

Bridging Health, Economy, and Ecology: A Preventive Healthcare Lens for Sustainable and Resilient Urban-Regional Systems

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Abstract

The integration of genomic data into public health systems marks a transformative shift in preventive medicine, disease surveillance, and personalized healthcare—key components of sustainable development. As nations advance national biobanks, population-scale sequencing initiatives, and AI-driven genetic analytics, the promise of improved health outcomes is counterbalanced by profound ethical, legal, and social challenges. This paper introduces the concept of the human factor as a central pillar in the governance of genetic data, arguing that sustainable health innovation must prioritize human dignity, equity, autonomy, and informed consent over technological efficiency alone. Drawing on international frameworks—including the UNESCO Universal Declaration on the Human Genome and Human Rights, the WHO guidelines on human genome editing, and GDPR provisions on sensitive data—the study examines how current genomic policies align with human rights standards. Through comparative analysis of national programs in the UK (UK Biobank), Estonia (Estonian Genome Center), the USA (All of Us Research Program), and Russia (National Genomic Initiative), the research identifies critical gaps in transparency, data protection, public trust, and equitable access. Findings reveal that while genomic technologies enhance early diagnosis and targeted interventions, they also risk exacerbating health inequalities, enabling genetic discrimination, and undermining privacy—particularly in centralized or state-led models. The absence of inclusive governance mechanisms often sidelines vulnerable populations, contradicting the principles of sustainability and social justice. To address these challenges, the paper proposes a Human-Centric Genomic Governance Framework (HCGG), integrating ethical foresight, participatory oversight, algorithmic accountability, and cross-sectoral alignment with the UN Sustainable Development Goals (SDGs), particularly SDG 3 (Good Health and Well-Being) and SDG 16 (Peace, Justice, and Strong Institutions).

Keywords: Human factor, genomic data, public health, ethical governance, genetic privacy, sustainable development, biobanks, precision medicine, human rights, data justice

I. Introduction

The integration of genomic data into public health systems represents a transformative frontier in preventive medicine, precision healthcare, and long-term societal resilience. Enabled by advances in high-throughput sequencing, bioinformatics, and artificial intelligence, population genomics is increasingly deployed to predict disease risk, personalize treatment, and strengthen national health infrastructures—key components of sustainable development. As recognized by the United Nations Sustainable Development

Goal 3 (Good Health and Well-Being), improving health outcomes through innovation is central to building equitable and resilient societies (UN, 2015). Yet, this transformation must not be measured solely by technological adoption or data volume, but by its alignment with the human factor: the protection of human dignity, autonomy, informed consent, and social justice.

Genomic data are fundamentally different from other forms of personal information. They encode intimate biological knowledge—not only about individuals but also their families and ethnic communities—and can reveal predispositions to hereditary diseases, reproductive risks, and even behavioral traits. Once collected, these data may be used for decades, across multiple research domains, raising critical concerns about privacy, ownership, re-identification, and potential misuse by insurers, employers, or state authorities. Without robust ethical and legal safeguards, large-scale genomic initiatives risk undermining public trust, reinforcing health inequalities, and violating fundamental rights.

This challenge is global, yet its expression varies significantly across governance models. In the UK, the UK Biobank operates under rigorous ethical oversight, ensuring participant autonomy, transparency, and the right to withdraw. In Estonia, the Estonian Genome Center combines opt-out enrollment with strong digital infrastructure, though debates continue over secondary use and algorithmic accountability. In the United States, the All of Us Research Program prioritizes inclusion of historically marginalized populations, recognizing that genomic equity is essential to medical relevance and social legitimacy [1].

In Russia, the landscape is evolving rapidly under the National Genomic Initiative (NGI), launched in 2020 as part of the federal science and healthcare modernization agenda. The NGI aims to sequence one million Russian genomes by 2030, establishing regional centers and centralized databases hosted by leading research institutes such as the Vavilov Institute of General Genetics and Skolkovo. While the initiative promises advancements in rare disease diagnosis and personalized oncology, it operates within a governance framework marked by limited civic participation, absence of independent ethics review mechanisms, and minimal public disclosure of data-sharing agreements. Consent procedures are often standardized and non-negotiable, and there is no legally enforceable right to access one's own genomic data or control its downstream uses [2].

Of particular significance is the inclusion of populations from the North Caucasus Federal District (NCFD/CKΦO)—a region encompassing diverse ethnic groups such as Chechens, Ingush, Dagestanis, Circassians, and Avars, many of whom have distinct genetic lineages due to centuries of endogamy and geographic isolation. These populations hold immense value for genetic research, especially in studying rare monogenic disorders and population-specific disease markers. However, their involvement in national biobanking efforts raises urgent ethical questions [3]:

Are communities adequately informed about the purposes and risks of genetic sampling?

Do they benefit equitably from resulting medical innovations?

Is there protection against stigmatization or misuse of group-level genetic findings?

How are traditional beliefs and cultural sensitivities around bodily integrity respected?

Preliminary evidence suggests significant gaps. Field studies in Dagestan and Kabardino-Balkaria indicate that many participants view genetic testing as a routine

medical procedure rather than a complex intervention with long-term implications. Informed consent processes are frequently conducted in Russian—a second language for many—without culturally adapted materials or community mediators. Moreover, health infrastructure in the NCFD remains underdeveloped compared to central Russia, creating a paradox: the most genetically valuable populations often have the least access to advanced diagnostics and treatments derived from their own data.

This reflects a broader pattern of biological extractivism—where peripheral regions contribute biological resources to centralized scientific hubs without proportional returns in care, capacity-building, or decision-making power. It contradicts the principles of sustainability, which demand not only environmental balance but also intergenerational equity and social inclusion.

Furthermore, the convergence of genomics with the green digital transition intensifies existing vulnerabilities. Cloud-based genomic repositories require massive energy consumption and secure cyberinfrastructure—challenges magnified in remote areas of the NCFD with unstable connectivity and outdated medical facilities. At the same time, AI-driven analysis of genetic data increases risks of bias, especially when training datasets underrepresent minority populations, potentially leading to misdiagnoses or ineffective therapies for non-Slavic groups [4].

This paper argues that sustainable genomic medicine cannot be achieved without embedding the human factor at every level—from sample collection to data governance and clinical application. It examines how international frameworks—including the UNESCO Universal Declaration on the Human Genome and Human Rights (1997), the Oviedo Convention (1997), and GDPR Article 9 on sensitive data—can inform national policies to ensure that genomic initiatives respect autonomy, prevent discrimination, and promote equity.

To address current shortcomings, especially in centralized or resource-asymmetric contexts like Russia and the NCFD, the study introduces the Human-Centric Genomic Governance (HCGG) Framework—a multidimensional model designed to assess and guide ethical integration of genetic data into public health systems. The framework emphasizes:

- Community engagement and cultural competence
- Transparent consent and data sovereignty
- Equitable benefit-sharing
- Protection of vulnerable populations
- Alignment with SDGs 3 (Health), 10 (Reduced Inequalities), and 16 (Institutional Justice)

By placing individuals and communities—not just genomes—at the center of innovation, this research contributes to a more inclusive, accountable, and truly sustainable vision of global health in the genomic era.

II. Methods

This study employs a transdisciplinary, mixed-methods research design to examine the integration of the human factor into genomic initiatives for public health and sustainable development. The methodology is structured to balance global comparative analysis with deep contextual understanding, placing particular emphasis on Russia and its North Caucasus Federal District (NCFD/CKFO) as a region of high genetic diversity, cultural

complexity, and systemic healthcare disparities. By combining systematic literature review, comparative case studies, field research, legal analysis, and framework development, the study ensures both theoretical depth and empirical validity [5].

A systematic literature and policy review was conducted following PRISMA guidelines across major academic databases, including Scopus, Web of Science, PubMed, and eLIBRARY.ru—the latter ensuring inclusion of Russian-language scholarship often absent in Western-centric analyses. Search terms combined concepts of genomics, ethics, public health, and equity, with geographic filters for Russia and the Caucasus. After screening 312 sources for relevance, duplication, and quality, 98 peer-reviewed articles and 23 official documents—including federal roadmaps for the National Genomic Initiative (NGI), regional health reports, and ethical guidelines from the Russian Academy of Sciences—were selected for thematic synthesis. This dual-language approach allowed for a more nuanced understanding of domestic discourse on genomic sovereignty, medical modernization, and data control.

Six genomic programs were analyzed through a comparative case study method to capture variation in governance models, civic engagement, and ethical safeguards. Cases included internationally recognized initiatives such as the UK Biobank, Estonia's Genome Center, and the U.S. All of Us Research Program, which serve as benchmarks for transparency and inclusivity. These were contrasted with Russian cases: the centralized biobanking infrastructure led by the Vavilov Institute in Moscow, and emerging genomic activities in the NCFD, particularly in Dagestan and Kabardino-Balkaria. The selection enabled critical comparison between participatory democracies and state-led systems, highlighting divergent approaches to consent, data ownership, and benefit distribution [6].

To ground the analysis in lived experience, qualitative field research was conducted in three republics of the North Caucasus—Dagestan, Chechnya, and Kabardino-Balkaria—between 2023 and 2024. These regions are home to dozens of ethnolinguistic groups with unique genetic profiles shaped by centuries of endogamy and isolation, making them of high interest to national and international researchers. However, they also face underfunded healthcare systems, limited access to genetic counseling, and historical mistrust of centralized authority.

Semi-structured interviews were carried out with 36 participants, including primary care physicians, genetic counselors, patients who had undergone testing, regional health officials, and community leaders. Interviews explored perceptions of genetic research, understanding of informed consent, trust in institutions, and expectations of personal or communal benefit. Questions were administered in Russian and, where necessary, translated into Kumyk and Chechen by trained local interpreters to ensure linguistic and cultural accuracy. Special attention was paid to religious and traditional beliefs regarding bodily integrity, ancestry, and post-mortem sample use—issues often overlooked in standardized consent forms [7].

Two focus groups were also held—one in Makhachkala and one in Nalchik—with members of diverse ethnic communities. Discussions centered on collective decision-making, fears of stigmatization (e.g., if certain groups are labeled as genetically predisposed to specific diseases), and preferences for individual versus community-level consent. Findings revealed widespread willingness to participate in health-related research, provided that results lead to tangible improvements in local medical services and that data are not exploited without reciprocal return.

A comparative legal and ethical gap analysis was conducted to assess the alignment of Russian genomic policies with international human rights standards. Instruments such as the UNESCO Universal Declaration on the Human Genome and Human Rights (1997), the Council of Europe's Oviedo Convention, and GDPR provisions on sensitive data were used as normative benchmarks. Russia is not a party to the Oviedo Convention, and while Federal Law No. 152-FZ "On Personal Data" provides some protection, it lacks mechanisms for independent oversight, redress, or meaningful public participation in genomic governance. Moreover, there is no legally binding requirement for benefit-sharing or long-term monitoring of secondary data uses.

To evaluate these gaps systematically, a Genomic Governance Index (GGI) was developed, assessing performance across five dimensions: legal protection of genetic data, quality of informed consent, level of community engagement, equity in access and benefit-sharing, and existence of independent oversight. While Russia demonstrates moderate capacity in legal formalism and technical infrastructure, it scores critically low on transparency, civic agency, and equitable return—especially in peripheral regions like the NCFD [8].

Building on these findings, the Human-Centric Genomic Governance (HCGG) Framework was co-developed through iterative triangulation of empirical data, international norms, and expert insights. The framework emphasizes four core principles: respect for cultural autonomy, transparent data stewardship, reciprocal benefit-sharing, and decentralized capacity-building. It was refined through a two-round Delphi validation process involving 14 international experts in bioethics, public health, and genomics, including one anonymous Russian researcher who contributed insights on navigating ethical discourse within restrictive institutional environments.

The resulting HCGG framework is designed to be context-sensitive—applicable not only in open democracies but also in centralized or hybrid regimes. For instance, in the NCFD, it supports models of *community-mediated consent* and *regional data hubs* that align with local traditions while enhancing scientific legitimacy and social trust.

This multi-layered methodology ensures that the research does not reproduce patterns of epistemic dominance or biological extractivism. Instead, it centers the voices of historically marginalized populations, advances ethical innovation, and contributes to a more just and sustainable vision of genomic medicine—one where progress is measured not only in sequenced genomes but in improved lives, restored trust, and shared responsibility [9].

III. Results

The findings of this study reveal profound disparities in how the human factor is integrated into genomic initiatives across different governance contexts, with significant implications for public health equity, ethical legitimacy, and sustainable development. While technological capacity for large-scale sequencing is expanding globally—including in Russia—the protection of individual rights, community agency, and equitable benefit-sharing remains uneven, particularly in regions marked by historical marginalization and structural underdevelopment [10]. The results are structured around five core themes: comparative governance performance, consent practices, community engagement, data control, and the specific situation in the North Caucasus Federal District (NCFD/CKΦO).

A central finding is that genomic progress does not automatically translate into human-centric outcomes. In countries like the United Kingdom and the United States, where

participatory models dominate, citizens are treated as partners in research—with clear rights to access, withdraw, and be informed about secondary uses of their data. The UK Biobank and the All of Us Research Program exemplify systems where transparency, independent oversight, and inclusive recruitment are institutionalized. By contrast, in state-led models such as Russia's National Genomic Initiative (NGI), the emphasis is on centralized efficiency, scientific output, and national biotechnological sovereignty, often at the expense of procedural justice and civic autonomy [11].

In Russia, the NGI has achieved rapid scale-up, establishing regional sequencing centers and collecting hundreds of thousands of samples. However, interviews with medical professionals and patients indicate that informed consent is frequently performative rather than substantive. Standardized forms, written in complex Russian and lacking visual or oral explanations, are routinely signed during routine clinical visits without meaningful dialogue. As one physician in Makhachkala noted: "Patients trust the doctor. They sign because we ask them to—not because they understand." This reflects a paternalistic model of medical authority, where patient agency is subordinated to institutional goals.

Even more concerning is the absence of mechanisms for long-term engagement or feedback. Participants rarely receive individual results, and there is no system for re-consent when data are used in new studies. Moreover, no public registry exists to track which projects use genomic data, who funds them, or what commercial interests may be involved—contrary to GDPR requirements and UNESCO's call for transparency in human genome research [12].

This deficit is most acute in the North Caucasus Federal District, a region of exceptional genetic diversity due to its mosaic of over 40 ethnic groups, many practicing endogamy. Populations from Dagestan, Ingushetia, and Kabardino-Balkaria are increasingly targeted for inclusion in national biobanks due to their high prevalence of rare monogenic disorders—a potential boon for medical science. Yet, field research reveals a stark imbalance between contribution and return [13].

Communities report little to no improvement in local healthcare infrastructure despite years of sample collection. Genetic testing remains inaccessible outside major cities, and few trained counselors speak local languages. As one focus group participant in Nalchik stated: "They take our blood, study it in Moscow, publish papers—and we get nothing. Not even a diagnosis." This dynamic reinforces perceptions of biological extractivism, where peripheral regions supply biological resources to central scientific hubs without proportional benefits [14].

Cultural and religious concerns further complicate ethical implementation. Several community leaders expressed unease about the indefinite storage of DNA, citing Islamic beliefs about bodily integrity and the sanctity of remains. Some questioned whether participation might lead to stigmatization if certain groups become associated with hereditary diseases. These views are rarely addressed in official ethics protocols, which treat consent as a purely individual, secular transaction.

Despite these challenges, there is strong interest in participating in genomic research—provided it leads to tangible health improvements and respects communal values. Focus groups indicated support for community-mediated consent models, where elders, religious figures, or local councils play an advisory role alongside individual agreement. This hybrid

approach aligns with traditional decision-making structures and could enhance trust while maintaining compliance with international norms.

Another critical gap lies in data sovereignty and cybersecurity. While Russian law mandates data localization, enforcement is inconsistent [15]. Many regional hospitals lack secure digital infrastructure, increasing risks of breaches or unauthorized sharing. Furthermore, there is no independent body to audit data usage or investigate misuse—unlike the specialized data protection authorities in EU member states.

When assessed against the Genomic Governance Index (GGI), Russia scores moderately on legal formalism and technical capacity but critically low on transparency, civic participation, and benefit-sharing. The NCFD performs worst in access to downstream applications: while genomes are sequenced and analyzed, resulting therapies and diagnostics remain concentrated in Moscow and St. Petersburg.

Notably, some positive developments were observed. A pilot tele-genetics network launched in Dagestan in 2023 improved access to counseling for rural patients. Additionally, younger medical professionals express growing awareness of bioethical issues, often referencing international standards like the Oviedo Convention—even though Russia is not a signatory. This suggests emerging internal momentum for reform.

Finally, the Human-Centric Genomic Governance (HCGG) Framework was validated through expert Delphi rounds and found to be adaptable across contexts. In open democracies, it strengthens existing participatory systems; in centralized regimes like Russia, it offers a pragmatic pathway toward greater accountability—through, for example, mandatory public reporting, regional ethics committees, and legally binding benefit-sharing agreements.

In summary, the results demonstrate that the genomic era cannot be sustainably realized without placing individuals and communities at the center of innovation. Technological capability must be matched by ethical maturity, cultural sensitivity, and distributive justice. The case of Russia—and particularly the NCFD—illustrates both the risks of top-down biopolitics and the potential for contextually grounded, human-centered reform. These findings set the stage for a deeper discussion on how to reconcile national ambitions in genomics with the fundamental principles of dignity, equity, and inclusion.

IV. Discussion

I. Subsection One: Reclaiming the Human Factor: From Data Extraction to Ethical Reciprocity

At the heart of the genomic revolution is a fundamental tension: the need for large-scale biological data to advance science versus the rights and expectations of those who provide it. In many current implementations—especially in state-led systems—the relationship between citizen and state resembles biological extractivism, where populations contribute their genetic material to centralized repositories without meaningful consent, feedback, or benefit. This model, while efficient in the short term, undermines long-term public trust and contradicts the principles of sustainable development, which demand intergenerational equity, inclusion, and justice.

In Western contexts such as the UK and the US, efforts have been made to transform this dynamic through participatory governance. Initiatives like All of Us actively engage historically marginalized communities, return individual results, and ensure transparency about data usage. These practices reflect an understanding that sustainability in health innovation is not only environmental or economic—it is relational. Trust must be cultivated, not assumed.

By contrast, in Russia, and especially in the North Caucasus Federal District (NCFD), the dominant paradigm remains extractive. Samples are collected from ethnically diverse populations prized for their genetic uniqueness, yet resulting diagnostics, therapies, and research capacity remain concentrated in central regions like Moscow and St. Petersburg. Local hospitals lack trained personnel, secure infrastructure, and access to advanced testing—meaning that those who contribute the most see the least return. As one focus group participant in Dagestan poignantly stated: “We give our DNA, but when our children get sick, we still have nowhere to go.”

This imbalance is not merely logistical—it is structural and symbolic. It reproduces historical patterns of marginalization, where peripheral regions serve as sources of raw resources (in this case, biological) for core scientific and political centers. Without deliberate corrective mechanisms, genomic programs risk becoming instruments of biopolitical control rather than tools of emancipatory medicine.

However, the human factor offers a pathway toward ethical reciprocity—a model in which participation is met with tangible benefits, mutual respect, and shared ownership. Field research in the NCFD revealed strong willingness among communities to engage in genomic research, provided that:

They receive clear, culturally adapted information,

Their traditional decision-making structures (e.g., elders, religious leaders) are respected,

Results lead to improved local healthcare services,

There is transparency about who uses their data and for what purpose.

These insights challenge the assumption that top-down, standardized approaches are the only viable option in large, heterogeneous nations. Instead, they suggest that cultural competence and decentralized governance can enhance both scientific validity and social legitimacy.

Moreover, the concept of informed consent must evolve beyond a one-time signature on a form. In genetically significant but medically underserved regions, dynamic, community-mediated consent models could serve as a bridge between universal bioethical principles and local realities. For example, allowing families or clans to consult collectively before individual enrollment aligns with North Caucasian traditions while preserving personal autonomy. Such hybrid models do not weaken ethical standards—they enrich them.

Ultimately, reclaiming the human factor means shifting from a paradigm of genomic surveillance to one of genomic solidarity—where the value of data is matched by investment in people, institutions, and health equity. This requires more than technical solutions; it demands political will, redistributive policies, and institutional accountability.

II. Subsection Two: Toward Culturally Sensitive and Decentralized Governance in Multi-Ethnic States

The findings underscore a fundamental flaw in current genomic governance models, particularly in large, multi-ethnic nations like Russia: the assumption that a uniform, centralized policy can equitably serve populations with vastly different linguistic, cultural, religious, and historical contexts. This "one-size-fits-all" approach not only undermines trust but also compromises the scientific validity of genomic research by failing to account for social determinants of health and local knowledge systems. In response, this study advocates for a culturally sensitive and decentralized governance framework—one that integrates ethical oversight, capacity-building, and community agency at the regional level, especially in historically marginalized areas such as the North Caucasus Federal District (NCFD).

In regions like Dagestan, Chechnya, and Ingushetia, genetic diversity is shaped not only by biological isolation but also by centuries of endogamous marriage practices, tribal affiliations, and oral traditions about hereditary illness. These sociocultural dimensions are rarely captured in standardized medical questionnaires or biobank metadata, leading to incomplete phenotypic profiles and potential misinterpretation of genetic risk. For instance, a variant associated with a rare metabolic disorder may be prevalent in one Avar village due to founder effects—but without understanding local kinship structures and reproductive customs, researchers risk pathologizing entire communities rather than addressing specific clinical needs.

Moreover, informed consent processes conducted exclusively in Russian, using technical jargon and devoid of visual or oral explanation, fail to meet even basic standards of comprehension. As interviews revealed, many participants view genetic testing as an extension of routine blood work, unaware that their DNA may be stored indefinitely, used in commercial research, or shared internationally. This gap is not merely linguistic—it reflects a deeper epistemic injustice, where local ways of knowing and decision-making are excluded from scientific practice.

To address these challenges, governance must shift from centralized control to contextual empowerment. Drawing on principles of procedural justice and co-production of knowledge (Fricker, 2007; Nowotny et al., 2001), we propose a decentralized model featuring:

Regional Genomic Ethics Committees

Composed of local healthcare providers, community leaders, linguists, and bioethicists, these bodies would review research protocols, monitor consent procedures, and ensure alignment with cultural norms. In republics like Kabardino-Balkaria, such committees could incorporate traditional councils (kenezes) into advisory roles, recognizing collective dimensions of decision-making without overriding individual autonomy.

Multilingual, Culturally Adapted Consent Tools

Moving beyond written forms, digital platforms with audio-visual explanations in Kumyk, Nogai, Chechen, and other native languages can enhance understanding. Animated videos explaining DNA storage, data sharing, and the right to withdraw have proven effective in other multicultural settings (e.g., Māori communities in New Zealand) and should be piloted in the NCFD.

Community Benefit Agreements (CBAs)

Legally binding contracts between research institutions and donor communities, specifying how benefits—such as improved diagnostics, training for local doctors, or infrastructure investment—will be delivered. CBAs prevent exploitation and institutionalize reciprocity, ensuring that genomic progress translates into tangible improvements in public health.

Decentralized Data Hubs and Tele-Genetics Networks

Instead of routing all sequencing and analysis to Moscow, regional centers equipped with secure cloud-based platforms could process data locally, reducing latency and increasing ownership. Tele-genetics consultations via secure video links can connect rural patients with specialists while keeping data within jurisdictional boundaries, enhancing both accessibility and cybersecurity.

Capacity Building and South-South Collaboration

Investment in local training programs for genetic counselors, laboratory technicians, and bioinformaticians is essential. Partnerships between NCFD medical institutes and international networks (e.g., H3Africa, ASEAN Genetics Consortium) can facilitate knowledge transfer without dependency on central Russian or Western hubs.

This model does not reject national coordination—it reimagines it as a federated system, where federal agencies set ethical standards and quality controls, while regional actors adapt implementation to local realities. Such polycentric governance has succeeded in other domains, including environmental management and disaster response, and is increasingly recognized as essential for equitable digital health transformation.

Notably, even within Russia's highly centralized political structure, there are precedents for regional autonomy in science and health policy. The Republic of Tatarstan, for example, operates its own biotechnology cluster with international partnerships. Scaling this model to the NCFD would require political will, budgetary reallocation, and recognition that true national resilience depends on strengthening the periphery, not just the core.

Furthermore, decentralized governance enhances scientific robustness. When communities participate as partners rather than subjects, they are more likely to report accurate family histories, adhere to follow-up protocols, and support longitudinal studies—leading to higher-quality data and more meaningful outcomes.

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