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Social Innovation: A Critical Mechanism for Translating Genetic Research into Public Health Practice

Zahra Bagheri [1] **Mohammad Rasouli** [1*]

[1.] Department of Biology, Islamic Azad University of Karaj.Iran.
[2.] Caspian Faculty of Engineering, College of Engineering, University of Tehran, Tehran, Iran.Email: rasouli.mohammad@ut.ac.ir

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Abstract

Context: Advances in genetics, genomics, and precision medicine have created unprecedented opportunities to improve population health. However, translating these scientific breakthroughs into equitable public health practice remains a major challenge, particularly in low- and middle-income countries (LMICs), where financial, organizational, policy, and workforce barriers limit implementation. This review examines how social innovation can bridge the gap between genomic discoveries and public health impact.

Evidence Acquisition: A narrative review of the literature was conducted using major scientific databases, including PubMed, Scopus, Web of Science, and Google Scholar, together with reports from international organizations. Relevant evidence on social innovation, public health genomics, precision medicine, implementation science, and health equity was identified, critically appraised, and synthesized, with particular attention to experiences from LMICs and Iran.

Results: The evidence indicates that successful translation of genomics into public health depends not only on technological advances but also on social innovation. Four complementary domains were identified: innovative service delivery, sustainable financing mechanisms, participatory governance, and supportive policy and regulatory frameworks. International case studies demonstrate that approaches such as task-shifting, tele-genetics, community engagement, and digital health platforms can substantially improve equitable access to genomic services. Iran possesses important strengths, including an extensive primary healthcare network, a nationwide newborn screening program, and established community health workers (Behvarzes). Nevertheless, workforce shortages, fragmented genomic infrastructure, financing limitations, and policy inconsistencies remain major barriers to implementation.

Conclusion: : Social innovation is a critical mechanism for translating genomic research into equitable public health practice. Integrating genomics within existing primary healthcare systems, strengthening governance, investing in workforce capacity, and promoting community participation can accelerate the implementation of precision public health, particularly in Iran and other LMICs.

Keywords: Social Innovation, Public Health Genomics, Precision Medicine, Health Equity, CRISPR, Community Engagement

1. Context

Modern advances in genetics and genomics are rapidly reshaping public health. High-throughput genomic technologies now enable whole-genome sequencing at a population scale, with applications in disease surveillance and epidemiological investigations worldwide. Concurrently, breakthroughs in genetic diagnostics and gene-based therapies have opened “unprecedented” opportunities for personalized medicine (1). For example, WHO’s Global Genomic Surveillance Strategy emphasizes the importance of sequencing pathogen genomes for tracking and containing outbreaks. At the same time, experts note

that advances in genetically informed diagnosis and treatment are creating entirely new opportunities for precision healthcare (2). Taken together, these innovations promise more effective prevention, earlier diagnosis, and more targeted treatments for both infectious and chronic diseases globally.

Contemporary genetic technologies have progressed from proof-of-concept to clinical and public health use. These include genome editing (e.g., CRISPR/Cas systems), gene and cell therapies, and RNA-based platforms. They enable precise correction of genetic defects and rapid development of vaccines and therapeutics. CRISPR and viral-vector gene therapies have yielded early clinical successes for monogenic disorders, while mRNA platforms proved their speed and scalability during the COVID-19 pandemic and are being expanded to other infectious diseases and oncologic applications. When integrated with multi-omic profiling, these tools support precision medicine approaches through risk stratification and tailored prevention and treatment at both individual and population levels.

These innovations hold particular relevance in contexts such as Iran, where the health system faces the dual challenge of a high burden of non-communicable diseases (NCDs) and a significant prevalence of inherited disorders. NCDs, including cardiovascular diseases, diabetes, and cancer, account for nearly 74.4% of mortality, and many of these conditions have strong genetic determinants that could be addressed through precision prevention and targeted interventions (3, 4). Simultaneously, the high rate of consanguineous marriage contributes to the persistence of autosomal recessive disorders. Recognizing these needs, national health strategies are increasingly prioritizing genomics, with recent policy frameworks emphasizing the integration of genetic screening, newborn screening, and personalized therapies into mainstream care.

Against this backdrop, a comprehensive synthesis of the role of modern genetic technologies in public health and quality of life is both timely and necessary. However, the successful translation of these technical advances into tangible population health benefits faces a significant systemic hurdle. Traditionally, health interventions are deployed through expert-driven, top-down models that frequently overlook the critical role of community engagement in fostering sustainable health outcomes. This approach risks developing solutions that are misaligned with local cultural contexts, values, and practical realities, particularly in low- and middle-income countries (LMICs) such as Iran (5).

A growing body of literature argues that lasting innovation in healthcare is most effective when it emerges organically from collaborations between local institutions and the communities they serve. This process, known as social innovation, fundamentally links social change with health improvement by leveraging the unique strengths and insights of local actors. It provides creative, community-engaged solutions to pervasive healthcare delivery challenges, often by bridging multiple sectors beyond traditional health services (6-8).

Therefore, this narrative review aims to provide a dual-focused overview. First, it summarizes the current landscape of promising genetic and genomic technologies. Second, and crucially, it discusses the need for complementary social innovations ― including novel policies, inclusive delivery models, and participatory strategies ―to ensure that these powerful tools are integrated equitably, affordably, and acceptably into public health systems. The ultimate objective is to clarify how the synergy between technological and social innovation can reduce the burden of disease and enhance the quality of life at both the individual and population levels, with specific consideration for the Iranian healthcare system context.

Therefore, this narrative review aims to: (1) summarize key genomic and precision health technologies relevant to public health; (2) examine major conceptual frameworks of social innovation in healthcare; and (3) identify domain-specific strategies for equitable implementation in low- and middle-income countries, with particular attention to Iran.

2. Evidence Acquisition

Because the aim of this review is to provide a broad, integrative overview of how social innovation can facilitate the translation of genetic research into public health practice rather than to answer a single, narrow quantitative question a narrative (non-systematic) review approach was chosen. Narrative reviews are particularly suited to synthesizing heterogeneous evidence from multiple disciplines, including genomics, public health, health policy, and implementation science.

2.1 Search Strategy and Databases

A systematic literature search was conducted in the following electronic databases:

- PubMed/MEDLINE (including ahead of print citations)
- Web of Science Core Collection (Science Citation Index Expanded and Social Sciences Citation Index)
- Scopus
- Google Scholar (for grey literature and cross referencing, limited to the first 200 most relevant results per search string)

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In addition, the reference lists of key included articles and relevant review papers were manually screened (snowballing) to identify further eligible studies. For context specific information on Iran (e.g., consanguinity, screening programs, PHC system, and sanctions), a targeted search was also performed in SID (Scientific Information Database, the largest Persian language scientific database) and IranMedex, using Persian equivalents of the search terms; however, only English full texts or detailed English abstracts were included for data extraction.

2.2 Time Frame and Search Terms

The search covered the period from January 2000 to March 2025. The starting year, 2000, was chosen because it marks the completion of the Human Genome Project draft and the subsequent rapid expansion of both high-throughput genomic technologies and the academic literature on social innovation in health.

Domain Search terms (title/abstract/keywords)

Genetics/Genomics "genetic research", "genomics", "precision medicine", "precision public health", "CRISPR", "genome editing", "gene therapy", "high throughput sequencing", "next generation sequencing", "newborn screening", "genetic screening", "pharmacogenomics"

Social innovation "social innovation", "community based participatory research", "CBPR", "co design", "task shifting", "telemedicine", "multilevel perspective", "design thinking", "community engagement", "participatory governance"

Implementation & equity "health equity", "access", "low and middle income countries", "LMIC", "health system", "implementation science", "financing", "outcome based payment", "public health practice"

2.3 Inclusion and Exclusion Criteria

Inclusion criteria:

- Peer-reviewed original research articles, systematic reviews, narrative reviews, policy analyses, and case studies.
- Official reports from WHO, the World Bank, national health ministries (e.g., the Iran Ministry of Health), and recognized global health organizations (e.g., the CDC and the African CDC).
- Studies that explicitly addressed at least one of the following:
  - o A genetic or genomic technology with actual or potential public health application (including screening, diagnosis, therapy, or surveillance).
  - o A social innovation framework, model, or intervention applied to healthcare delivery, financing, governance, or policy.
  - o Implementation barriers or facilitators for genetic services in LMICs or among specific vulnerable populations.
- English-language full text articles (or, for Iranian sources, English abstracts with sufficient detail to extract relevant data).

Exclusion criteria:

- Studies focusing exclusively on basic molecular biology or animal models without any translational or implementation component.
- Opinion pieces, editorials, or conference abstracts without sufficient methodological detail.
- Studies on non-health social innovation (e.g., education, housing, or energy).
- Articles published before 2000, unless they were seminal works (e.g., early CBPR definitions) cited to establish conceptual foundations.

2.4 Data Extraction and Narrative Synthesis

Two authors (Z.B. and M.R.) independently screened titles and abstracts of all retrieved records. Disagreements were resolved through discussion or, if needed, consultation with a third reviewer. Full texts of potentially eligible articles were obtained and assessed against the inclusion criteria.

Data from included studies were extracted into a standardized Excel form covering:

- First author, year, country/region
- Study design and setting
- Genetic technology or innovation discussed
- Social innovation domain (service delivery, financing, governance, policy – as defined in section 3 of this review)
- Key findings relevant to bridging genetics and public health
- Identified barriers or facilitators
- Reported outcomes (health, equity, cost, acceptability, etc.)

Because this is a narrative review, no formal meta-analysis or quantitative pooling of effect sizes was performed. Synthesis followed an iterative thematic approach:

1. Familiarisation – Both authors read the extracted data repeatedly to identify recurrent themes.
2. Coding – Relevant text segments were coded according to the four core domains of social innovation (service delivery, financing, governance/engagement, and policy/regulatory).
3. Framework development – The Multi-Level Perspective (MLP) and Community-Based Participatory Research (CBPR) models were used as organizing theoretical frameworks.
4. Narrative integration – Findings were grouped into logical sections: first an overview of genetic technologies; then, conceptual models of social innovation; followed by applications to specific areas

such as multi-omic infrastructure, CRISPR therapies, and precision medicine; and finally, a country case study on Iran. The synthesis focused on identifying common patterns, transferable lessons, and context-specific barriers across different LMIC settings.

To enhance transparency and reproducibility, the authors documented all search decisions, exclusion reasons, and the final set of included references (n = 53 primary sources, as listed in the reference list). The review does not claim to be exhaustive but aims to provide a representative and theoretically grounded overview of the intersection between genomic research and social innovation in public health practice.

2.5 Limitations of the Methodology

Narrative reviews are subject to potential selection bias and a lack of formal bias assessment. The authors attempted to mitigate these by using multiple databases, explicit inclusion criteria, and independent screening. Grey literature (other than a few key reports) was not systematically searched, which may have resulted in the omission of some local implementation experiences. Furthermore, because the literature on social innovation in genomics is still emerging, many studies are descriptive case reports rather than rigorous evaluations; this limits the strength of causal inferences. The Iran-specific analysis, while based on the best available peer-reviewed and official sources, is constrained by the fact that some recent policy changes (e.g., enforcement of the Youth and Population Law) have not yet been fully evaluated in the international literature. Despite these limitations, the methodology provides a robust and transparent foundation for the conceptual arguments and policy recommendations presented in this review

3.Social Innovation and its conceptual models

Social innovation has been variously defined across disciplines, but central to all conceptions is the idea of novel solutions to social problems that are more effective, efficient, sustainable, or just than existing alternatives (9, 10). Phills et al. provide a particularly nuanced definition, describing social innovation as "a novel solution to a social problem that is more effective, efficient, sustainable, or just than existing solutions and for which the value created accrues primarily to society as a whole rather than private individuals" (9). This definition emphasizes both the process of innovation and the outcomes that benefit society broadly rather than privileging individual or corporate interests.

The European Commission offers a more operational definition, characterizing social innovation as "innovative activities and services that are motivated by the goal of meeting a social need and that are predominantly developed and diffused through organizations whose primary purposes are social". What distinguishes social innovation from other forms of innovation is its dual focus on being social in both ends and means – prioritizing social value creation through processes that engage and empower stakeholders (11). In the context of healthcare, social innovation refers to the design and implementation of new strategies, concepts, policies, and organizational models that aim to address systemic healthcare delivery challenges in ways that are more effective, efficient, sustainable, and just than existing solutions. Its focus is not on the biological technology itself, but on the social and systemic structures required to deliver it.

Based on analysis of multiple conceptualizations, social innovation in healthcare typically exhibits several core characteristics, as mentioned in table 1. These characteristics distinguish social innovation from both technological innovation (which may focus primarily on technical advancements without considering social implementation) and social service delivery (which may maintain existing systems without transforming them).

The application of social innovation in healthcare generally progresses through three interrelated stages. The first stage, idea development and participatory design, begins with identifying a complex health challenge (often one that existing systems have failed to address) and creating a safe, collaborative environment for stakeholders to co design solutions. This process actively involves community members, patients, frontline workers, and policymakers, using methods such as co design workshops, design sprints, or crowdsourcing. The emphasis is on generating context specific, culturally aligned solutions, with early community ownership to enhance legitimacy and uptake.

The second stage, transfer, diffusion, and scaling, focuses on adapting and expanding promising innovations beyond their initial setting. Effective scaling requires alignment with existing health system structures, strategic partnerships with policymakers and institutions, and, in many cases, the use of digital tools to extend reach. Common barriers at this stage include limited resources, insufficient evidence of impact, and resistance from entrenched actors.

Finally, institutionalization embeds the innovation into formal systems to ensure long term sustainability. This involves deliberate institutional work—including advocacy to reframe the issue in moral or social justice terms, engagement with or creation of governance bodies, and the development of training or certification mechanisms to maintain quality. At this stage, the innovation becomes part of the health

system's norms and practices, enabling systemic transformation rather than temporary improvement.

Table 1. Core Characteristics of Social Innovation in Healthcare

Characteristic	Description	Source	Implications for Public Health Genomics
Community Engagement	Active involvement of community members in identifying problems and co-creating solutions	(12)	Ensures that genetic screening programs address locally relevant conditions and respect cultural beliefs regarding inheritance and privacy.
Systemic Change	Focus on transforming underlying systems and structures rather than addressing symptoms	(13, 14)	Shifts genomics from specialist, hospital-based services to integrated primary care and public health surveillance.
Novelty	Introduction of new or significantly improved products, processes, or approaches	(15-17)	Enables novel delivery models (e.g., tele-genetics, task-shifting) that make genomic tests and counselling accessible in LMICs.
Social Value Creation	Primary goal is to create benefits for the society rather than enable private value capture	(18, 19)	Prioritizes equitable access to gene therapies and genomic diagnostics over commercial profitability.
Sustainability	Solutions designed for long-term impact rather than short-term fixes	(20)	Supports development of sustainable financing (e.g., pooled funds, outcome-based payments) for high-cost genomic interventions.

3. Results

3.1 A Toolkit for Change: Key Models and Frameworks

The following sections present key conceptual frameworks central to social innovation.

3.1.1 Community-Based Participatory Research (CBPR)

Community-Based Participatory Research (CBPR) represents one of the most well-developed and relevant models for social innovation in healthcare contexts. CBPR is defined as "a collaborative research approach that equitably involves community members, researchers, and other stakeholders in the research process and recognizes the unique strengths that each bring". Unlike traditional research approaches, which often treat communities as passive subjects, CBPR actively engages community partners throughout the entire research process – from identifying problems and research questions to disseminating and applying results (21).

3.1.2 Multi-Level Perspective (MLP) Framework

The Multi-Level Perspective (MLP) offers a valuable framework for understanding how social innovations scale and transform complex systems. Originally developed to analyze sustainability transitions, the MLP provides a conceptual model for understanding how innovations emerge and interact across different levels of socio-technical systems (14). The framework identifies three analytical levels (22):

1. Niche (innovations): Protected spaces where radical innovations develop, often through the efforts of small networks of actors willing to invest in novel approaches despite uncertain outcomes.
2. Regimes: The dominant structures, rules, and practices that stabilize existing systems and often resist transformative change.
3. Landscape: The broader exogenous environment that influences both niches and regimes, including demographic trends, cultural patterns, and macroeconomic conditions.

The MLP framework helps explain why many technically sound innovations fail to achieve

widespread impact, while others successfully transform systems—a critical consideration for implementing genetic technologies in public health. By analyzing the interactions among niche innovations, regime resistance, and landscape pressures, the MLP provides a diagnostic tool for identifying leverage points for systemic change. The framework consists of three horizontal layers representing different scales. At the top is the Landscape (macro pressures), which includes broad contextual forces such as pandemics, demographic change, and health policy. The middle layer is the Regime (health system), symbolizing stable structures, including hospitals, insurers, and clinical guidelines. At the bottom is the Niche (innovations), representing protected experimental spaces, such as telemedicine pilots, digital health applications, and community health initiatives.

Table 2. Comparison of Traditional Research and CBPR Approaches

Research Component	Traditional Research	CBPR Approach
Research Question	Driven by researcher interests	Co-created with community partners
Relationship	Researcher-subject dynamic	Collaborative partnership
Data Collection	Researchers control process	Community involvement in collection
Data Interpretation	Researcher analysis alone	Collaborative analysis with community
Outcomes	Academic publications	Action and change benefiting community
Beneficiaries	Primarily academic advancement	Community and researchers equally

3.1.3 Design Thinking for Social Innovation

Design thinking approaches have been increasingly applied to social innovation by emphasizing human-centered design processes that begin with developing deep empathy for users' experiences and needs. This approach typically involves iterative cycles of inspiration, ideation, and implementation, supported by ongoing prototyping and feedback (7). When applied to social innovation, design thinking emphasizes co-design processes that engage stakeholders directly in developing solutions.

3.2. Core Domains of Social Innovation

The theoretical models of social innovation provide a framework for understanding how change occurs. To translate this theory into practice, it is essential to consider the core domains in which these innovations are implemented. These domains represent key leverage points within health systems where intentional, socially innovative interventions can be applied to overcome implementation barriers and promote equitable change. The following domains provide a practical framework for identifying and designing social innovations, with specific applications to public health genomics discussed in Part 3.

3.2.1 Service Delivery

This domain encompasses the innovative redesign of how health services are organized and delivered to end users. It moves beyond the technical effectiveness of an intervention to focus on the processes, channels, and human resources required to ensure that services are accessible and acceptable. Social innovations in service delivery are characterized by patient-centricity and flexibility, and are often designed to overcome geographic, cultural, or logistical barriers to care. Examples include telemedicine and virtual health platforms, which extend specialist services to remote populations; mobile clinics that deliver point-of-care services directly within communities; and task-shifting, a process in which specific clinical responsibilities are delegated to trained non-specialist health workers to maximize the efficiency of the available workforce.

3.2.2 Financing

A critical barrier to the adoption of advanced health technologies is the development of sustainable economic models. This domain focuses on innovating how care is paid for to ensure financial sustainability for the providers while protecting patients from catastrophic health expenditures. Innovative financing mechanisms are designed to align incentives with value-based and equitable outcomes rather than the volume of services. Key examples include outcome-based payments (or pay-for-performance schemes), in which reimbursement is linked to the achievement of predefined health outcomes, and pooled funds, which combine financial resources from multiple public and private contributors to create insurance schemes or subsidize care for specific conditions, thereby spreading financial risk and increasing access to high-cost treatments such as gene therapies.

3.2.3 Governance and Engagement

This domain addresses the critical question of who is involved in decision-making processes. It focuses on innovating structures of power, authority, and participation to ensure that health interventions are co-created, legitimate, and trusted by the communities they serve. Effective models in this domain actively shift the dynamic from top-down, expert-led governance to more inclusive and horizontal partnerships. This includes establishing community advisory boards to provide ongoing oversight and feedback on research and health programs, and conducting co-design workshops that engage patients, community leaders, and frontline health workers as equal partners throughout the design process. Such approaches help ensure that solutions are culturally appropriate and address locally prioritized needs (23).

3.2.4 Policy and Regulatory

The translation of innovation into practice often requires changes to the legal and policy environment. This domain involves creating new rules, standards, and guidelines that enable rather than inhibit innovation while safeguarding ethical principles and protecting the public. Social innovation in this area works to modernize frameworks to keep pace with technological advances. Relevant examples include adaptive licensing (or progressive pathways), which allow the conditional approval of promising therapies based on early evidence while requiring continued monitoring of real-world outcomes, and genetic privacy laws that are robust, culturally informed, and explicitly protect individuals from discrimination based on their genetic information. Such protections are essetial for building public trust in genetic screening and testing programs.

Table 3. Core Domains of Social Innovation in Healthcare

Domain	Primary Focus	Key Examples	Primary Function
Service Delivery	How care is accessed and delivered	Telemedicine, mobile clinics, task-shifting	To enhance reach, accessibility, and acceptability of services
Financing	How care is funded and sustained	Outcome-based payments, pooled funds	To ensure economic sustainability and equitable access
Governance & Engagement	Who holds power and is involved in decisions	Community advisory boards, co-design workshops	To build legitimacy, trust, and ensure cultural congruence
Policy & Regulatory	What rules enable safe and ethical innovation	Adaptive licensing, genetic privacy laws	To create an enabling environment that protects citizens

These four domains are not mutually exclusive; rather, the most powerful social innovations often integrate elements from several domains simultaneously. For instance, a community-based genetic screening program (Service Delivery) may be financed through a public-private pooled fund (Financing), governed by a board of community stakeholders (Governance), and implemented under a new policy of informed consent (Policy). The following section examines the application of these domains specifically to the field of public health genomics.

Table 4 highlights six fundamental differences between traditional and social innovation approaches. In the traditional approach, problems are defined by experts, services are delivered through centralized hospitals, and financing relies on out-of-pocket payments. Governance is top-down, consent is collected once, and evaluation focuses solely on clinical effectiveness. In contrast, social innovation engages communities in defining problems, shifts services to primary care and community health workers, and uses blended or outcome-based financing models. Governance is participatory, informed consent is dynamic, evaluation emphasizes equity and trust, and scaling occurs through horizontal integration into existing systems.

4. Social Innovation in Action: Applying the Models to Public Health Genetics

4.1. Innovating Genomic Infrastructure for Equitable Multi-Omic Integration

High-throughput sequencing and multi-omic integration are already reshaping public health practice by enabling high-resolution outbreak surveillance, discovery of biomarkers for screening, and stratified prevention and treatment strategies. National and transnational efforts to coordinate sequencing and data resources show how these technologies can scale when embedded within shared

infrastructure and governance. They also illustrate the potential of multi-omic data to improve detection, risk stratification, and policy responses (24).

The principal obstacles are practical and social rather than purely technical. Heterogeneous omics formats and metadata prevent interoperability; high computational and storage needs limit participation by resourced-constrained institutions; small sample sizes and dimensionality increase the risk of overfitting and unstable integrative models; and concerns related to privacy, consent and trust issues hinder data sharing and representative sampling. These constraints create bottlenecks in translating multi-omic approaches into routine public health workflows, as even powerful algorithms and assays are ineffective if data cannot be pooled, interpreted, or used safely and equitably (25, 26).

Table 4. Traditional vs. Social Innovation Approaches in Genomics

Aspect	Traditional Approach	Social Innovation Approach
Problem definition	Defined by researchers or technology developers	Co-defined with communities and end-users
Service delivery	Centralized, hospital-based, specialist-driven	Decentralized, primary care-based, task-shifting to community health workers
Financing	Out-of-pocket or donor-dependent	Blended finance, outcome-based payments, pooled risk mechanisms
Governance	Top-down, expert-led	Participatory, community advisory boards, co-design
Consent model	One-time, generic, often incomprehensible	Dynamic, layered, culturally adapted, ongoing control
Evaluation focus	Clinical efficacy, cost per test	Health equity, acceptability, trust, long-term sustainability
Scale-up strategy	Vertical program, separate infrastructure	Horizontal integration into existing PHC and digital systems

To overcome these challenges, a coordinated package of social innovations is needed that combines governance, shared infrastructure, cost reduction, and community capacity building. Standardization of metadata and workflows through frameworks such as MIxS and BioCompute Object can ensure interoperability and reproducibility. Establishing regional sequencing and computational hubs, supported by transparent cost-sharing, could expand access for smaller laboratories while avoiding duplication of infrastructure. Privacy-preserving federated analysis should be piloted to enable collaborative research without the centralization of sensitive data. Costs can be further reduced by adopting low-cost protocols, such as BRB-seq, and collective procurement of reagents. Capacity building requires regular hackathons, bioinformatics training, and ELSI programs developed with community input to foster a diverse and skilled workforce. Embedding participatory governance, transparent consent mechanisms, and open benchmarking across all initiatives will enhance trust, accountability, and quality. Collectively, these measures transform high-throughput genomics into an equitable and scalable tool for public health.

Challenges (technical and social)

High-throughput sequencing and multi-omic integration face several challenges, including heterogeneous data formats, lack of interoperability, high computational costs, limited participation by low-resource institutions, and overfitting due to small sample sizes and privacy/trust concerns that hinder data sharing.

Application of social innovation domains

- Governance: Standardization via MIxS and BioCompute frameworks and participatory oversight.
- Financing: Regional sequencing hubs with cost-sharing models and collective procurement of reagents.
- Service delivery: Federated analysis to avoid the centralization of sensitive data.

• Policy: Open-access benchmarking and transparent consent mechanisms (27).

Available evidence

ELIXIR EXCELERATE in Europe and African CDC initiatives demonstrate the feasibility of shared infrastructure. Privacy-preserving federated analysis has been piloted in rare disease cohorts. However, evidence from low- and middle-income countries (LMICs) remains limited.

Practical recommendations (with considerations for Iran)

Establish a national genomic data coordination center linked to the Ministry of Health. Pilot federated analysis between Tehran University of Medical Sciences and regional laboratories. Train bioinformaticians through accredited short courses. Integrate genomic data with the existing primary care electronic health record (SIB system) (4, 28).

4.2. Democratizing CRISPR Therapies Through Financing and Delivery Innovation

e of the most transformative tools is CRISPR/Cas9 genome editing. This technology enables precise and efficient modification of DNA and has rapidly become the preferred editing system due to its simplicity and low cost (29, 30). Early applications have already targeted serious diseases, with the WHO reporting that somatic genome editing has been used experimentally for conditions such as HIV infection and sickle-cell disease (31). In late 2023 this potential translated into clinical practice when the U.S. FDA approved Casgevy, the first CRISPR-based cell therapy for sickle cell disease. These therapies, which edit patients' hematopoietic stem cells to increase fetal hemoglobin, have been recognized as landmark "cell-based gene therapies…to improve public health". Such approvals demonstrate that CRISPR is moving from experimental research in the laboratories toward clinical applications for genetic disorders (32). Other gene therapies using viral vectors (e.g. for hemophilia or retinal diseases) similarly illustrate how writing new DNA can correct hereditary defects (33). Across medicine and public health, gene editing holds promise for targeting the underlying causes of diseases that were previously untreatable.

However, the transformative potential of these therapies is tempered by profound implementation challenges that are social and systemic in nature. The extremely high costs of treatments such as Casgevy risk creating an unprecedented genomic equity divide, in which life-changing therapies are available only to the wealthiest individuals or within the most well-funded healthcare systems (34). Furthermore, their complexity necessitates administration through specialized tertiary care centers, creating significant geographic and logistical barriers to access for rural and low-resource populations (35). Beyond access challenges, these technologies raise complex ethical concerns related to justice, priority-setting, and potential misuse, which can negatively affect public trust and hinder adoption if not proactively addressed (36).

Applying the Multi-Level Perspective (MLP) framework reveals that these therapies represent powerful niche innovations emerging from protected research and development environments. Their transition into mainstream care requires changes within the current socio-technical regime of drug approval, reimbursement, and specialized care delivery. This transition can be facilitated by mounting landscape-level pressures, such as powerful patient advocacy movements, a shifting ethical consensus on genetic medicine, and national political priorities to address the burden of inherited disorders, creating a window of opportunity for systemic change.

Concrete, actionable pathways forward emerge from the core domains of social innovation. To address catastrophic costs, health systems must innovate financing through models like outcome-based payment agreements, where reimbursement is contingent on achieving sustained clinical benefits, thereby mitigating financial risk and aligning payment with value. Simultaneously, developing a hub-and-spoke service delivery model can expand access; centralized "Centers of Excellence" handle the complex cell-editing process, while trained healthcare teams at regional hospitals manage patient identification and long-term follow-up using standardized protocols and tele-mentoring, effectively task-shifting responsibilities to maximize system efficiency.

4.3. The Framework of Precision Medicine

Precision medicine is broadly defined as tailoring prevention and treatment to the individual's genetic, environmental and lifestyle characteristics, while precision public health applies similar principles at the population level to deliver "the right intervention to the right population at the right time" (37, 38). In practice, precision medicine has transformed areas

such as oncology and rare-disease diagnosis: for example, next-generation sequencing of tumors guides targeted therapies and immunotherapy decisions (39). Precision public health is also emerging in infectious-disease surveillance, where real-time pathogen genomics helps track outbreaks, and in targeted screening programs such as newborn screening (37).

Despite these advances, important challenges limit fair implementation. Major data inequities persist because genomic databases and biobanks overwhelmingly represent people of European ancestry, leaving many populations under-screened and poorly represented (40). Workforce shortages and uneven distribution of trained geneticists, genetic counselors and data scientists further restrict access. Consent, privacy, and governance remain contentious: genomic data are sensitive, one-off consent models are often opaque, and communities with histories of exploitation may distrust research (40). Affordability also limits uptake because many advanced tests and targeted therapies are expensive and not routinely reimbursed (41), and only a fraction of eligible patients receive these services in many systems (42).

To overcome these gaps, social innovation can help extend precision approaches equitably. For instance, community co-design means involving patients and communities in developing precision interventions (43). By partnering with communities and even incorporating Indigenous data-sovereignty principles, programs can build trust and ensure cultural relevance. Task-shifting or task-sharing, where nurses or trained primary-care staff perform family-history intake and basic genetic education, multiplies capacity and reserves specialists for complex cases (44). Tele-genetics expands access by enabling rural or underserved patients to receive counseling remotely; evidence indicates remote counseling achieves comparable satisfaction and outcomes to in-person services (45). Blended finance, combining public, private, and philanthropic funding, can subsidize testing and counseling during scale-up and help pilot sustainable payment models (46).

Governance and consent innovations are central to ethical scale-up. Dynamic or decentralized consent platforms that give participants ongoing control over data use can increase transparency and willingness to share genomic data, and embedding such frameworks in biobanks and studies helps include historically underrepresented groups by respecting local norms (47). Integrating genetics into primary care by embedding genetic counselors or decision-support in family medicine settings improves early identification of at-risk patients and smooths pathways to testing and follow-up, which enhances equity of access (48).

Social innovation strategies strengthen genetic counseling in practical ways. Co-designed counseling materials improve cultural relevance and comprehension; tele-genetics allows patients without local specialists to attend appointments by video; task-shifting trains nurses or community health workers to deliver standardized pre-test education while genetic counselors focus on interpretation and complex cases; blended finance and insurance reforms can lower out-of-pocket costs; and decentralized consent gives patients ongoing control over how their genetic information is used and shared. Embedding genetics within primary care creates a clear pathway to counseling and follow-up for underserved patients, making precision medicine and precision public health more accessible, equitable, and effective.

4.4 Opportunities and Barriers Specific to Iran

The preceding sections have examined social innovation as a generic enabling mechanism for translating genetic research into public health practice. However, the specific opportunities and barriers encountered in any given country are shaped profoundly by its unique demographic, cultural, economic, and political context. Iran presents a particularly instructive case study. The nation faces a high burden of genetic disorders, largely driven by deeply embedded sociocultural practices, yet it possesses a robust primary healthcare (PHC) infrastructure and a demonstrated capacity for scientific resilience under challenging conditions. Understanding this duality is essential for designing contextually appropriate social innovations that bridge genomics and equitable health outcomes

4.4.1 The Burden of Consanguinity and Inherited Disorders

Consanguineous marriage remains a deeply rooted cultural preference in Iran. Across different studies and regions, national estimates indicate that approximately 30–40% of all marriages in Iran are consanguineous. A recent 2024 study in Zahedan, southeastern Iran, found the prevalence of consanguineous unions to be as high as 46.7% of all total marriages, with first cousin unions constituting the largest category (30.2%). This practice, while culturally valued for reinforcing family and social ties,

has significant public health consequences. The average inbreeding coefficient (F) among consanguineous couples has been calculated at approximately 0.0516, which translates to a markedly elevated risk of autosomal recessive disorders in offspring. Indeed, studies have shown that the prevalence of congenital malformations in neonates from consanguineous marriages can be more than three times higher than in those from non-consanguineous ones (7% vs. 2%) (49).

The genetic burden in Iran is substantial. The country has a particularly high prevalence of thalassemia, with approximately 23,000 Iranians affected, making Iran "one of the major centers" for the disease globally. Iran also has a high frequency of other inherited conditions such as G6PD deficiency and various autosomal recessive intellectual disability syndromes. A large Iranian cohort study of intellectual disability identified AP4 deficiency syndrome as the most common syndromic forms and ASPM as the most common non-syndromic autosomal recessive intellectual disability. Notably, the same study emphasized that countries with high consanguinity rates, such as Iran, provide an excellent opportunity to identify novel autosomal recessive genes. This dual reality—a high burden of recessive disorders coexisting with a genetically rich, understudied population—creates both an urgent need for genomic services and a unique scientific opportunity (50).

4.4.2 Screening Programs: Successes and Legal Constraints

Iran has a long, and in many respects, exemplary history of genetic screening. The most well-known success is the national thalassemia prevention program, initiated in 1997. This program was integrated into the country's premarital testing framework and linked to a five-level primary healthcare network covering the entire population. It has been hailed as a model of how genetic screening can succeed even in lower-resource settings. Feedback from communities through systematic evaluation led to national acceptance of prenatal diagnosis, demonstrating that top-down policy can be effectively combined with community engagement (51).

Similarly, Iran's newborn screening program is a remarkable achievement. Since 2002, screening for congenital hypothyroidism, phenylketonuria (PKU), and G6PD deficiency has been mandatory nationwide. Over time, as Iranian nuclear medicine capabilities advanced, the program expanded significantly. Today, every newborn in Iran receives free screening for 58 inherited metabolic disorders using tandem mass spectrometry (MS/MS), a technology rooted in nuclear science. The program has operated for over two decades, with 100% screening coverage achieved in some provinces. However, recent legal developments have introduced considerable constraints. The "Supporting Family and Regenerating Population Act" (commonly referred to as the "Youth and Population Law"), enacted in 2021, has significantly restricted prenatal screening. Article 53 of this law effectively prohibits screening for diseases that may lead to the birth of a baby with a difficult-to-treat condition, and doctors and health workers are not required to recommend screening. As a result, access to screening kits for congenital anomalies has been restricted in Iran, with the Ministry of Health ceasing to issue permits for diagnostic tools such as PAPP A, free beta-hCG, and ELISA tests used in first-trimester screening. Officials have denied that this has led to an increase in birth defects, but critics argue that restricting prenatal screening represents a retrogressive step that undermines women's reproductive health rights and could increase the burden of preventable genetic conditions. These legal and policy contradictions, between an advanced newborn screening program on one hand and restrictive prenatal screening policies on the other, highlight the profoundly politicized and contested nature of genetic services in Iran (52).

4.4.3 Human Resource and Infrastructure Gaps

Despite policy commitments and some areas of success, Iran faces acute shortages in the human resources necessary for genomic medicine. There is no formal medical genetics residency program in the Iranian health education system. Despite the high demand for genetic services due to consanguinity, the country lags significantly behind global standards in terms of trained geneticists, genetic counselors, and bioinformaticians. One source describes the shortage as a "big gap" requiring an "immediate response". A policy brief on the Iranian health system highlighted critical shortages of healthcare workers overall, compounded by geographic maldistribution, workforce migration, inadequate training, and limited support systems. Some efforts have been made to address these. The State Welfare Organization established a genetic counseling network in 1997, which has gradually expanded to include approximately 132 governmental and private genetic

counseling centers across the country. These centers have served about 400,000 clients and trained around 900 genetic counselors. However, the distribution is highly uneven: Tehran alone has 15 centers, while some provinces have only a single center. A qualitative study on community health workers (Behvarzes) also revealed that service provision challenges include ambiguity of roles, non-compliance with the referral system, and, inadequate training, all of which would be amplified if Behvarzes were expected to take on genetic counseling responsibilities without proper support. The bioinformatic workforce remains particularly underdeveloped, with limited access to advanced genomic analysis, lack of accreditation in bioinformatic training, and an underdeveloped career path for bioinformaticians (53).

4.4.4 Leveraging the Primary Healthcare Network and Behvarz System

Perhaps the single most important asset for translating genetic technologies into public health practice in Iran is its extensive and well-functioning PHC network. Iran has a five level PHC network covering the entire population, with responsibility for health and medical education merged throughout the system. The network includes rural health houses staffed by trained community health workers known as Behvarzes. As of 2022, over 31,000 Behvarzes were providing primary care services to rural residents nationwide. Behvarzes are the backbone of the Iranian health system and play a key role in providing efficient, responsive, and equitable services at the first-level of service provision. Their responsibilities include maternal and child health, communicable and non-communicable disease management, health education, an annual census of the population covered, and the collection of health information.

The thalassemia prevention program demonstrated that genetic screening can be successfully integrated into this PHC network. Premarital testing, genetic counseling, and follow-up were systematically linked across different levels of the network, from rural health houses to provincial referral centers. This existing infrastructure offers a ready-made platform for expanding genomic services, including cascade screening for genetic disorders, community-based genetic education, and task-shifting of basic genetic counseling tasks from scarce specialists to trained Behvarzes and general practitioners. The WHO has recognized Iran's PHC system as a model for achieving health for all, with particular reference to its community health worker program (54).

However, realizing the potential of the PHC network for genomics will require addressing several challenges. Behvarzes already face significant occupational challenges, including heavy workloads, role ambiguity, inadequate training resources, and perceived inequities in job satisfaction and benefits. Adding genetic responsibilities without appropriate investment in training, supervision, and remuneration would risk overburdening an already stretched workforce. Moreover, the digitization of health information systems, essential for genomic data management and linking screening results across levels of care, remains incomplete in many rural areas. A carefully designed social innovation strategy would thus involve: (1) expanding and accrediting formal training programs for genetic counselors and bioinformaticians; (2) task-shifting basic genetic literacy, family history collection, and pretest counseling to trained Behvarzes and GPs, with clear referral pathways to specialist centers; (3) investing in interoperable digital health records that can securely manage genomic data; (4) leveraging tele-genetics to connect rural patients with urban specialists; and (5) integrating genetic services into existing maternal and child health, premarital, and newborn screening programs rather than creating parallel, resource-intensive vertical programs (55).

Ultimately, Iran's experience demonstrates that even under severe resource and political constraints, genomic technologies can be translated into population health benefits if they are embedded within strong PHC systems, adapted to local cultural and legal contexts, and supported by social innovations that build trust, capacity, and equitable access. The country's network of Behvarzes, its five-tiered PHC system, and its demonstrated scientific resilience provide a foundation that many other low-and-middle income countries lack. Leveraging this foundation through thoughtful, participatory social innovation will determine whether Iran's considerable genomic assets reduce or widen the existing inequities in health outcomes.

4.Conclusion

This narrative review has articulated a critical thesis: the unprecedented pace of discovery in genetics and genomics is a necessary but insufficient condition for improving public health outcomes. Translating

genomic and precision-health advances into population benefits in LMICs will require more than technology alone. Evidence shows that without addressing social and systemic barriers, technical innovations risk widening existing inequities. Indeed, even low-cost sequencing or gene-based interventions "will require thoughtful implementation" and supportive community education to succeed in LMIC settings (56). Social innovation (novel, community-driven changes in service delivery, financing, governance, and policy) thus emerges as an essential "bridge" to equity. As others have observed, limited access to diagnostics and treatments in LMICs "hinders public health efforts," and can only be overcome by deploying these tools via new, participatory models (57). In line with broader health equity literature, social innovation in genomics aligns with calls for people-centered systems that deliberately engage underserved groups.

Social innovation reforms health delivery by leveraging local assets and agency. For example, Malawi's "Learner Treatment Kit" program redesigns service delivery by training school teachers to diagnose and treat malaria in students (57). This school-based care model effectively extended access to malaria testing and treatment where clinics are scarce. Evaluations showed increased care-seeking among sick children, fewer absences and dropouts, and relief of overburdened clinics (57). Similarly, in Peru community health workers (CHWs) distributed self-collection kits for cervical cancer screening in remote villages. Over 98% of women returned viable samples and 87% of HPV-positive women received followed-up with care (58). In each case, task-shifting to trusted local figures and "meeting people where they are" dismantled traditional access barriers. Likewise, crowdsourced community campaigns in China dramatically boosted HIV screening: a contest for testing promotion materials achieved an 8.9% absolute increase in testing uptake among target populations, while slashing outreach costs and fostering local ownership (59). These cases demonstrate that rethinking delivery – from schools to homes – can overcome implementation challenges in diagnostics and screening. By involving users in co-design and implementation, social innovations mobilize existing community networks to embed genomic or other health services into everyday settings.

Innovations in financing, governance, and policy are likewise critical to ensure equitable scale-up. The Lancet Commission on high-quality health systems emphasizes that service delivery redesign often requires external investment, and that funders should align support with country-led strategies towards quality and equity (60). For genomic health, novel financing might include public–private consortia, development bonds or blended funds dedicated to capacity building and subsidizing access. For example, government philanthropy partnerships have underwritten regional sequencing hubs (e.g. African CDC initiatives), while some Latin American countries use social security and insurance reforms to cover genetic testing. At the governance level, national strategies can enshrine equity goals: Nigeria's National Genomics Surveillance Strategy, for instance, explicitly mandates "robust community engagement" and a "quadruple helix" partnership among academia, industry, policymakers and the public (61). By building local research capacity and inclusive oversight, such policy frameworks aim to keep genomics "needs-driven" and context-sensitive. Comparable initiatives in South and Southeast Asia (e.g. ASEAN rare-disease networks) also illustrate how regional collaboration and shared guidelines can harmonize data use and drive equity. In short, embedding equity requires aligning financial and regulatory levers as much as adopting new technologies (62).

These insights have concrete implications. Policymakers should champion participatory models from the outset by investing in community genetics education, ethics infrastructure, and health workforce training parallel to technological rollout. Reimbursement policies and insurance schemes may be re-engineered (e.g. microinsurance or voucher programs) to finance genomic services for the poor. Engaging civil society and patient groups can ensure culturally appropriate messaging and consent frameworks. Researchers should incorporate equity metrics into genomics studies and use implementation science methods (e.g. community-based participatory research) to co-create solutions. Cross-disciplinary teams can adapt multilevel frameworks (MLP) to map how social, organizational and policy factors influence genomic adoption. Importantly, implementation research must go beyond feasibility and examine the outcomes (health, economic, and trust) of social innovations. On the ground, implementers can leverage existing community structures – schools, CHW networks, and local laboratories – and employ digital tools (telemedicine, mHealth) to extend reach.

Institutions like SIHI (Social Innovation in Health Initiative) and WHO's community genetics programs highlight best practices and lessons. In practice, a mixed strategy – blending top-down support with grassroots engagement – appears most effective.

Despite promising examples, current evidence has gaps. Many social innovations have been evaluated only in pilot studies or short-term trials, often within single communities. Robust data on long-term impact, cost effectiveness, and scalability are lacking. Context matters: a model that works in rural Malawi may not translate directly to urban slums or different cultural settings. Moreover, the sustainability of external funding or volunteer engagement is uncertain. Implementing genomic programs faces additional challenges such as data privacy, the need for bioinformatics, and variable health literacy. Future research should systematically assess which social strategies yield the greatest equity gains in genomic medicine. Comparative studies across LMICs could identify transferable models, while political economy analyses can clarify how to align stakeholder incentives. Evaluation frameworks that integrate social and economic outcomes will be especially valuable**.**

6.Policy and Practice Implications for Iran and Other LMICs

Based on the synthesis of evidence and social innovation frameworks, the following actionable recommendations are directed at Iranian policymakers (the Ministry of Health and Medical Education, the National Genetic Policy Council, and medical universities) and can be adapted by other LMICs.

For the Ministry of Health:

• Integrate basic genomic literacy and family history collection into the standard training curriculum of Behvarzes (community health workers). Allocate a dedicated budget for their supervision and remuneration for genetic tasks.

• Expand the national newborn screening program (already covering 58 disorders) to include a pilot program for whole-genome sequencing of infants with unexplained intellectual disability, using a hub-and-spoke model to reduce costs.

• Establish a national tele-genetics platform connecting rural health houses to provincial genetic counselling centers, with subsidized internet and video consultation tools.

For the National Genetic Policy Council:

• Revise Article 53 of the Youth and Population Law to allow first-trimester screening for severe congenital anomalies while maintaining ethical safeguards. This would align Iran with WHO recommendations on reproductive health.

• Approve a national dynamic consent framework for genomic data, giving patients ongoing control over how their data are used, and mandate its use in all publicly funded biobanks.

• Create a multi-stakeholder task force (including patient advocates, religious scholars, and clinical geneticists) to develop culturally appropriate guidelines for CRISPR-based therapies, prioritizing conditions with high local prevalence (beta thalassemia, sickle cell disease).

For medical universities (e.g., Tehran University of Medical Sciences and Iran University):

• Establish the country's first formal medical genetics residency program within two years, with an initial intake of 20 residents per year.

• Develop accredited short-term certificate courses in bioinformatics and genetic counselling for existing healthcare professionals (nurses, midwives, and laboratory technicians).

• Partner with the private sector to develop a low-cost, domestically produced NGS panel for common recessive disorders (e.g., ASPM-related intellectual disability, G6PD deficiency, and thalassemia).

For international donors and LMIC networks:

• Fund implementation science research that rigorously evaluates social innovations in genomics using mixed methods and long-term follow up.

• Establish a South-South collaborative platform for sharing open-source genetic testing protocols, task-shifting guidelines, and dynamic consent tools.

Bridging genomics to equitable health in LMICs depends fundamentally on social innovation. The cases above underscore that cutting-edge technologies alone will not close gaps; they must be embedded within redesigned delivery systems, inclusive financing schemes, and accountable governance structures. By centering community needs and participation, social innovation ensures that genomic advances become accessible and beneficial for all

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strata of society. As the field of precision public health evolves, synergy between technological and social change is crucial. Policymakers, funders, and researchers should therefore treat social innovation not as optional, but as the linchpin that will determine whether genomics delivers on its promise for global health equity.

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The authors declare no conflicts of interest regarding the publication of this paper.

AI Using Declaration

The authors used DeepSeek solely to assist with language editing, improving readability, refining sentence structure, and organizing sections of the manuscript during preparation. The AI tool was not used for study design, literature selection, data analysis, interpretation of findings, or generation of scientific conclusions.

Author's contributions

Both authors contributed equally to the conception, drafting, and revision of the manuscript, and approved the final version for submission.

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