneurs. Asilomar's scientific heirs opportunistically leveraged their arcane knowledge into cash for themselves and risk for the remainder of humanity. The result was royalties and riches for a few, and, to pick examples from agriculture, ruin for family farms and ubiquitous herbicide contamination for the population at large (Connolly et al., 2022; Chang et al., 2024).

As nonprofits working for farmers' rights, food sovereignty and food justice, medical ethics, and ecological sustainability and against seed patents, we have unique first-hand experience of biotechnology. The scientific findings described below are incomplete but nevertheless they are representative of that experience.

Biotechnology is inherently problematic due to its abundance of off-target effects and unexpected consequences (Wilson, 2021). **Fifty years of poorly regulated or unregulated applications inflicted on non-consensual and uninformed populations has yielded very significant negative consequences for human health and the environment.**

Example 1) Insect-resistant (Bt) crops…
Example 2) Herbicide-tolerant (HT) GM crops…
Example 3) Viruses…
Example 4) The three gene-edited babies of He Jiankui…

Conclusions
The first and broadest lesson we take from these examples and other manifestations of biotechnology is that the vast majority of biotechnology is aimed at fixing problems that are man-made or fictitious.

Thus **the grand underlying problem of biotechnology is society dodging its responsibilities**. The remaining lessons are as follows:
a) Enormous harms can derive from biotechnology and these can arise by many routes, both directly and indirectly and from commercial products or laboratory experiments equally;

b) Irrespective of a technology's specifics, whoever controls it inevitably determines whether good or ill ultimately results;

c) Public understanding of biotechnology is weak and easily manipulated but also unnecessarily compounded by 'confidential business information' and lack of government-mandated transparency;

d) Hence the use and oversight of new technology, especially biotechnology, makes exceptional moral, ethical and intellectual demands. Meeting such demands requires the precautionary principle and confronting inherent uncertainties (e.g. Harremoes et al., 2002);

e) However, biotechnologists have shown, for example through hostility to the precautionary principle, cultural unwillingness to study or learn from past mistakes;

f) Regulation of biotechnology should ultimately be by governments acting in the best interests of society as a whole and using the precautionary principle; but this requires the regulator to have:

i) the necessary political authority,
ii) financial independence and
iii) clearly defined responsibilities. Regulators who become cheerleaders for a technology, as commonly happens, have lost their way.

Nevertheless, expert regulators are necessary because the unacceptable alternative to society regulating biotechnology is biotechnology regulating society.

References at title link above.

Institutional signatories from 23 countries as of Feb 26 2025:

1. Alliance for Humane Biotechnology
2. Family Farm Defenders
3. World Family (UK)
4. OGM dangers
5. GeneEthics Ltd
6. The Bioscience Resource Project
7. GMWatch
8. R.I.S.K. Consultancy
9. Global Justice Ecology Project
10. Vigilance OGM
11. Institute for Responsible Technology
12. Human Genetics Alert
13. Coltivatori custodi Campania
14. Associazione Verdi Ambiente e Società
15. Coordinamento zeroogm
16. Ka Ohana O Na Pua
17. Federazione Nazionale Peo Natura
18. MASIPAG
19. Philippine Misereor Partnership Inc.
20. A Bigger Conversation/Beyond GM
21. INOFO INTERCONTINENTAL NETWORK OF ORGANIC FARMER ORGANISATIONS
22. Foll'avoine
23. GMOScience
24. Food Today, Food Tomorrow
25. National Federation of Peasant Women
26. Miljøbevægelsen NOAH (FoE DK)
27. Food in Neighborhoods; Community Coalition
28. IFOAM Seeds Platform
29. Bangladesh Krishok Federation

30. Organic Shizukuishi IFOAM Recognized PGS Initiative
31. Organic Consumers Association
32. VÍA REGENERATIVA Y ORGÁNICA A.C.
33. Regeneration International
34. Københavns Fødevarefællesskab
35. Farmworker Association of Florida
36. PAN Asia Pacific
37. Tanzania Organic Agriculture Movement
38. Canadian Biotechnology Action Network (CBAN)
39. International Coalition to Stop Designer Babies
40. Centro Ecologico (Brazil)
41. Labour Resource Center (LRC)
42. ENSSER (European Network of Scientists for Social and Environmental Responsibility)
43. Centro Internazionale Crocevia
44. Permaculture Association (Britain)
45. AGROLINK Association
46. The Community Supported Agriculture Network UK
47. GE Free New Zealand in Food and Environment
48. GE Free Northland in Food and Environment
49. Pesticide Action and Agroecology Network
50. Association Quinta das Águias
51. THE ORGANIC & NON-GMO REPORT
52. Hatchard Report
53. Pesticide and Agroecology Network (PAN)
54. VIA CAMPESINA
55. Good Food Community (Philippines)
56. Réseau Semences Paysannes
57. Landworkers' Alliance
58. Amis de la Terre (FoE France)
59. Hawaii SEED
60. GMO Free Kaua'i
61. AlleBurgers Netherlands
62. Sow Diverse
63. GRAIN
64. Grøn Hverdag
65. South East Essex Organic Gardeners
66. Sito Seeds

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Public Consultations

In this section we identify relevant public consultations from multilateral organizations, UN system agencies, governments, NGOs, etc. The GE2P2 Global Foundation has a program to actively respond to public consultations where we assess we can make a substantive contribution.

New developments in biotechnology applied to animals: an assessment of the adequacy and sufficiency of current EFSA guidance for animal risk assessment

Public Consultation
EU – European Food Safety Authority :: EFSA Panel on Genetically Modified Organisms
Issue Date: 22 Jan 2025 :: 87 pages **Submissions due 19 March 2025**

PDF:
https://connect.efsa.europa.eu/RM/sfc/servlet.shepherd/document/download/069Tk000008lMi3IAE
Abstract

EFSA received a request by the European Commission (in accordance with Article 29 of Regulation (EC) No 178/2002) **to provide a scientific opinion on new developments in biotechnology, including synthetic biology (SynBio) and new genomic techniques (NGTs), as applied to current or near-market animals for food, feed and other agricultural uses**, with implications for risk assessment methodologies and applicability and sufficiency of the current EFSA risk assessment guidance documents, covering all aspects of molecular characterisation, food and feed safety, animal health and welfare, and environmental safety.

A horizon scanning exercise identified a variety of animals obtained with new genomic techniques (NGT animals), with the potential to reach the EU market in the short, medium and long term, based on the current stage of market development (commercial, pre-commercial, research and development). Site-directed nucleases (SDN) 1 and 2 modify an endogenous DNA sequence without the intended introduction of any foreign genetic material. No novel hazards have been identified that are linked to either the modification process or the newly introduced trait, when these genomic alterations were compared to established genomic techniques (EGTs) and conventional breeding.

Hazards posed by SDN-3 are of the same nature as those posed by EGTs; the targeted insertion may reduce the potential hazards associated with the disruption of endogenous genes and/or regulatory elements in the recipient genome. Hazards posed by the new trait resulting from the introduced transgenic (SDN3) or intragenic DNA sequence are of the same nature as those posed by EGTs. Hazards posed by the new trait resulting from the introduced cisgenic DNA sequence are of the same nature as those posed by conventional breeding. Off-target mutations from genome editing are similar in nature to those from conventional breeding and do not pose novel hazards.

Consequently, no new potential hazards, and thus no new risks to humans, animals, or the environment are anticipated. A thorough evaluation of existing EFSA guidance documents for the risk assessment of GM animals revealed that their principles and recommendations provide the basis for assessing the risks of NGT animals for food, feed and other agricultural uses; however, **the current text covers only partially the topics in several areas (e.g. animal health and welfare), and might require further updates, adaptations, or enhancements on an ad hoc basis, to address the risk assessment of NGT animals, as outlined in this opinion.**

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The multilateral mechanism for the fair and equitable sharing of benefits from the use of digital sequence information on genetic resources, including a global fund ("The Cali Fund"): Submission of views on possible additional modalities of the multilateral mechanism [Public Consultation]

CBD Convention on Biological Diversity, Notification 2024-114 2024-12-10 **Comments no later than 21 March 2025**

As noted in notification 2024-113, at its sixteenth meeting, by decision 16/2, the Conference of the Parties adopted the modalities for operationalizing the multilateral mechanism for benefit-sharing from the use of digital sequence information on genetic resources, including the global fund, which are set out in the annex to the decision, and decided that the global fund will be known as the Cali Fund for the Fair and Equitable Sharing of Benefits from the Use of Digital Sequence Information on Genetic Resources. By the same decision, Parties also set out some intersessional work.

While the Conference of the Parties, in decision 16/2, adopted the modalities of the multilateral mechanism, it also decided (in paragraph 3 of the decision) to explore possible additional modalities, including, in the context of paragraph 7 of decision 15/9 and the annex to decision 16/2, to take products and services into account.

Parties, other Governments, indigenous peoples and local communities, and relevant organizations are invited to submit their views on this issue as soon as possible …

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The multilateral mechanism for the fair and equitable sharing of benefits from the use of digital sequence information on genetic resources, including a global fund ("The Cali Fund"): Submission of views on possible new tools and models, such as databases, for making digital sequence information on genetic resources publicly available and accessible [Public Consultation]

CBD Convention on Biological Diversity, Notification 2024-115 2024-12-10 **Comments no later than 4 April 2025**

As noted in notification 2024-113, at its sixteenth meeting, by decision 16/2, the Conference of the Parties adopted the modalities for operationalizing the multilateral mechanism for benefit-sharing from the use of digital sequence information on genetic resources, including the global fund, which are set out in the annex to the decision, and decided that the global fund will be known as the Cali Fund for the Fair and Equitable Sharing of Benefits from the Use of Digital Sequence Information on Genetic Resources. By the same decision, Parties also set out some intersessional work.

In particular, the Conference of the Parties, in decision 16/2, decided to explore possible new tools and models, such as databases, for making digital sequence information on genetic resources publicly available and accessible in a transparent and accountable manner to all Parties.

Parties, other Governments, indigenous peoples and local communities, and relevant organizations are invited to submit their views on this issue as soon as possible…

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Organization Watch *– Selected Events*

See list of monitored organizations here. Currently we are not listing commercially-organized conferences/meetings.

ARM [Alliance for Regenerative Medicine]
https://alliancerm.org/press-releases/
Upcoming Event
Cell & Gene Meeting on the Mediterranean
April 15–17, 2025, Rome

The Cell & Gene Meeting on the Mediterranean is the leading conference bringing together the entire cell and gene therapy community from Europe and beyond. Covering a wide range of commercialization topics from market access and regulatory issues to manufacturing and financing the sector, this program features expert-led panels, extensive one-on-one partnering capabilities, exclusive networking opportunities, and 60+ dedicated presentations by leading publicly traded and privately held companies in the space. Join ARM for Europe's premier conference for advanced therapies. Visit the program's website at www.meetingonthemed.com for additional details.

Global Observatory for Genome Editing
https://global-observatory.org/
Upcoming Event
Global Observatory International Summit
May 21 – 23, 2025

The Global Observatory will convene an international summit at the American Academy of Arts and Sciences in Cambridge, Massachusetts.
Program now posted. *Registration information not yet posted.*

Global Genomic Medicine Consortium [G2MC]
https://g2mc.org/
Upcoming Event
G2MC 8th International Conference, 2025
DATES TO BE CONFIRMED
The Global Genomic Medicine Consortium (G2MC) 8th International Conference will be held in 2025 in Colombo, Sri Lanka [dates to be confirmed]. The theme of this year's conference is "Collaboration Beyond Borders for Global Implementation of Genomic Medicine" and aims to bring together key stakeholders in the field of genomic medicine to discuss best practices and strategies for implementation, with a particular focus on under-represented regions and low-resource settings.

American Society for Gene and Cell Therapy [ASGCT]
https://asgct.org/
Upcoming Event
ASGCT 28th Annual Meeting
May 13-17, 2025 | New Orleans

Global Alliance for Genomics and Health
https://www.ga4gh.org/
Event
13th Plenary
Uppsala, Sweden from 6 to 10 October 2025
GA4GH 13th Plenary will bring together the global genomics and health community for workshops, presentations, and keynote talks that uncover opportunities to scale genomic and clinical data sharing.
Register for this Event

American Society of Human Genetics (ASHG)
http://www.ashg.org/
Upcoming Event
ASHG 2025 Annual Meeting
The ASHG 2025 Annual Meeting will be held in Boston from October 14-18. The meeting will feature a wide range of scientific sessions, including plenary lectures, symposia, workshops, and poster presentations.
2025 Key Dates & Deadlines: Scientific Abstract Submissions June 9

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African Society of Human Genetics
https://www.afshg.org/about/
Past Event *[No content/recordings identified as yet]*
15th African Society of Human Genetics Conference and the 1st Ugandan Society of Human Genetics and Bioinformatics
3 to 7 February 2025
Entebbe, Uganda
Theme: Harnessing Data Science and Artificial Intelligence for African Genomics

NIH National Human Genome Research Institute (NHGRI)
https://www.genome.gov/
Past Event – Documentation/Recordings
Genomic Medicine XVI: Host Genomics and Infectious Disease
December 12-13, 2024
YouTube Channel for Session Recordings:
https://www.youtube.com/playlist?list=PL1ay9ko4A8sllNYK4dC6EbFDixnVS5xJv
The meeting aims to identify needs, opportunities, and challenges for applying a patient's genomic information (genome sequence, transcriptomic, epigenomic, etc. data) in the diagnosis, prevention, and treatment of infectious diseases. Persistent barriers and evidence gaps will be examined as opportunities for additional research.
Meeting Objectives
The objectives of the meeting were to:
- Define currently available approaches for using host genomic information in the diagnosis, prevention, and treatment of infectious diseases
- Examine obstacles and potential solutions to incorporating these and on-the-horizon approaches in clinical care (e.g., cost, reimbursement, regulatory, access, education, insufficient guidelines, and sparse ascertainment of underrepresented groups)
- Identify research opportunities for increasing implementation of host genomic information in clinical care of infectious diseases

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Organization Watch – *Selected Announcements*
See list of monitored organizations here.

American College of Medical Genetics and Genomics
https://www.acmg.net/
New Releases
The American College of Medical Genetics and Genomics Launches E3 Program to Address Workforce Shortage in Clinical Genetics and Genomics
BETHESDA, MD – February 11, 2025| The American College of Medical Genetics and Genomics (ACMG) announces an innovative approach to confronting the workforce shortage in the field of clinical genetics and genomics. With the launch of the first phase of its E3 (Engage, Equip, Empower) Program at its annual meeting in Los Angeles next month, ACMG and its partners will begin providing early exposure to genetics careers to high school, community college, and undergraduate students from underrepresented backgrounds…

American Society for Gene and Cell Therapy [ASGCT]
https://asgct.org/
Podcast
The When, What, How, and Why of FDA Engagement with Niki Gallo
Listen to The Issue on the ASGCT Podcast Network! | March 11, 2025

American Society of Human Genetics (ASHG)
http://www.ashg.org/
Press Releases/Events
ASHG Responds to Federal Agency Layoffs
February 17, 2025

ASHG Statement on Cuts to NIH-Funded Research Support
February 14, 2025

Australian Genomics
https://www.australiangenomics.org.au/
News & Events
Genomic profiling of cancers key to precision treatment
The integration of genomic profiling and precision oncology into Australia's cancer care system could transform...
February 5, 2025

Broad Institute of MIT and Harvard
https://www.broadinstitute.org/
News 03.12.2025
New technology puts a spatial lens on CRISPR screening
Perturb-FISH reveals impacts of perturbations on gene expression and phenotype with single-cell, spatial resolution, allowing study of effects within and between cells.

News 02.27.2025
An ancient RNA-guided system could simplify delivery of gene editing therapies

CDC – Office of Genomics and Precision Public Health
https://www.cdc.gov/genomics/default.htm
"CDC's Public Health Genomics and Precision Health Knowledge Base (PHGKB) was discontinued effective August 1, 2024. The Tier-Classified Guidelines Database has been removed. All other PHGKB content will remain searchable and be preserved online for historical purposes only until 2029."

Center for ELSI Resources and Analysis (CERA)
https://elsihub.org/about/our-mission
Event Recording
ELSI - GC Exchange | The ELSI of Polygenic Scores for Social Traits
Publicly-funded researchers frequently transfer their gene therapy and gene-editing medical research to venture capital-funded startups for clinical development. In tandem, the public sector financial crisis in many countries has meant that partnerships with commercial entities are used to leverage the full potential of publicly-held genomic data. However, public-private partnerships in the genomics translational pipeline raise several key questions. Which benefits should be returned to the public, if any? How should products be priced? How should data be managed? Does involvement of publicly funded scientists in the commercial sector conflict with the commitment to deliver societally beneficial innovation?
Moderator: Philip J. Brooks, PhD
Panelists: John Conley, JD, PhD & Eva Winkler, Prof, Dr.med., Dr.phil.

Global Alliance for Genomics and Health
https://www.ga4gh.org/
News, Events
6 Mar 2025
Sasha Siegel joins GA4GH as Chief Product Officer

27 Feb 2025
GA4GH Inc. welcomes four new Board Members

The Global Alliance for Genomics and Health (GA4GH) is pleased to welcome Krystal Tsosie (Arizona State University), David Glazer (Verily), Arcadi Navarro (Universitat Pompeu Fabra and Centre de Regulació Genòmica [Center for Genomic Regulation]), and Patrick Tan (Precision Health Research Singapore) to the Board of Directors of GA4GH, Inc.

Event
13th Plenary
Uppsala, Sweden from 6 to 10 October 2025
GA4GH 13th Plenary will bring together the global genomics and health community for workshops, presentations, and keynote talks that uncover opportunities to scale genomic and clinical data sharing.
Register for this Event

Genomics England
https://www.genomicsengland.co.uk/
Latest
20 Feb 2025
Almost 90% of people would agree to genetic testing to tailor medication use, survey finds
New research shows almost 90% of people in England would agree to genetic testing to get the most effective medication and reduce the risk of side effects

Genetics Society of America (GSA)
https://genestogenomes.org/news-events/
News & Events
Policy & Advocacy
A Call to Action: Learn what you can do now to protect science
A message to the GSA Community from the Executive Committee of the Genetics Society of America. GSA is committed to supporting the genetics community in continuing to advocate for scientific research and the advancement of the field.
February 19, 2025

Global Observatory for Genome Editing
https://global-observatory.org/
Event
Global Observatory International Summit
May 21-23, 2025

Innovative Genomics Institute
https://innovativegenomics.org/about-us/
News, Events
Wolf Prize Laureate Brian Staskawicz on 40 Years of Plant Immunity Research
March 11, 2025 *Press Releases*
By Hope Henderson
IGI's Director of Sustainable Agriculture, Brian Staskawicz, was awarded the 2025 Wolf Prize in Agriculture for key discoveries in plant immunity. The Wolf Prize in Agriculture, considered by many the Nobel Prize for agriculture, has been awarded annually since 1978 and carries a monetary award of $100,000.

NIH – All of Us Research Program
https://allofus.nih.gov/news-events/announcements

News and Events

***All of Us* Releases New Cognitive and Behavioral Health Data**

The National Institutes of Health's All of Us Research Program has released a vast and novel set of data to help advance and improve how mental and cognitive health disorders are defined, diagnosed, and treated. The All of Us dataset is now even better positioned to accelerate research in mental health and chronic conditions as the data are included in the program's Researcher Workbench alongside genomic, clinical, and lifestyle information.
February 24, 2025

***All of Us* Adds Data from 50% More Participants in Largest Data Expansion to Date**

The National Institutes of Health's All of Us Research Program has expanded its data available for research to now include data from more than 633,000 participants – a 50% increase from the previous release. Additionally, the program has increased its genomic dataset by nearly 70% and quadrupled the number of participants with Fitbit wearable data. These updates enhance the program's vast and comprehensive dataset, one of the largest globally, to enable discoveries that will advance our understanding of health and disease.
February 24, 2025

National Organization for Rare Disorders (NORD)
https://rarediseases.org/news/
News & Articles
Highlights from Rare Disease Day 2025
Published March 11, 2025 by NORD

Penn Center for Global Genomics & Health Equity [University of Pennsylvania]
https://globalgenomics.med.upenn.edu/index.php
Event
Inclusive Genomics to Promote Health Excellence
May 14-15, 2025 *[Save the Date]*

Wellcome Sanger Institute
https://www.sanger.ac.uk/
News
Largest ever DNA sequencing dataset on UK child development studies available
News 4 Mar 2025

For the first time, large-scale DNA sequence data on three UK long-term birth cohorts has been released, creating a unique resource to explore the relationship between genetic and environmental factors in child health and development.

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Month in Review – *Milestones, Strategic Announcements, Analysis, Guidance*
Organization Watch – *Selected Events*
Organization Watch – *Selected Announcements*
Journal Watch – *Spotlight Articles, Thematic Sections*
Journals/Pre-Print Sources Monitored
Institutions/Organizations Monitored

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Journal Watch

In preparing *Journal Watch*, we formally monitor a broad range of academic journals [listed here] and, in parallel, utilize Google Scholar to identify articles aligned with our areas of focus. After careful consideration, a selection of these results appear in the digest, organized under thematic areas to help readers navigate.

Thematic Areas

HGE/HIGA – Heritable Genome Editing; Intentional Genomic Alteration

GENOMIC ENGINEERING/GENOME EDITING [SOMATIC]

PRECISION MEDICINE

DISEASE-SPECIFIC GENOMICS

CLINCIAL TRANSLATION

GENOMICS RESEARCH ETHICS, REGULATION, INTEGRITY

GENOMIC DATA, BIOBANKING

PUBLIC AND COMMUNITY ENGAGEMENT/EDUCATION

GENETIC SEQUENCING/SCREENING/GENETIC COUNSELLING

ANIMALS, PLANTS, MICROORGANISMS

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HGE/HIGA – HERITABLE [INTENTIONAL GENOMIC ALTERATION]

The Precautionary Principle: A Public Policy Tool to Support the Application of Heritable Human Genome Editing?

Research Article

Olga C. Pandos, Lecturer, The University of Adelaide, Adelaide Law School

Abstract

The Precautionary Principle ('PP') is a legal, ethical and regulatory chameleon. It acts as a guide to decision-making, in conditions of scientific uncertainty. Therefore, a fundamental aim of it is to offer some certainty under conditions that are largely uncertain. The advent of Clustered Regularly Interspaced Short Palindromic Repeats ('CRISPR') technology epitomises an emerging technology which does not lend itself to regulatory convenience. Its far-reaching scientific, ethical, social, legal and regulatory implications, renders the task of applying a rigid, uniform framework or decision-making mechanism impossible. Unsurprisingly, the current regulatory approach for Heritable Human Genome Editing ('HHGE') is highly prohibitive, manifested as a blanket moratorium. However, as the technology continues to mature, it is prudent to consider pathways for its eventual legal and regulatory permissibility.

Subsequently, this principle offers a means to formulate future public policy and regulation. The primary aim of this article is to advance an argument for the practical utility of this principle in supporting a therapeutic use of HHGE. Namely, to prevent Huntington's Disease – a fatal monogenic genetic disease. As observed with somatic genome editing, it is feasible to presume the first therapeutic use of HHGE may target fatal monogenic genetic diseases (caused by a single mutation). Through the application of the framework provided by the World Commission on the Ethics of Scientific Knowledge and Technology, this article argues that this principle does not necessarily translate to a strict regulatory prohibition. In the context of emerging technologies, its application

must be tempered to accommodate for research development, thereby enabling technological advancement.

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GENETIC ENGINEERING/GENE EDITING [SOMATIC]

No new, substantive journal content identified.

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PRECISION MEDICINE

A roadmap to precision medicine through post-genomic electronic medical records

Perspective

Kevin M. Mendez, Stacey N. Reinke, Rachel S. Kelly, Qingwen Chen, Mark Su, Michael McGeachie, Scott Weiss, David I. Broadhurst & Jessica A. Lasky-Su

Nature Communications volume 16, Article number: 1700 (2025). 17 Feb 2025

Abstract

The promise of integrating Electronic Medical Records (EMR) and genetic data for precision medicine has largely fallen short due to its omission of environmental context over time. Post-genomic data can bridge this gap by capturing the real-time dynamic relationship between underlying genetics and the environment. This perspective highlights the pivotal role of integrating EMR and post-genomics for personalized health, reflecting on lessons from past efforts, and outlining a roadmap of challenges and opportunities that must be addressed to realize the potential of precision medicine.

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DISEASE-SPECIFIC GENOMICS

Sickle Cell Disease in Sub-Saharan Africa: Is CRISPR-Cas9 the Breakthrough We've Been Waiting for?

Review Article

Simeon Christopher Aloy, Godae Fidelis Beega, Covenant Oluwadamilola Adeshina, Elizabeth Funmi Bassey, Prudence Nkechinyere Nkpurukwe, and Ekprikpo Erens Spiff

Asian Journal of Biochemistry, Genetics and Molecular Biology 17 (2):59- 86. https://doi.org/10.9734/ajbgmb/2025/v17i2443**. 5 Feb 2025**

Abstract

Sickle cell disease, which results from a single nucleotide substitution in the beta-globin gene (HBB) is recognized as a significant global health concern. Approximately 7.74 million people worldwide were living with sickle cell disease in 2021. Sub-Saharan Africa carries the highest disease burden, with mortality rates ranging from 50 to 90% among affected children within the first five years of life. Current FDA-approved therapies (hydroxyurea and glutamine) offer symptomatic relief but are not sufficient to fully prevent the disease from progressing into a chronic condition. Allogeneic hematopoietic stem cell transplantation is the only curative treatment but is limited by donor availability and immunological complications. Advances in gene-editing technologies, particularly CRISPR-Cas9, present promising solutions by enabling precise genetic modifications. CRISPR-Cas9 is employed to treat sickle cell disease either through direct correction of the causative mutation in the HBB gene or by inducing fetal haemoglobin production. The FDA's recent approval of CASGEVY™ marks a historic milestone as the first CRISPR-based therapy for sickle cell disease. CASGEVY™, which induces fetal haemoglobin production, showed 93.5% efficacy in preventing severe vaso-

occlusive crises in sickle cell disease patients, with no graft failures or rejections reported. Despite its promise, challenges remain, including technical barriers such as delivery strategies, off-target effects, and unintended genetic alterations, as well as ethical, societal, and regulatory concerns. In Sub-Saharan Africa, inadequate healthcare infrastructure, high treatment costs, and limited public awareness further hinder widespread adoption. To harness CRISPR's potential, Africa must invest in advanced genomic laboratories, interdisciplinary training for healthcare professionals, and robust educational programs in molecular biology and biotechnology. Regional and international collaborations are essential to overcome these barriers, streamline regulatory processes, and foster public acceptance as CRISPR-Cas9 holds transformative potential for addressing sickle cell disease in Africa, offering a pathway toward reducing mortality and improving quality of life for affected populations.

Gene therapy for the eyes and ears: hopes and challenges

Editorial, The Lancet

The Lancet, Feb 22, 2025 Volume 405 Number 10479 p597-670

This week, The Lancet publishes a first-in-human interventional study of gene supplementation therapy for children with AIPL1-associated retinal dystrophy, which causes severe impairment of sight from birth. The four children in the study showed improved functional vision without serious adverse effects. Inherited retinal diseases (IRDs) affect 5–6 million people worldwide and are a heterogenous group of diseases caused by mutations in over 300 mapped genes responsible for the structure and function of retinal cells. Genes that determine retinal function other than AIPL1 have been targeted with similar therapies, with the gene of interest being delivered via recombinant adeno-associated virus, but only voretigene neparvovec for RPE65 mutation is approved as a treatment for IRDs. Promising results have also been reported for gene therapy in some forms of congenital deafness. These preliminary findings are encouraging and bring hope to those affected, but what do they mean for blind and deaf communities and what are the challenges of these therapies?

The roll-out of gene therapy has not been without difficulties, mostly related to side-effects and complex technology but also, that such therapy will not work for every genetic condition. The retina and ear are particularly good candidates for gene therapy. They are relatively easy to access surgically for vector delivery, allowing for localised treatment and reduced vector requirements, reducing potential side-effects and immune reactions. The effects of delivering the viral vector to the right cells can be easily measured and, since retinal and ear cells mostly do not divide, the therapeutic gene can last a long time after a single treatment, possibly providing long-term benefits after a one-off intervention.

These interventions can help transform lives. Visual perception attainment is a gradual process that depends on exposure to visual stimuli during postnatal development. As the eye develops so does the visual cortex, and there is a critical period after which neuroanatomical changes due to blindness are irreversible, so early interventions are key. Importantly, although cochlear implant might be available for deafness in some cases, there are mostly no treatments available for inherited retinal diseases. Vision is the main influence that shapes the social brain in the first years of life, and visually impaired children show an increased risk for developmental delay in areas such as communication, mobility, and behaviour. Similarly, children who are born deaf and do not receive early intervention are at an increased risk for poor literacy outcomes and a reduced quality of life. Parents and teachers of children receiving the AIPL1 gene therapy reported positive behavioural changes after treatment, supporting benefits beyond vision.

The main challenges for these therapies are cost and accessibility—voretigene neparvovec is estimated to cost US$425 000 per eye…

Comment

Gene therapy for young children with congenital blindness

Artur V Cideciyan, Tomas S Aleman

Articles

Gene therapy in children with AIPL1-associated severe retinal dystrophy: an open-label, first-in-human interventional study
Michel Michaelides, et al

Genomics of rare diseases in the Greater Middle East
Perspective
Chekroun, I., Shenbagam, S., Almarri, M.A. et al
Nature Genetics (2025). https://doi.org/10.1038/s41588-025-02075-8**. 3 Feb 2025**
Abstract
The Greater Middle East (GME) represents a concentrated region of unparalleled genetic diversity, characterized by an abundance of distinct alleles, founder mutations and extensive autozygosity driven by high consanguinity rates. These genetic hallmarks present a unique, yet vastly untapped resource for genomic research on Mendelian diseases. Despite this immense potential, the GME continues to face substantial challenges in comprehensive data collection and analysis. This Perspective highlights the region's unique position as a natural laboratory for genetic discovery and explores the challenges that have stifled progress thus far. Importantly, we propose strategic solutions, advocating for an all-inclusive research approach. With targeted investment and focused efforts, the latent genetic wealth in the GME can be transformed into a global hub for genomic research that will redefine and advance our understanding of the human genome.

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CLINCIAL TRANSLATION

Clinical trials to gene therapy development and production in Brazil: a review
Review
Morales Saute, Jonas Alex et al.
The Lancet Regional Health – Americas, Volume 43, 100995. 29 Jan 2025
Summary
Challenges related to the implementation of gene therapy products are daunting for low-to middle-income countries, such as Brazil, and include the creation of an appropriate technical, regulatory, and economic environment. In this manuscript, we give an overview of historical aspects, as well as the current state of clinical trials and approved gene therapy products for commercialization in Brazil. Focusing on gene replacement and CAR-T cell therapies, we discuss the main advances, limitations, and difficulties faced by the country in the production, approval, and incorporation of such products into the public health system. Finally, we highlight the potential leading role that low-to middle-income countries can have in this industry, not only by providing their own vector supply but also by addressing important issues related to the sustainability and long-term global affordability of gene therapy products.

Inequalities and Inclusion in Genomics Applied to Healthcare: A Latin American Perspective
Review Article
Iscia Lopes-Cendes and Thais C. de Oliveira
Annual Review of Genomics and Human Genetics, Vol. 26 https://doi.org/10.1146/annurev-genom-111224-100329**. 30 Jan 2025**
Summary
Integrating genomics into healthcare within the precision medicine (PM) framework poses distinct challenges in resource-limited regions like Latin America and the Caribbean (LAC). These challenges arise partly from the lack of PM models tailored for low- and middle-income countries. To address

this, healthcare authorities in LAC should adopt predictive models to estimate costs and infrastructure needed for PM programs. The predominance of admixed populations in LAC adds complexity, given their underrepresentation in genomic studies. Establishing a robust regulatory framework is essential for managing ethical, legal, and privacy concerns related to genomic data. Despite these challenges, current regional efforts showcase the feasibility of integrating genomics in LAC and highlight the importance of expanded collaborations. By sharing data, resources, and expertise, LAC countries can overcome funding and infrastructural barriers while upholding ethical standards and data protection across the region.

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GENOMICS RESEARCH ETHICS, REGULATION, INTEGRITY

Ethics and Intellectual Property Rights in Genetic Therapy

Article

Raymond R. Tjandrawinata, Ina Heliany, Henry Soelistyo Budi

Asian Journal of Social and Humanities, Vol. 3 No. 5 (2025). 22 Feb 2025

Abstract

Genetic technology, particularly CRISPR-Cas9, has transformed the paradigm of treating genetic diseases by offering new hope for more effective and precise therapies. However, this advancement also presents significant ethical and intellectual property rights (IPR) challenges. This article explores the impact of patents on the development and accessibility of genetic therapy, as well as the ethical issues arising from human genetic modification, especially at the germline level. Using a qualitative analytical approach that combines literature reviews and case studies, the article examines patent disputes that have emerged in the development of CRISPR and how applied patent policies can exacerbate inequities in access to critically needed medical therapies. Furthermore, the article discusses ethical concerns regarding the misuse of genetic technology and its potential impact on future generations. In conclusion, the article proposes the need for more inclusive and balanced policies that prioritize both innovation and accessibility, as well as strict regulations to ensure the safe and ethical application of genetic technology, while considering broader social and cultural impacts.

Research Guideline Recommendations for Research on Stem Cells, Human Embryos, and Gene Editing

Review Article

Var SR, Strell P, Shetty A, et al

Cell Transplantation. 2025;34. 25 Feb 2025 doi:10.1177/09636897241312793**.**

Abstract

Recent advances in biomedical technologies have extended the boundaries of previously established regulatory guidelines pertaining to stem cell research. These guidelines constrained the study of human pluripotent stem cells (hPSCs) and their derivatives from use under various conditions, including the introduction of hPSCs into the brains of host animals because of concerns of humanizing the brains of animal species. Other guidelines constrained the use of hPSCs in creating human-animal chimeras because of the potential contribution of human stem cells not only to the brain but also to the germline. Some regulatory guidelines forbid the growing of human embryos *ex vivo* beyond the stage of primitive streak development because of concerns regarding the creation of human forms of life *ex vivo*. At the subcellular level, there are guidelines regulating the transfer of mitochondria within human embryos. At the molecular level, there are guidelines regulating genome editing to prevent permanent genetic alterations in germline cells. These and other issues related to stem cells have been reviewed, and new research guidelines established by the International Society for Stem Cell Research (ISSCR) for its membership. Because many of the recommended changes by the ISSCR impact research being conducted by members of the American Society for Neural Therapy and Repair

(ASNTR), the ASNTR established a task force to review relevant recommendations by the ISSCR to determine which new guidelines to adopt for research conducted by the ASNTR society membership. The final ASNTR recommendations are presented in this document.

From Data to Harm: Exploring Ethical and Social Implications of Polygenic Scores for Social Traits

Open Peer Commentaries

Cadigan, R. J., Watson, S., & Prince, A. E. R.

The American Journal of Bioethics, 25(2), 82–84. 29 Jan 2025

https://doi.org/10.1080/15265161.2024.2441743**.**

Abstract

In their paper, Chapman and colleagues (2025) argue how key regulations and "data-centric" research practices neglect to address potential group harms. They utilize the case of genomic research on same-sex sexual behaviors (Ganna et al. 2019) to highlight the potential for harm to LGBTQ+ communities and the inadequacy of broad consent to anticipate research on traits that stretch the bounds of health-related research. While this and similar research on social and behavioral traits could increase understanding of gene-environment interactions, some worry findings could contribute to negative downstream effects. Indeed, the group harms that Chapman and colleagues may worry about are primarily outside of, and downstream from, the research endeavor, such as discrimination, criminalization, or eugenics. The same-sex sexual behavior study exemplifies an entire field of research, called sociogenomics, which seeks to understand genetic contributions to social or behavioral traits. Within this field, researchers use methodologies originally developed to identify risk for complex health conditions via polygenic scores (PGS). Such scores are created using genomic data from biobanks to measure the aggregate contribution of thousands of genetic variants, each weighted by their association with the trait of interest. Sociogenomic PGS research most often identifies genetic associations with responses to social science survey questions, such as about same-sex sexual behaviors. Because PGS research requires vast datasets, biobanks that house genomic samples as well as phenotypic and lifestyle data from hundreds of thousands of participants (eg, UK Biobank, All of Us) play a pivotal role in advancing sociogenomic research. Chapman and colleagues call for empirical research to investigate how IRBs, researchers, and research participants consider group harms….

Perspective Chapter: Ethical Implications and International Human Rights Protections of Gene Editing of DNA Sequences

Book Chapter

Dorkina Myrick

IntechOpen, 25 Feb 2025 doi: 10.5772/intechopen.1009025.

Abstract

CRISPR-Cas9 studies have implicated gene editing of DNA sequences for medical treatment of diseases such as sickle cell anemia, thalassemia, AIDS, blindness, muscular dystrophy, Huntington's disease, and cystic fibrosis. Moreover, gene editing technology has contributed to the detection of viruses responsible for the dissemination of communicable diseases such as COVID-19. Despite current scientific progress, many uses of gene editing of DNA sequences are ethically questionable, bordering upon antithetical to principles of human rights protections. The history of genetics, genetic modification of DNA sequences, and human rights has included pseudoscientific practices such as those of the eugenics movement, which dominated much of the nineteenth and early twentieth centuries. Later, United Nations measures such as the International Bill of Human Rights and the Universal Declaration on the Human Genome and Human Rights prompted improvements in human rights practices. Still, genetics rights and human rights in many nations required codification, as human rights standards—including the right to privacy and the protection of genetic data—have been challenged by a host of stakeholders and commercial entities. Ethical limits and international human

rights protections relevant to the use of gene editing technology must be preserved. Considerable progress in disease diagnostics and therapeutics using gene editing and genetic engineering has bolstered the fight for the concurrent preservation of gene editing, ethics, and international human rights protections. As such, this chapter will examine the critical importance of upholding human rights as an essential component of the advancement of gene editing.

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GENOMIC DATA, BIOBANKING

Biobanking as a Contentious Issue in Global Health Governance Diversification and contestation of policy frames in international biobanking debates

Article

Maria Weickardt Soares, Anna Holzscheiter, Tim Henrichsen

Social Science & Medicine, Volume 369, March 2025, 117773. 1 Feb 2025

Abstracts

Biobanks are an integral part of contemporary biomedical and biotechnological research, nationally and internationally. Over time, biobanking has also become invariably more transnationalised, following broader developments of biomedical research across borders and the increasing transnational circulation of human specimen and related data. The manifold technical, legal, ethical and governance challenges resulting from such transboundary, potentially global, circulation of human specimens and related data, however, have to date not resulted in any binding truly international agreement regulating transnational issues with biobanking. In this paper, we analyse when and in what way biobanking has been subject to policy debates in international organisations, with a particular interest in the most prominent policy frames that have informed these debates. We identify biobanking as an underexplored area of research on international policy-making, notwithstanding its prominence in global health cooperation and the many contentious issues that surround it. Our empirical analysis traces the diversification of policy frames over time (1995 to 2019) and, zooming in on those policy frames that emerge as salient yet contested in our analysis, exposes the trajectories of debates on the rules and norms that should govern the transnational circulation and commodification of the human body. We find that biobanking has evolved from a technical, apolitical matter into a multi-faceted issue, which is reflected in the diversification of frames circulating in international organisations. On the basis of our study, we identify a number of policy frames that have emerged as particularly contested over time, with human rights frames standing out as having the most divisive potential.

Data Sovereignty and Genomic Data Across Borders: Taiwan in a Comparative Perspective

Book Chapter

Chih-hsing Ho

International Transfers of Health Data. Perspectives in Law, Business and Innovation, pp 139–157. 4 Feb 2025 Springer, Singapore. https://doi.org/10.1007/978-981-97-9983-1_7**.**

Abstract

This chapter delves into the critical role of genomic data sharing in advancing scientific research, amidst the backdrop of varying international legal frameworks and the concerted efforts of global consortia. Through a detailed examination of regulations such as the European Union's General Data Protection Regulation (GDPR) and the European Health Data Space (EHDS), aimed at fostering a harmonized data ecosystem, alongside the initiatives of the Global Alliance for Genomics and Health (GA4GH), we navigate the complex landscape of genomic data exchange. The case study of Taiwan's approach to genomic data governance illuminates the intricate balance required between protecting data sovereignty and promoting global data sharing. This exploration highlights the importance of a

nuanced strategy that honors both the autonomy of nations and individuals over their genomic data, while also encouraging the cooperative exchange essential for scientific breakthroughs. The insights gained from international experiences, including Taiwan's, offer crucial guidance for developing policies that support the ethical and equitable distribution of genomic data. Such policies are vital for harnessing the potential of genomic research in enhancing global health outcomes and fostering the collective advancement of knowledge.

Protecting Privacy When Genetic Databases Are Commercialized

Viewpoint

Anya E. R. Prince, JD; Kayte Spector-Bagdady, JD, MBE

JAMA, February 25, 2025, Vol 333, No. 8, Pages 647-732 doi:10.1001/jama.2024.26279

Large databases with genomic, phenotypic, and other health data are increasingly important to ensuring successful design and implementation of data-driven health technologies such as artificial intelligence (AI) and machine learning (ML). This makes building large, harmonized, and representative health databases a potentially lucrative business model.[1] But the individuals represented in such databases—whether their data were collected when they were patients, research participants, or consumers—generally have little to no understanding of how they ended up there. When informed, most report discomfort with the commercialization of their health data.[1,2]

Genetic Data Governance in Crisis: Policy Recommendations for Safeguarding Privacy and Preventing Discrimination

Preprint

Vivek Ramanan, Ria Vinod, Cole Williams, Sohini Ramachandran, Suresh Venkatasubramanian

Computers and Society, 13 Feb 2025 arXiv:2502.09716 [cs.CY].

Abstract

Genetic data collection has become ubiquitous today. The ability to meaningfully interpret genetic data has motivated its widespread use across forensics, clinical practice, and research, providing crucial insights into human health and ancestry while driving important public health initiatives. Easy access to genetic testing has fueled a rapid expansion of direct-to-consumer offerings, many of which are recreational in nature. However, the growth of genetic datasets and their applications has created significant privacy and discrimination risks, particularly as our understanding of the scientific basis for genetic traits continues to evolve. In this paper, we organize the uses of genetic data along four distinct 'pillars': clinical practice, research, forensic and government use, and recreational use. Using our scientific understanding of genetics, genetic inference methods and their associated risks, and existing regulatory mechanisms, we build a risk assessment framework that identifies key values that any governance system must preserve. We then analyze case studies from each of the pillars using this framework to assess how well existing legal and regulatory frameworks preserve desired values. Our investigation reveals critical gaps in existing regulatory frameworks and identifies specific threats to privacy and personal liberties, particularly through genetic discrimination. To address these challenges, we call for and propose comprehensive regulatory reforms including: (1) updating the legal definition of genetic data to protect against modern technological capabilities, (2) expanding the Genetic Information Nondiscrimination Act (GINA) to cover currently unprotected domains, and (3) establishing a unified regulatory framework under a single governing body to oversee all applications of genetic data. We conclude with three open questions about genetic data: the challenges posed by its relational nature, including consent for relatives and minors; the complexities of international data transfer; and its potential integration into large language models.

Data stewardship and curation practices in AI-based genomics and automated microscopy image analysis for high-throughput screening studies: promoting robust and ethical AI applications

Article

Asefa Adimasu Taddese, Assefa Chekole Addis, Bjorn T Tam
Human Genomics. 2025 Feb 23;19(1):16. doi: 10.1186/s40246-025-00716-x.
Abstract

Background

Researchers have increasingly adopted AI and next-generation sequencing (NGS), revolutionizing genomics and high-throughput screening (HTS), and transforming our understanding of cellular processes and disease mechanisms. However, these advancements generate vast datasets requiring effective data stewardship and curation practices to maintain data integrity, privacy, and accessibility. This review consolidates existing knowledge on key aspects, including data governance, quality management, privacy measures, ownership, access control, accountability, traceability, curation frameworks, and storage systems.

Methods

We conducted a systematic literature search up to January 10, 2024, across PubMed, MEDLINE, EMBASE, Scopus, and additional scholarly platforms to examine recent advances and challenges in managing the vast and complex datasets generated by these technologies. Our search strategy employed structured keyword queries focused on four key thematic areas: data governance and management, curation frameworks, algorithmic bias and fairness, and data storage, all within the context of AI applications in genomics and microscopy. Using a realist synthesis methodology, we integrated insights from diverse frameworks to explore the multifaceted challenges associated with data stewardship in these domains. Three independent reviewers, who systematically categorized the information across critical themes, including data governance, quality management, security, privacy, ownership, and access control conducted data extraction and analysis. The study also examined specific AI considerations, such as algorithmic bias, model explainability, and the application of advanced cryptographic techniques. The review process included six stages, starting with an extensive search across multiple research databases, resulting in 273 documents. Screening based on broad criteria, titles, abstracts, and full texts followed this, narrowing the pool to 38 highly relevant citations.

Results

Our findings indicated that significant research was conducted in 2023 by highlighting the increasing recognition of robust data governance frameworks in AI-driven genomics and microscopy. While 36 articles extensively discussed data interoperability and sharing, AI-model explain ability and data augmentation remained underexplored, indicating significant gaps. The integration of diverse data types—ranging from sequencing and clinical data to proteomic and imaging data—highlighted the complexity and expansive scope of AI applications in these fields. The current challenges identified in AI-based data stewardship and curation practices are lack of infrastructure and cost optimization, ethical and privacy considerations, access control and sharing mechanisms, large scale data handling and analysis and transparent data-sharing policies and practice. Proposed solutions to address issues related to data quality, privacy, and bias management include advanced cryptographic techniques, federated learning, and blockchain technology. Robust data governance measures, such as GA4GH standards, DUO versioning, and attribute-based access control, are essential for ensuring data integrity, security, and ethical use. The study also emphasized the critical role of Data Management Plans (DMPs), meticulous metadata curation, and advanced cryptographic techniques in mitigating risks related to data security and identifiability. Despite advancements, significant challenges persisted in balancing data ownership with research accessibility, integrating heterogeneous data sources, ensuring platform interoperability, and maintaining data quality. Ongoing risks of unauthorized access and data breaches underscored the need for continuous innovation in data management practices and stricter adherence to legal and ethical standards.

Conclusions

These findings explored the current practices and challenges in data stewardship, offering a roadmap for strengthening the governance, security, and ethical use of AI in genomics and microscopy. While robust governance frameworks and ethical practices have established a foundation for data integrity and transparency, there remains an urgent need for collaborative efforts to develop interoperable

platforms and transparent data-sharing policies. Additionally, evolving legal and ethical frameworks will be crucial to addressing emerging challenges posed by AI technologies. Fostering transparency, accountability, and ethical responsibility within the research community will be key to ensuring trust and driving ethically sound scientific advancements.

Opportunities for promoting open data in the Caribbean through biobanks

Article

Sushant Saluja, Simon G Anderson

Revista Panamericana de Salud Publica. 2025 Feb 13;49:e11. doi: 10.26633/RPSP.2025.11

Abstract

The establishment of a biobank in the Caribbean represents a vital opportunity to enhance biomedical research and tackle health issues in the area. The Caribbean's unique genetic diversity, shaped by migration and environmental factors, underscores a well-managed biobank's potential impact on global health, especially for underrepresented groups. This paper examines biobanking's potential in the Caribbean, focusing on precision medicine, public health improvements and regional scientific self-sufficiency. It analyzes successful models such as the UK Biobank, the All of Us Research Program at the United States' National Institutes of Health, and Human Heredity and Health in Africa (known as H3Africa), hosted at the University of Cape Town, pinpointing key lessons on data-sharing, ethical governance and infrastructure that could be applied to the Caribbean context. The UK Biobank and H3Africa are relevant examples due to their contributions to large-scale data and health research in diverse populations. The UK Biobank project is a large-scale study with deep genetic and phenotypic data from about 500 000 participants in the United Kingdom. It offers unprecedented insights into health data through extensive follow up and collection of genome-wide genotype data. H3Africa focuses on genomics research that addresses health disparities among African populations, which parallels the Caribbean's challenges. Its ethical governance and community engagement focus are crucial for Caribbean biobank development. This article highlights the challenges of developing biobanks, including ensuring sufficient sample storage and data security, and the need for strong governance. It recommends solutions that involve regional collaboration, stakeholder engagement and increased investment in infrastructure. Establishing a Caribbean biobank with equitable data-sharing principles can significantly enhance global genomic data sets and ensure that the benefits of precision medicine reach the Caribbean. This study promotes a strategic, ethical and inclusive approach to biobanking for long-term success.

The wisdom of claiming ownership of human genomic data: A cautionary tale for research institutions

ORIGINAL ARTICLE

Donrich Thaldar
School of Law, University of KwaZulu-Natal, Durban, South Africa.

Developing World Bioethics, Volume 25, Issue 1 Pages: 1-79 March 2025

Abstract

This article considers the practical question of how research institutions should best structure their legal relationship with the human genomic data that they generate. The analysis, based on South African law, is framed by the legal position that although a research institution that generates human genomic data is not automatically the owner thereof, it is well positioned to claim ownership of newly generated data instances. Given that the research institution exerts effort to generate the data, it can be argued that it has a moral right to claim ownership of such data. Combined with the fact that it has an interest in having comprehensive rights in such data, it appears that the prudent policy for research institutions is to claim ownership of the human genomic data instances that they generate. This policy is tested against two opposing policy positions. The first opposing policy position is that research *participants* should own the data that relate to them. However, in light of data protection legislation that already provides extensive protections to research participants, bestowing data

ownership on research participants would offer little benefit to such individuals, while leading to significant practical problems for research institutions. The second opposing policy position is that the concept of ownership should be abandoned in favour of data *custodianship*. This opposing position is problematic, as avoiding reference to ownership is a denial of legal reality and hence not a useful policy. Also, avoiding reference to ownership will leave research institutions with limited legal remedies in the event of appropriation of data by third parties. Accordingly, it is concluded that the wisest policy for research institutions is indeed to explicitly claim ownership of the human genomic data instances that they generate.

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PUBLIC AND COMMUNITY ENGAGEMENT/EDUCATION

Facing Democratic Challenges: The Role of Civil Society Organizations in the Governance of Genomic Technologies

Reflection
Federica Frazzetta and Andrea Felicetti
Perspectives on Politics (2025): 1-15. 18 Feb 2025
Abstract
The discovery of CRISPR has fuelled the debate surrounding new genomic techniques (NGTs). This is of paramount importance given their potential impact on societies and ecosystems. Despite early enthusiasm about the potential of NGTs to "democratize" genome editing, it is increasingly evident that their introduction poses substantial challenges from a democratic point of view. Although greater engagement with the public sphere is urgently needed, it is something that is currently not widely studied from a political science standpoint. In this paper we offer an overview of the actors who have mobilized in relation to NGTs, with a particular focus on unduly neglected actors, such as civil society organizations. We also consider the views of those who have made proposals regarding the governance of NGTs more generally. The perspectives of these actors are not easy to reconcile with those of stakeholders, and we reflect on the democratic implications of this aspect.

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GENETIC SEQUENCING/SCREENING/GENETIC COUNSELLING

Unresolved ethical issues of genetic counseling and testing in clinical psychiatry

Original Article
Perry, Julia; Bunnik, Eline; Rietschel, Marcella; Bentzen, Heidi Beate; Ingvoldstad Malmgren, Charlotta; Pawlak, Joanna; Chaumette, Boris; Tammimies, Kristiina; Bialy, Filip; Bizzarri, Virgini; Borg, Isabella; Coviello, Domenic; Crepaz-Keay, David; Ivanova, Eliza; McQuillin, Andrew; Mežinska, Signe; Johansson Soller, Maria; Suvisaari, Jaana; Watson, Melanie; Wirgenes, Katrine; Wynn, Sarah L.; Degenhardt, Franziska; Schicktanz, Silke
Psychiatric Genetics, 35(2):p 26-36, April 2025 | DOI: 10.1097/YPG.0000000000000385
Abstract
Objective
This position article discusses current major ethical and social issues related to genetic counseling and testing in clinical psychiatry (PsyGCT).
Methods
To address these complex issues in the context of clinical psychiatry relevant to PsyGCT, the interdisciplinary and pan-European expert Network EnGagE (Enhancing Psychiatric Genetic Counseling, Testing, and Training in Europe; CA17130) was established in 2018. We conducted an

interdisciplinary, international workshop at which we identified gaps across European healthcare services and research in PsyGCT; the workshop output was summarized and systematized for this position article.
Results
Four main unresolved ethical topics were identified as most relevant for the implementation of PsyGCT: (1) the problematic dualism between somatic and psychiatric disorders, (2) the impact of genetic testing on stigma, (3) fulfilling professional responsibilities, and (4) ethical issues in public health services. We provide basic recommendations to inform psychiatrists and other healthcare professionals involved in the clinical implementation of PsyGCT and conclude by pointing to avenues of future ethics research in PsyGCT.
Conclusion
This article draws attention to a set of unresolved ethical issues relevant for mental health professionals, professionals within clinical genetics, patients and their family members, and society as a whole and stresses the need for more interdisciplinary exchange to define standards in psychiatric counseling as well as in public communication. The use of PsyGCT may, in the future, expand and include genetic testing for additional psychiatric diagnoses. We advocate the development of pan-European ethical standards addressing the four identified areas of ethical–practical relevance in PsyGCT.

Analysis of informed consent forms of patients undergoing cancer genetic testing in the era of next-generation sequencing

Research Article
Tina Kerševan, Tina Kogovšek, Ana Blatnik & Mateja Krajc
Hereditary Cancer in Clinical Practice volume 23, Article number: 8 (2025). 21 Feb 2025
Abstract
Background
The Department of Clinical Cancer Genetics at the Institute of Oncology Ljubljana offers genetic counselling and testing to cancer patients and their relatives. Before undergoing genetic testing, patients sign the informed consent form. In addition to giving consent for collection of biological material and genetic testing, patients decide about storage of biological material and participation in international databases. Furthermore, patients decide whether the information regarding their test results may be revealed to their blood relatives and whether they want to be informed about secondary findings.
Methods
Using the signed consent forms, we investigated the effect of selected factors on patients' decisions. Using different statistical methods, we tried to determine the proportion of patients who opted for different items and the effect of gender, age and cancer diagnoses on their decisions.
Results
Nearly all (99.6%) patients, regardless of gender, age, and presence of oncological diagnosis, consented to the storage of their biological material, 98.4% of patients, regardless of gender, age, and presence of oncological diagnosis, wanted to be included in international databases in a pseudo-anonymised form, 98.8% of patients, irrespective of gender, age, and presence of oncological diagnosis, allowed blood relatives to see their results, and 98.4% of patients, irrespective of gender, age and presence of oncological diagnosis, wanted to know whether secondary findings were detected when genetic analysis of their biological material was performed. Men are, on average, more likely to consent but the difference between genders is not statistically significant. Patients without oncological disease were more likely to agree to be included in international databases than patients with a confirmed oncological diagnosis.
Conclusions
Our results show that the vast majority of patients were in favour of the options they were offered. Most importantly, the majority of them allow their genetic test results be revealed to their blood relatives when needed and would participate in international databases. Research in rare diseases,

including rare cancer genetic predisposition syndromes, is crucial for optimal diagnostic, prevention and treatment options for patients with rare genetic disorders. The results are also important for refining the approach to pre-and post-test cancer genetic counselling.

Towards a Responsible Implementation of NIPT as a First-Tier Test in Canada: Decision-Makers' Perspectives

Original Research

Marie-Christine Roy, Marie-Françoise Malo, Tierry Morel-Laforce, Vardit Ravitsky, Anne-Marie Laberge

Prenatal Diagnosis., 31 Jan 2025 https://doi.org/10.1002/pd.6753**.**

Abstract

Objective:

To explore decision makers' perspectives on the conditions for a responsible implementation of non-invasive prenatal testing (NIPT) as a first-tier test in Canadian provinces' healthcare systems.

Method:

A qualitative study was conducted with 16 Canadian decision makers who were interviewed between February 2021 and July 2022. After anonymization and transcription, interviews were coded inductively using thematic analysis.

Results:

Our interviews showed the complexity of the decision making environment regarding prenatal screening funding. Participants agreed that NIPT is superior to maternal serum screening as a first-tier test, but they also recognized that first-tier NIPT has limits and barriers. They described the following conditions for its responsible implementation: (1) need for time and evidence; (2) taking stakeholders' perspectives into account; (3) limit costs for the healthcare system; (4) ensure appropriate logistical conditions and harmonize the test offer; (5) ensure appropriate clinical services; (6) ensure informed consent; (7) ensure the test is presented as an individual choice to avoid eugenic concerns.

Conclusion:

Multiple barriers and issues need to be addressed before moving NIPT from second- to first-tier. Decision makers' perspectives should be contrasted with those of other important stakeholders, including pregnant people, disability advocates and healthcare professionals.

Boundary-work in genomic medicine: Safeguarding the future of diagnostic next-generation sequencing in the clinic

Research article

Janneke M.L. Kuiper, Pascal Borry, Danya F. Vears, Ine Van Hoyweghen

Social Science & Medicine, Volume 365 January 2025, 117498

Highlights

- Genomic specialist care is under competitive pressure from 'mainstreaming' trends.
- Genomic healthcare professionals engage in several forms of ongoing boundary work.
- Genomic medicine successfully upholds professional authority and autonomy.
- Genomic medicine holds a close grip on ethical problem definition and policy making.
- The value of next-generation sequencing is redefined to suit current situation.

Abstract

Next-generation sequencing (NGS) technologies – which allow to look at large parts or even the whole genome at once - are making their way into diagnostic clinical care. With trends towards 'mainstreaming' genetic services into general medicine, significant ethical challenges, and a disputed clinical utility and cost-benefit ratio, genomic medicine's autonomy and dominance in defining and offering NGS care may come under increased pressure from the outside (e.g., regulators, other healthcare providers and facilities, ethicists, and patients). In this paper, we show how the field of genomic medicine engages in substantial boundary-work in reaction to these circumstances. Building on multi-sited fieldwork in two centers for human genetics in Belgium and the Netherlands, we show

how acts of demarcation serve to uphold an image of expertise and authority which helps maintain the field's autonomy and dominance. Through examining the delineations put forward in interviews, practice (based on observations in multidisciplinary meetings and consultations), and grey and academic literature, we show the politics involved in moving NGS forward fairly seamlessly in a way that suits the field. First, we show how genetic healthcare professionals have redefined what makes a genetic test 'valuable' so that it underlines its current value. Secondly, we examine how a genetic imaginary is put forward that both emphasizes the extraordinary character of genomic medicine and the normalcy of NGS testing. By underlining the need for their expertise whilst simultaneously normalizing the ethical challenges and positioning themselves as most capable of reflecting on these, the field minimized external regulation and kept a close grip on defining ethical issues and policy. Despite their current dominance in shaping the future of genomic care, we argue that the closedness of the field hinders it from benefiting from external expertise, reflection, and monitoring to ensure enduring and broad support for this future

Editor's Note:

We include this article as part of the emerging literature but with some caution about its argumentation which deserves further careful examination.

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ANIMALS, PLANTS, MICROORGANISMS

CRISPR/Cas genome editing: Innovations and impacts on animal protein production

Review Article

Mariana Rocha Maximiano, Octávio Luiz Franco

CABI Reviews, 20:1.0003 28 Jan 2025 https://doi.org/10.1079/cabireviews.2025.0003.

Abstract

Food security has become an urgent global challenge as global population growth and climate change intensify. Livestock production systems must adapt to meet the growing demand for high-quality animal protein while minimizing environmental impacts. CRISPR/Cas genome editing has emerged as a transformative technology, enabling precise genetic modifications that enhance productivity, improve disease resistance, and promote animal welfare. In this context, this review aims to provide a comprehensive analysis of the current advancements in CRISPR/Cas genome editing tools for animal protein production, while addressing the challenges and future prospects of applying genome editing in livestock farming. Several studies have targeted genes associated with meat production, milk improvement, disease susceptibility, and animal welfare. The results have shown success in developing edited animals that increase meat production and milk quality and make animals more resilient to various infections, thereby reducing the economic losses associated with disease outbreaks. However, this advance still faces challenges, including technical, regulatory and ethical issues, and public acceptance. Even so, some of these edited animals are in the advanced stages of the regulatory approval process in some countries, including cattle with heat tolerance, pigs with resistance against PRRS-virus, and some fish that present an increase in meat production. In this context, this review consolidates current knowledge on CRISPR/Cas applications in animal protein production, highlights significant achievements, and addresses challenges related to the regulatory landscape, public perception, and ethical concerns. Furthermore, it emphasizes the importance of adaptable regulatory frameworks to ensure the responsible and sustainable advancement of genome editing in livestock.

"It's all about factory farming:" German public imaginaries of gene editing technologies in animal agriculture

Symposium/Special Issue

Amy Clare, Ruth Müller & Julia Feiler

Agriculture and Human Values (2025). 18 Feb 2025

Abstract
Since its development, scientists have proclaimed that the novel gene editing technology CRISPR-Cas will allow them to modify organisms with unprecedented speed and accuracy. In agriculture, CRISPR-Cas is said to significantly extend the possibilities to genetically modify common livestock animals. Genetic targets in livestock include edits to optimize yield, minimize environmental impacts, and improve animal health, among other targets that could be environmentally, medically, and economically beneficial. In Germany, a transdisciplinary research consortium consisting of geneticists, local animal breeding organizations, social scientists and legal scholars co-developed a "vanguard vision" (Hilgartner in Science and democracy: Making knowledge and making power in the biosciences and beyond, Routledge, London, 2015) for CRISPR-Cas edits in livestock that would improve animal health and benefit local small- to medium-scale farmers. Part of our social science work in this consortium was to discuss these specific application scenarios with members of the public in focus group settings. In this article, we trace how the public engaged with the consortium's vision of gene editing in smaller-scale animal agriculture. We found that instead of engaging with the vision proposed, a majority of participants held an entrenched "sociotechnical imaginary" (Jasanoff and Kim in Minerva 47:119–146, 2009) that was rooted in "storylines" (Hajer in The politics of environmental discourse: Ecological modernization and the policy process, Clarendon, Oxford, 1995) focused on factory farming, drawing upon arguments from German public and media discourses, NGO campaigning, and political decision-making about genetically modified organisms in the early 2000s. Our analysis points to the difficulties of establishing alternative visions of technology use once a specific sociotechnical imaginary has been established in a distinct national context, and raises questions regarding the possibilities of responsible research and innovation for highly contested technologies.

Strategies and Protocols for Optimized Genome Editing in Potato

Research Article Open access

Authors: Frida Meijer Carlsen, Ida Westberg, Ida Elisabeth Johansen, Erik Andreasson, and Bent Larsen Petersen https://orcid.org/0000-0002-2004-9077 blp@plen.ku.dkAuthors Info & Affiliations

The CRISPR Journal, Volume 8, Issue 1 / February 2025 Published Online: 14 February 2025
https://doi.org/10.1089/crispr.2024.0068

Abstract
The potato family includes a highly diverse cultivar repertoire and has a high potential for nutritional yield improvement and refinement but must in line with other crops be adapted to biotic and abiotic stresses, for example, accelerated by climate change and environmental demands. The combination of pluripotency, high ploidy, and relative ease of protoplast isolation, transformation, and regeneration together with clonal propagation through tubers makes potato highly suitable for precise genetic engineering. Most potato varieties are tetraploid having a very high prevalence of length polymorphisms and small nucleotide polymorphisms between alleles, often complicating CRISPR-Cas editing designs and strategies. CRISPR-Cas editing in potato can be divided into (i) characterization of target area and *in silico*-aided editing design, (ii) isolation and editing of protoplast cells, and (iii) the subsequent explant regeneration from single protoplast cells. Implementation of efficient CRISPR-Cas editing relies on efficient editing at the protoplast (cell pool) level and on robust high-throughput editing scoring methods at the cell pool and explant level. Gene and chromatin structure are additional features to optionally consider. Strategies and solutions for addressing key steps in genome editing of potato, including light conditions and schemes for reduced exposure to hormones during explant regeneration, which is often

CRISPR/Cas genome editing for cotton precision breeding: mechanisms, advances, and prospects

Review Article

Sheri Vijay, Mohan Harikrishnan, Jogam Phanikanth, Alok Anshu, Rohela Gulab Khan & Zhang Baohong
Journal of Cotton Research 8, 4 (2025). 3 Feb 2025 https://doi.org/10.1186/s42397-024-00206-w**.**
Abstract
Cotton (*Gossypium hirsutum* L.) is one of the most important global crops that supports the textile industry and provides a living for millions of farmers. The constantly increasing demand needs a significant rise in cotton production. Genome editing technology, specifically with clustered regularly interspaced short palindromic repeats (CRISPR)/CRISPR-associated protein (Cas) tools, has opened new possibilities for trait development in cotton. It allows precise and efficient manipulation within the cotton genome when compared with other genetic engineering tools. Current developments in CRISPR/Cas technology, including prime editing, base editing, and multiplexing editing, have expanded the scope of traits in cotton breeding that can be targeted. CRISPR/Cas genome editing has been employed to generate effectively CRISPRized cotton plants with enhanced agronomic traits, including fiber yield and quality, oil improvement, stress resistance, and enhanced nutrition. Here we summarized the various target genes within the cotton genome which have been successfully altered with CRISPR/Cas tools. However, some challenges remain, cotton is tetraploid genome having redundant gene sets and homologs making challenges for genome editing. To ensure specificity and avoiding off-target effects, we need to optimize various parameters such as target site, guide RNA design, and choosing right Cas variants. We outline the future prospects of CRISPR/Cas in cotton breeding, suggesting areas for further research and innovation. A combination of speed breeding and CRISPR/Cas might be useful for fastening trait development in cotton. The potentials to create customized cotton cultivars with enhanced traits to meet the higher demands for the agriculture and textile industry.

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Month in Review – *Milestones, Strategic Announcements, Analysis, Guidance*
Organization Watch – *Selected Events*
Organization Watch – *Selected Announcements*
Journal Watch – *Spotlight Articles, Thematic Sections*
Journals/Pre-Print Sources Monitored
Institutions/Organizations Monitored

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Institutions/Organizations – Monitored

We recognize this listing is incomplete, unbalanced and skewed to the Global North…please help us make it more complete, more inclusive, and more useful by recommending additional organizations/ institutions/programs to monitor.

Academy of Medical Sciences [UK]
https://acmedsci.ac.uk/

Africa CDC - Institute of Pathogen Genomics [IPG]
https://africacdc.org/institutes/ipg/

Africa Pathogen Genomics Initiative (Africa PGI)
https://africacdc.org/africa-pathogen-genomics-initiative-africa-pgi/

African Society of Human Genetics
https://www.afshg.org/

Paul G. Allen Frontiers Group
https://alleninstitute.org/news-press/

American Board of Medical Genetics and Genomics (ABMGG)
http://www.abmgg.org/pages/resources_appeal.shtml

American College of Medical Genetics and Genomics
https://www.acmg.net/

American Society for Gene and Cell Therapy [ASGCT]
https://asgct.org/

American Society of Human Genetics (ASHG)
http://www.ashg.org/

ARM [Alliance for Regenerative Medicine]
https://alliancerm.org/press-releases/

ARRIGE
https://www.arrige.org/

Australian Genomics
https://www.australiangenomics.org.au/

Bespoke Gene Therapy Consortium (BGTC)
https://ncats.nih.gov/research/research-activities/BGTC

BMGF - Gates Foundation [
https://www.gatesfoundation.org/ideas/media-center

Bill & Melinda Gates Medical Research Institute
https://www.gatesmri.org/news

Broad Institute of MIT and Harvard
https://www.broadinstitute.org/

CDC – Office of Genomics and Precision Public Health
https://www.cdc.gov/genomics/default.htm

Center for Genetics and Society [USA]
www.geneticsandsociety.org

Center for the Ethics of Indigenous Genomic Research [CEIGR] – University of Oklahoma
https://www.ou.edu/cas/anthropology/ceigr

Center for ELSI Resources and Analysis (CERA)
https://elsihub.org/about/our-mission

Chan Zuckerberg Initiative [to 18 Jan 2025]
https://chanzuckerberg.com/newsroom/

Francis Crick Institute
https://www.crick.ac.uk/news-and-reports

FDA Cellular & Gene Therapy Guidances
https://www.fda.gov/vaccines-blood-biologics/biologics-guidances/cellular-gene-therapy-guidances

The Genomic Medicine Foundation
https://www.genomicmedicine.org

Global Alliance for Genomics and Health
https://www.ga4gh.org/

Genetic Alliance
https://geneticalliance.org/about/news

Genomics England
https://www.genomicsengland.co.uk/

Genetics Society of America (GSA)
http://genetics-gsa.org/

Global Genomic Medicine Consortium [G2MC]
https://g2mc.org/

Global Observatory for Genome Editing
https://global-observatory.org/

HHMI - Howard Hughes Medical Institute [to 30 Aug 2023]
https://www.hhmi.org/news

H3Africa
https://h3africa.org/

Human Genome Organization (HUGO)
https://www.hugo-international.org/

ICH
https://www.ich.org/

Innovative Genomics Institute
https://innovativegenomics.org/about-us/

INSERM [to 30 Aug 2023]
https://www.inserm.fr/en/home/

Institut Pasteur [to 30 Aug 2023]
https://www.pasteur.fr/en/press-area

NIH [to 30 Aug 2023]
http://www.nih.gov/

NIH National Human Genome Research Institute (NHGRI)
https://www.genome.gov/

NIH – All of Us Research Program
https://allofus.nih.gov/news-events/announcements

National Organization for Rare Disorders (NORD)
https://rarediseases.org/news/

Nuffield Council on Bioethics [to 30 Aug 2023]
https://www.nuffieldbioethics.org/news

Penn Center for Global Genomics & Health Equity [University of Pennsylvania]
https://globalgenomics.med.upenn.edu/index.php

PHG Foundation
https://www.phgfoundation.org

The Royal Society
https://royalsociety.org/

UNESCO–The World Academy of Sciences
https://twas.org/

Wellcome Sanger Institute
https://www.sanger.ac.uk/

WHO
https://www.who.int/news

WHO - Human genome editing
https://www.who.int/teams/health-ethics-governance/emerging-technologies/human-genome-editing
[last update on page - July 2021]

World Organisation for Animal Health [OIE]
https://www.oie.int/

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Journals/Pre-Print Sources – Core/Penumbra Journals Monitored

If you would like to suggest other journal titles to include in this service, please contact David Curry at: david.r.curry@centerforvaccineethicsandpolicy.org

AJOB Empirical Bioethics
https://www.tandfonline.com/toc/uabr21/current

AMA Journal of Ethics
https://journalofethics.ama-assn.org/issue/peace-health-care

American Journal of Human Genetics
https://www.cell.com/ajhg/current

American Journal of Infection Control
http://www.ajicjournal.org/current

American Journal of Preventive Medicine
https://www.ajpmonline.org/current

American Journal of Public Health
http://ajph.aphapublications.org/toc/ajph/current

American Journal of Tropical Medicine and Hygiene
https://www.ajtmh.org/view/journals/tpmd/111/4/tpmd.111.issue-5.xml

Annals of Internal Medicine
https://www.acpjournals.org/toc/aim/current

Artificial Intelligence – An International Journal
https://www.sciencedirect.com/journal/artificial-intelligence/vol/336/suppl/C

BMC Cost Effectiveness and Resource Allocation
http://resource-allocation.biomedcentral.com/

BMC Health Services Research
http://www.biomedcentral.com/bmchealthservres/content

BMC Infectious Diseases
http://www.biomedcentral.com/bmcinfectdis/content

BMC Medical Ethics
http://www.biomedcentral.com/bmcmedethics/content

BMC Medicine
http://www.biomedcentral.com/bmcmed/content

BMC Pregnancy and Childbirth
http://www.biomedcentral.com/bmcpregnancychildbirth/content
(Accessed 16 Nov 2024)

BMC Public Health
http://bmcpublichealth.biomedcentral.com/articles

BMC Research Notes
http://www.biomedcentral.com/bmcresnotes/content

BMJ Evidence-Based Medicine
https://ebm.bmj.com/content/29/5

BMJ Global Health
https://gh.bmj.com/content/9/10

Bulletin of the World Health Organization
https://www.ncbi.nlm.nih.gov/pmc/issues/471305/

Cell
https://www.cell.com/cell/current

Clinical Pharmacology & Therapeutics
https://ascpt.onlinelibrary.wiley.com/toc/15326535/current

Clinical Therapeutics
http://www.clinicaltherapeutics.com/current

Clinical Trials
https://journals.sagepub.com/toc/ctja/21/6

Contemporary Clinical Trials
https://www.sciencedirect.com/journal/contemporary-clinical-trials/vol/146/suppl/C

The CRISPR Journal
https://www.liebertpub.com/toc/crispr/7/5

Current Genetic Medicine Reports
https://link.springer.com/journal/40142/volumes-and-issues/11-3

Current Medical Research and Opinion
https://www.tandfonline.com/toc/icmo20/current

Current Opinion in Infectious Diseases
https://journals.lww.com/co-infectiousdiseases/pages/currenttoc.aspx

Current Protocols in Human Genetics
https://currentprotocols.onlinelibrary.wiley.com/journal/19348258

Developing World Bioethics
https://onlinelibrary.wiley.com/toc/14718847/current

EMBO Reports
https://www.embopress.org/toc/14693178/current

Emerging Infectious Diseases
http://wwwnc.cdc.gov/eid/

Ethics & Human Research
https://onlinelibrary.wiley.com/toc/25782363/current

Ethics & International Affairs
https://www.cambridge.org/core/journals/ethics-and-international-affairs/latest-issue

Ethics, Medicine and Public Health
https://www.sciencedirect.com/journal/ethics-medicine-and-public-health/vol/31/suppl/C

The European Journal of Public Health
https://academic.oup.com/eurpub/issue/34/5

Expert Review of Vaccines
https://www.tandfonline.com/toc/ierv20/current

Frontiers in Medicine
https://www.frontiersin.org/journals/medicine/volumes?volume-id=1237

Gene Therapy – Nature
https://www.nature.com/gt/volumes/31/issues/11-12

Genetics in Medicines
https://www.sciencedirect.com/journal/genetics-in-medicine/vol/26/issue/11

Genome Medicine
https://genomemedicine.biomedcentral.com/articles

Global Health Action
https://www.tandfonline.com/toc/zgha20/current?nav=tocList

Global Health: Science and Practice (GHSP)
http://www.ghspjournal.org/content/current

Global Public Health
http://www.tandfonline.com/toc/rgph20/current

Globalization and Health
http://www.globalizationandhealth.com/

Health and Human Rights
https://www.hhrjournal.org/volume-26-issue-1-june-2024/

Health Economics, Policy and Law
https://www.cambridge.org/core/journals/health-economics-policy-and-law/latest-issue

Health Policy and Planning
https://academic.oup.com/heapol/issue/39/9

Health Research Policy and Systems
http://www.health-policy-systems.com/content

Human Gene Therapy
https://www.liebertpub.com/toc/hum/35/19-20

Human Vaccines & Immunotherapeutics (formerly Human Vaccines)
https://www.tandfonline.com/toc/khvi20/20/1?nav=tocList

Immunity
https://www.cell.com/immunity/current

Infectious Agents and Cancer
http://www.infectagentscancer.com/

Infectious Diseases of Poverty
http://www.idpjournal.com/content

International Health
https://academic.oup.com/inthealth/issue/16/6

International Human Rights Law Review
https://brill.com/view/journals/hrlr/13/1/hrlr.13.issue-1.xml

International Journal of Community Medicine and Public Health
https://www.ijcmph.com/index.php/ijcmph/issue/view/118

International Journal of Epidemiology
https://academic.oup.com/ije/issue/53/5

International Journal of Human Rights in Healthcare
https://www.emerald.com/insight/publication/issn/2056-4902/vol/17/iss/4

JAMA
https://jamanetwork.com/journals/jama/currentissue

JAMA Health Forum
https://jamanetwork.com/journals/jama-health-forum/issue

JAMA Pediatrics
https://jamanetwork.com/journals/jamapediatrics/currentissue

JBI Evidence Synthesis
https://journals.lww.com/jbisrir/Pages/currenttoc.aspx

Journal of Adolescent Health
https://www.jahonline.org/current

Journal of Artificial Intelligence Research
https://www.jair.org/index.php/jair

Journal of Community Health
https://link.springer.com/journal/10900/volumes-and-issues/49-5

Journal of Current Medical Research and Opinion
https://www.cmro.in/index.php/jcmro/issue/view/75

Journal of Empirical Research on Human Research Ethics
http://journals.sagepub.com/toc/jre/current

Journal of Epidemiology & Community Health
https://jech.bmj.com/content/78/11

Journal of Evidence-Based Medicine
https://onlinelibrary.wiley.com/toc/17565391/current

Journal of Global Ethics
http://www.tandfonline.com/toc/rjge20/current

Journal of Health Care for the Poor and Underserved (JHCPU)
https://muse.jhu.edu/issue/52935

Journal of Immigrant and Minority Health
https://link.springer.com/journal/10903/volumes-and-issues/26-5

Journal of Medical Ethics
http://jme.bmj.com/content/current

Journal of Patient-Centered Research and Reviews
https://institutionalrepository.aah.org/jpcrr/

The Journal of Pediatrics
https://www.sciencedirect.com/journal/the-journal-of-pediatrics/vol/274/suppl/C

Journal of Pharmaceutical Policy and Practice
https://www.tandfonline.com/toc/jppp20/17/1

Journal of Public Health Management & Practice
https://journals.lww.com/jphmp/pages/currenttoc.aspx

Journal of Public Health Policy
https://link.springer.com/journal/41271/volumes-and-issues/45-3

Journal of the Royal Society – Interface
https://royalsocietypublishing.org/toc/rsif/current

Journal of Virology
http://jvi.asm.org/content/current

The Lancet
https://www.thelancet.com/journals/lancet/issue/current

The Lancet Child & Adolescent Health
https://www.thelancet.com/journals/lanchi/issue/current

Lancet Digital Health
https://www.thelancet.com/journals/landig/issue/current

Lancet Global Health
https://www.thelancet.com/journals/langlo/issue/current

Lancet Infectious Diseases
https://www.thelancet.com/journals/laninf/issue/current

Lancet Public Health
https://www.thelancet.com/journals/lanpub/issue/current

Lancet Respiratory Medicine
https://www.thelancet.com/journals/lanres/issue/current

Maternal and Child Health Journal
https://link.springer.com/journal/10995/volumes-and-issues/28-11

Medical Decision Making (MDM)
http://mdm.sagepub.com/content/current

Molecular Therapy
https://www.cell.com/molecular-therapy/current

Nature
https://www.nature.com/nature/volumes/633/issues/8038

Nature Biotechnology
https://www.nature.com/nbt/volumes/42/issues/11

Nature Genetics
https://www.nature.com/ng/volumes/56/issues/11

Nature Human Behaviour
https://www.nature.com/nathumbehav/volumes/8/issues/10

Nature Medicine
https://www.nature.com/nm/volumes/30/issues/11

Nature Reviews Drug Discovery
https://www.nature.com/nrd/volumes/23/issues/11

Nature Reviews Genetics
https://www.nature.com/nrg/volumes/25/issues/11

Nature Reviews Immunology
https://www.nature.com/nri/volumes/24/issues/11

New England Journal of Medicine
https://www.nejm.org/toc/nejm/medical-journal

NEJM Evidence
https://evidence.nejm.org/toc/evid/current

njp Vaccines
https://www.nature.com/npjvaccines/

Pediatrics
https://publications.aap.org/pediatrics/issue/154/Supplement%203

PharmacoEconomics
https://link.springer.com/journal/40273/volumes-and-issues/42-11

PLoS Biology
https://journals.plos.org/plosbiology/

PLoS Genetics
https://journals.plos.org/plosgenetics/

PLoS Global Public Health
https://journals.plos.org/globalpublichealth/search?sortOrder=DATE_NEWEST_FIRST&filterStartDate=2021-10-01&filterJournals=PLOSGlobalPublicHealth&q=&resultsPerPage=60

PLoS Medicine
https://journals.plos.org/plosmedicine/

PLoS Neglected Tropical Diseases
http://www.plosntds.org/

PLoS One
http://www.plosone.org/

PLoS Pathogens
http://journals.plos.org/plospathoge ns/

PNAS - Proceedings of the National Academy of Sciences of the United States
https://www.pnas.org/toc/pnas/121/46

PNAS Nexus
https://academic.oup.com/pnasnexus/issue/3/10

Preventive Medicine
https://www.sciencedirect.com/journal/preventive-medicine/vol/187/suppl/C

Proceedings of the Royal Society B
https://royalsocietypublishing.org/toc/rspb/current

Public Health
https://www.sciencedirect.com/journal/public-health/vol/236/suppl/C

Public Health Ethics
http://phe.oxfordjournals.org/content/current

Public Health Genomics
https://karger.com/phg/issue/27/1

Public Health Reports
https://journals.sagepub.com/toc/phrg/139/6

Qualitative Health Research
https://journals.sagepub.com/toc/QHR/current

Research Ethics

http://journals.sagepub.com/toc/reab/current

Reproductive Health
http://www.reproductive-health-journal.com/content

Revista Panamericana de Salud Pública/Pan American Journal of Public Health (RPSP/PAJPH)
https://www.paho.org/journal/en

Risk Analysis
https://onlinelibrary.wiley.com/toc/15396924/current

Risk Management and Healthcare Policy
https://www.dovepress.com/risk-management-and-healthcare-policy-archive56

Science
https://www.science.org/toc/science/current

Science and Engineering Ethics
https://link.springer.com/journal/11948/volumes_-and-issues/30-6

Science Translational Medicine
https://www.science.org/toc/stm/current

Social Science & Medicine
https://www.sciencedirect.com/journal/social-science-and-medicine/vol/360/suppl/C

Systematic Reviews
https://systematicreviewsjournal.biomedcentral.com/articles

Theoretical Medicine and Bioethics
https://link.springer.com/journal/11017/volumes-and-issues/45-5

Travel Medicine and Infectious Diseases
https://www.sciencedirect.com/journal/travel-medicine-and-infectious-disease/vol/61/suppl/C

Tropical Medicine & International Health
https://onlinelibrary.wiley.com/toc/13653156/current

Vaccine
https://www.sciencedirect.com/journal/vaccine/vol/42/issue/25

Vaccines
https://www.mdpi.com/journal/vaccines

Value in Health
https://www.valueinhealthjournal.com/current

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Pre-Print Servers

arxiv
https://arxiv.org/
[Filters: Emerging Technologies; Neural and Evolutionary Computing; Computers and Society; Genomics; Neurons and Cognition; Populations and Evolution; Other Quantitative Biology; General Economics]

Gates Open Research
https://gatesopenresearch.org/browse/articles

medRxiv
https://www.medrxiv.org/content/about-medrxiv
[Filter: All articles]

OSF Pre-prints
https://osf.io/preprints/discover?provider=OSF&subject=bepress%7 CLife%20Sciences
[Provider Filter: OSF Pre-prints Subject filters: Medicine and Health Sciences Format Filter: Pre-

Wellcome Open Research
https://wellcomeopenresearch.org/browse/articles

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Appendix A

The expanding global genomics landscape: Converging priorities from national genomics programs

Perspective
Caitlin Howley,1,2,* Matilda A. Haas,1,2 Wadha A. Al Muftah,3,4 Robert B. Annan,5 Eric D. Green,6 Bettina Lundgren,7 Richard H. Scott,8,9,10 Zornitza Stark,1,11,12 Patrick Tan,13,14,15 Kathryn N. North,1,2,12 and Tiffany Boughtwood1,2
American Journal of Human Genetics (2025), Published online March 10, 2025

Web resources

- ALIGN, Our Governance, https://indigenousgenomics.com.au/about-us/our-governance/
- All of Us, From the All of Us CEO: Keeping Our Momentum Amidst Funding Uncertainties, https://allofus.nih.gov/news-events/announcements/all-us-ceo-keeping-our-momentum-amidst-funding-uncertainties
- Australian Genomics, DNA Dialogue, https://www.youtube.com/playlist?list=PLLqz_VdF_zMNDgQELAygSKceTBLwx4321
- Australian Genomics, Genomic Findings – Developing standardised approaches for genomic findings beyond the original scope of the test, https://www.australiangenomics.org.au/wp-content/uploads/2024/07/Genomic-Findings_Final-Report_March-2024.pdf
- Australian Genomics, National Approach to Genomic Information Management (NAGIM) Implementation Recommendations, https://www.australiangenomics.org.au/wp-content/uploads/2021/06/NAGIM-Implementation-Recommendations_January-2023.pdf
- Australian Genomics, "Precision health and the genomics ecosystem in Canada" featuring Dr. Rob Annan, DNA Dialogue August 2022," https://youtu.be/FcMev-aMzQc?si=x1NOhwOqvOphOrxU

- BC Children's Hospital Research Institute, Building an Indigenous Background Variant Library (IBVL) in Canada (Activity 3), https://www.bcchr.ca/silent-genomes-project/ibvl
- BC Children's Hospital Research Institute, Silent Genomes Project, https://www.bcchr.ca/silent-genomes-project
- CIHR, Government of Canada invests $15M in first-of-its-kind Pan-Canadian Genome Library, https://www.canada.ca/en/institutes-health-research/news/2023/10/government-of-canada-invests-15m-in-first-of-its-kind-pan-canadian-genome-library.html
- Danish Ministry of Health, National Strategy for Personalised Medicine 2021–2022, https://www.eng.ngc.dk/Media/637614364621421665/Danish%20Strategy%20for%20personalised%20medicine%202021%202022.pdf
- Department of Health and Aged Care, Australian Government, Establishing Genomics Australia, https://www.health.gov.au/ministers/the-hon-mark-butler-mp/media/establishing-genomics-australia
- Department of Health and Social Care, UK Government, Genome UK: 2022 to 2025 implementation plan for England, https://www.gov.uk/government/publications/genome-uk-2022-to-2025-implementation-plan-for-england
- Department of Health and Social Care, UK Government, Over £175 million for cutting-edge genomics research, https://www.gov.uk/government/news/over-175-million-for-cutting-edge-genomics-research
- DNA Today, #286 Qatar Genome Program with Dr. Said Ismail, https://dnapodcast.com/episodes/2024/4/26/286-qatar-genome-program-with-dr-said-ismail
- DNGC, Annual Report 2023, https://www.ngc.dk/Media/638493695691274048/NGC%20%C3%85rsrapport%202023%20WEB%20(1).pdf
- DNGC, Comprehensive genetic analysis – patient information, https://www.ngc.dk/Media/638441911379820785/Patient%20information%20concerning%20comprehensive%20genetic%20analysis.pdf
- European "1+ Million Genomes" Initiative, https://digital-strategy.ec.europa.eu/en/policies/1-million-genomes
- Genome Canada, Annual Report 2017-18, https://genomecanada.ca/wp-content/uploads/2023/03/GC-Annual-Report-2017-18-FINAL-EN-Revised-in-2023.pdf
- Genome Canada, Annual Report 2018-19, https://genomecanada.ca/wp-content/uploads/2022/06/Genome-Canada-Annual-Report-2018-19.pdf
- Genome Canada, Annual Report 2019-20. https://genomecanada.ca/wp-content/uploads/2021/12/2019-20-Annual-Report.pdf
- Genome Canada, Annual Report 2020-21, https://genomecanada.ca/wp-content/uploads/2021/12/2020-21-Annual-Report.pdf
- Genome Canada, Annual Report 2021-22, https://genomecanada.ca/wp-content/uploads/2022/08/GC-AnnualReport-2021-22_EN_Web-Accessible.pdf
- Genome Canada, Annual Report 2022-23, https://genomecanada.ca/wp-content/uploads/2023/08/GC-AnnualReport-2022-23_EN_web.pdf
- Genome Canada, CanCOGeN, https://genomecanada.ca/challenge-areas/cancogen/
- Genome Canada, CanCOGeN Update July 2023, https://genomecanada.ca/wp-content/uploads/2023/07/GC-CanCOGeN_update_July-27-ACCESSIBLE-EN-.pdf

- Genome Canada, CHEO and SickKids join forces to lead the way in data sharing, https://genomecanada.ca/cheo-and-sickkids-join-forces-to-lead-the-way-in-data-sharingchanging-the-course-of-rare-diseases-copy/
- Genome Canada, Corporate Plan 2023-24, https://genomecanada.ca/wp-content/uploads/2023/02/Genome-Canada-Corporate-Plan-2023-24-EN-Accessible-Version.pdf
- Genome Canada, Development of a reference genome representative of the population of Quebec, https://genomecanada.ca/project/development-reference-genome-representative-population-quebec/
- Genome Canada, Genome Canada launches national initiative to bring precision health to patients, https://genomecanada.ca/genome-canada-launches-national-initiative-bring-precision-health-patients/
- Genome Canada, Genome Canada and SING Canada partner to address the underrepresentation of Indigenous peoples in genomics, https://genomecanada.ca/events/sing-canada-partnership/
- Genomics England, Annual Report 2021, https://files.genomicsengland.co.uk/documents/Genomics-England-Annual-Report-2020-2021.pdf
- Genomics England, Annual Report 2022, https://files.genomicsengland.co.uk/documents/GenomicsEngland_AnnualReport_2022.pdf
- Genomics England, Data in the Research Environment, https://re-docs.genomicsengland.co.uk/data_overview/
- Genomics England, Diverse Data, https://www.genomicsengland.co.uk/initiatives/diverse-data
- Genomics England, Diverse Data Initiative at Genomics England: Our Strategy 2022–2025, https://docs.google.com/document/d/1lE-aGWYHQWXoYoN0YBzacANdzis6ZguaFjKT5iRhXVA/edit
- Genomics England, Genomics England's GeCIP virtual Research Environment comes online, https://www.genomicsengland.co.uk/news/gecip-research-begins
- Genomics England, Join the Research Network, https://www.genomicsengland.co.uk/join-us
- Genomics England, Language and Terminology Guide, https://files.genomicsengland.co.uk/documents/Genomics-England-Language-Guide.pdf
- Genomics England, Launching a global standard resource for cancer research, https://www.genomicsengland.co.uk/blog/launching-a-global-standard-resource-for-cancer-research
- Genomics England, Newborn Genomes Programme – Ethics, https://www.genomicsengland.co.uk/initiatives/newborns/ethics?chapter=ethics-working-group-members
- Genomics England, Origins, https://www.genomicsengland.co.uk/about-us/origins
- Genomics England, Podcasts https://www.genomicsengland.co.uk/podcasts
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