White Paper

The Evolving Global Landscape of Genomic Initiatives

Discovery and Disparity

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Table of contents

Introduction

The global landscape of initiatives dedicated to generating and aggregating human genomic data is both highly dynamic and diverse. As sequencing costs continue to fall and research advances accelerate, these initiatives are poised to play an increasingly vital role in the advancement of human health. However, most existing reports only offer a single snapshot in time of this landscape. Breaking new ground, IQVIA has comprehensively updated a proprietary database cataloguing these genomic initiatives, using publicly available information. The insights and trends presented in this paper offer stakeholders an overview of the current genomic landscape of 257 active initiatives, highlighting significant progress and developments since 2020. Amid shifting economic and political environments, stakeholders can evaluate the value and applications of genomic initiatives in furthering medical research and human data science.

This paper re-examines the global landscape of genomic initiatives, providing an update to the previous IQVIA Genomic Initiatives Database in 2020.[1] All genomic initiatives and databases were identified and catalogued using publicly available information. These initiatives were segmented by several key parameters such as geographic origin, funding type, genomic data collected, cohort size and patient linked data. To reflect research developments over the last 5 years, parameters have also been updated to record additional forms of omic data, extending to fields such as proteomics, metabolomics and transcriptomics.

Key applications of genomic data are also explored, spanning drug development, personalised medicine, pharmacogenomics, global health, as well as lifestyle and wellness. Specific examples from the database are highlighted to illustrate how existing initiatives are contributing to these applications and the broader advancement of human health. To further contextualise the global landscape of genomic initiatives, this paper investigates some of the wider challenges impacting the field of genomics, such as funding pressures and ethical considerations, and their associated implications upon genomic initiatives in years to come.

By providing stakeholders with a clear overview of progress and developments in this pioneering, fast-moving field, this landscape of global genomic initiatives offers substantial added value. It identifies key trends, opportunities and disparities, in addition to contextualising this landscape within the global economic and political environment. It is hoped that this paper will further serve as a benchmarking tool with which stakeholders can evaluate progress of existing initiatives or plan the creation of new ones. Ultimately, this paper seeks to promote genomic knowledge sharing, collaboration, transparency and the equitable advancement of genomic medicine and healthcare worldwide.

The evolving genomic landscape

In 2001, the notion that sequencing an entire genome could one day cost less than a smartphone would have seemed implausible. At that time, the cost of sequencing a single human genome was approximately $95 million,[2] thus confining such endeavours to large-scale, government-funded research initiatives. Today, the cost has plummeted to as low as $100,[3] marking one of the most significant reductions in cost across any scientific discipline.

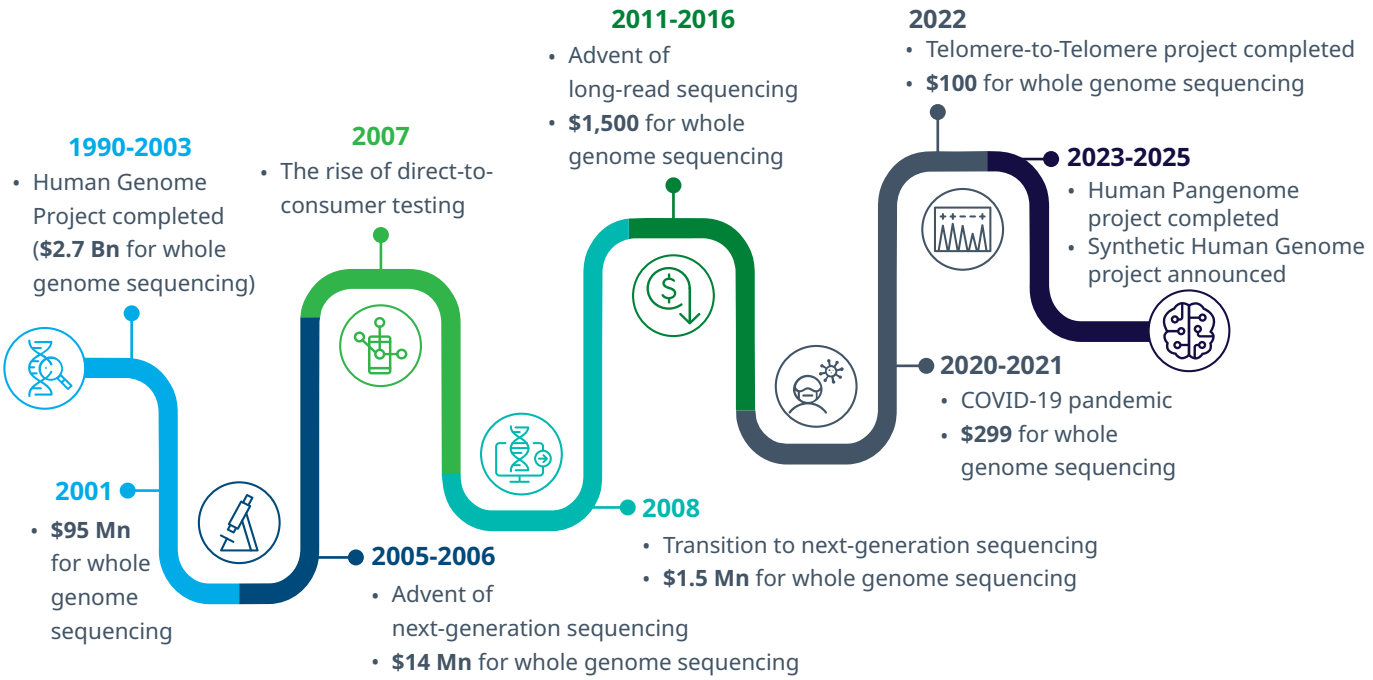
This unprecedented affordability has enabled widespread access to genomic technologies, beckoning a shift from a rare and resource intensive undertaking into a widely accessible tool. No longer limited to only the largest research institutions, DNA sequencing is now routinely harnessed by academic researchers, clinical laboratories, and pharmaceutical and biotechnology companies alike. Subsequent applications are extensive and span a myriad of fields, including drug development, personalised medicine and global health. As a result, sequencing techniques and other genomic technologies are likely to be increasingly integral to the advancement of human health.

Genomic research and sequencing cost evolution

Fundamentally, a genome refers to the complete set of genetic material in an organism, including all sequences of DNA. The human genome is comprised of approximately 3 billion base pairs and 20,000 protein-coding genes, which together constitute the blueprint of human life.[4] Sequencing technologies allow us to study these genetic sequences, revealing information about physical and intrinsic traits, susceptibility to disease, physiology, and evolution.

While early sequencing techniques were limited to the study of short sections of DNA, the transition to next-generation sequencing technologies in 2008 revolutionised genomics by dramatically increasing scale, speed, and affordability (Figure 1).[5] Furthermore, the genesis of long-read sequencing techniques between 2011–2014 further bolstered whole genome study, which has become routine and commonplace in many healthcare institutions worldwide. These advancements have been accompanied by a sharp decline in the cost of whole genome sequencing, culminating in the "$100 genome" delivered by Ultima Genomics in 2022.[3] However, standard sequencing costs are approximately $500 as of 2022.[2] This profound reduction in cost highlights the increased accessibility of genomic technologies and therefore presents significant opportunities.

Figure 1: The evolution of genomic research and sequencing cost



Source: National Human Genome Research Institute; Espinosa et al; Nurk et al; Ultima genomics; Wen-Wei et al; Wellcome; IQVIA EMEA Thought Leadership.

Landmark studies such as the Human Genome Project (HGP) have sought to sequence the entirety of the genome, a 13-year-long project which cost $2.7 billion and was completed in 2003.[6] This project successfully mapped 92% of the human genome, a feat which was recently surpassed in 2022 with the Telomere-to-Telomere project ("the first complete, gapless sequence of a human genome").[4] These genome-wide studies have enabled several medical breakthroughs and helped lay the groundwork for personalised medicine, improved disease diagnosis and therapeutic innovation. Most recently in June 2025, the Synthetic Human Genome Project was announced, which seeks to go one step further and artificially synthetise human genomes.[7] This leap from reading to writing DNA has the potential to transform medicine and pave the way for unparalleled disease understanding, which could in turn power a new generation of tailored therapies.

In 2023, a pioneering "pangenome reference genome" was created, merging the genomes of 47 individuals from across the world to account for genomic diversity.[8] While not yet commonplace in healthcare settings or research institutions, this marks a significant advancement in understanding genomic diversity across ancestral origins, with current genomic research heavily reliant upon European populations and a single reference genome. While over 99.9% of the shared human genome has been studied, it is the crucial 0.1% remainder which accounts for all human diversity.[9] It is therefore paramount that genomic initiatives are launched to study diverse populations across the globe, furthering our understanding of disease and human health. This reinforces the global rationale behind genomic initiatives, specifically those focusing upon previously under-represented populations.[10]

The COVID-19 pandemic

Beyond landmark research breakthroughs and the evolution of sequencing technologies, the unprecedented events of the COVID-19 pandemic hailed genomics as a critical global health tool. While responses to the pandemic focused on sequencing the viral SARS-CoV-2 genome (instead of human genomes), the widespread importance of sequencing technologies was highlighted, and genomics was at the forefront of research and global health. These technologies and genomic initiatives made it possible to monitor and track SARS-CoV-2 genetic lineages and emerging variants in near real time.

Consequently, genomics crucially contributed to worldwide pathogen surveillance, and later clinical development with the never-seen-before rapid production of vaccines saving millions of lives. The sheer scale of these efforts is exemplified by the number of SARS-CoV-2 genomes sequenced, reaching 67,000 genomes daily in December 2021. For comparison, less than 16,000 HIV genomes have been sequenced to date.[11] These extraordinary developments highlight the indispensable role of genomics in advancing human health, emphasising the need to apply the lessons learned during the pandemic to future genomic research and collaborative efforts.

The omics revolution

We are now entering "The Omics Era", which is characterised by the generation and integration of several layers of biological data, leveraging unparalleled insights into human health. These layers include genomics, transcriptomics, proteomics, metabolomics and epigenomics. Genomics is the cornerstone of these and includes techniques such as genotyping, whole exome sequencing and whole genome sequencing. Genotyping examines specific genetic variants at targeted sites, while whole exome sequencing (WES) focuses on all protein-coding regions, and whole genome sequencing (WGS) determines the complete DNA sequence of an organism's genome.

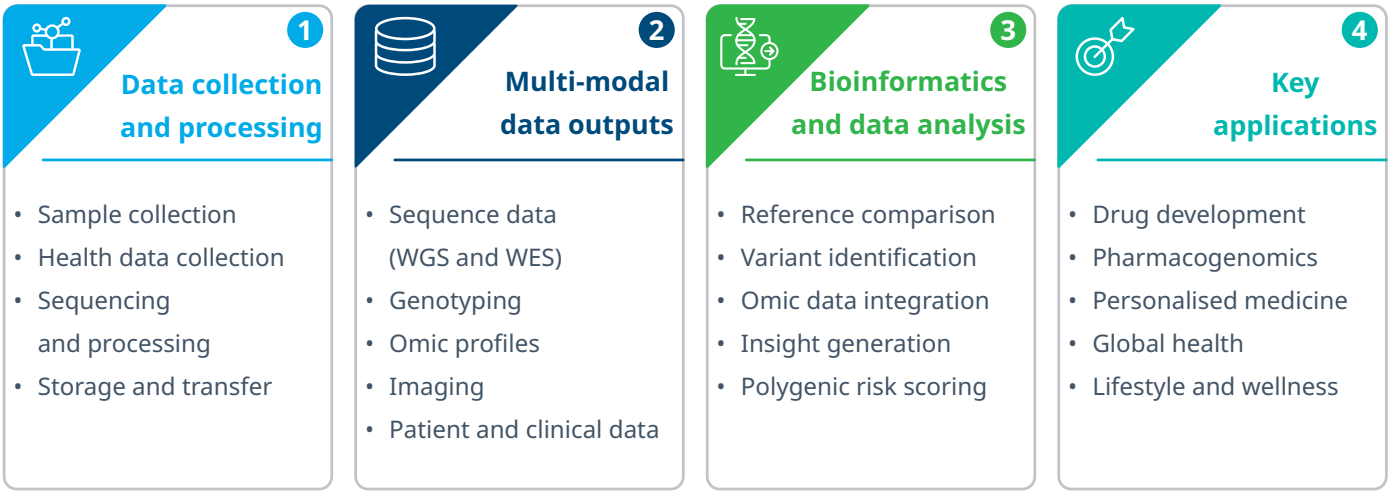
While powerful individually, the combination of omic fields to form "multi-omic" approaches offer a superior holistic insight into human health. This multidimensional perspective facilitates the study of intricate mechanisms underlying cellular function.[12]

- Transcriptomics refers to the analysis of the transcriptome — the complete set of RNA transcripts produced from the genome.
- Proteomics refers to the analysis of the proteome — the complete set of proteins expressed by a cell, tissue or organism.
- Metabolomics refers to the analysis of the metabolome — the complete set of metabolites and low-molecular weight compounds within a cell, tissue or organism.
- Epigenomics refers to the comprehensive analysis of the epigenome — the complete set of epigenetic modifications that regulate gene expression without altering the underlying DNA sequence.

As genomic initiatives continue to advance, they are now generating vast amounts of biological and healthcare data, including these diverse omic data types. Figure 2 illustrates a broad protocol followed by such initiatives, highlighting the key stages from the initial sample collection to the ultimate objective of real-world applications. While these multi-modal data outputs and omic disciplines have propelled biological research forward, the wider field of genomics is now grappling with a deluge of data and a deficit of interpretable, actionable insights. This highlights the increasingly profound role of bioinformatics, the computational field used to analyse and derive insights from biological data.[13]

Most importantly, sophisticated bioinformatics tools are required to integrate and decipher the inter-relationships between these layers of omic data. As we look ahead, artificial intelligence will play an increasingly paramount role within this field, through harnessing sophisticated models such as machine learning to power data analysis. Despite this, there remains a critical need for innovation in this space to increase utility of this data and translate findings from genomic initiatives such that they can be applied to human health.

Figure 2: Broad protocol of genomic research initiatives



Source: IQVIA EMEA Thought Leadership.

Characterising genomic initiatives

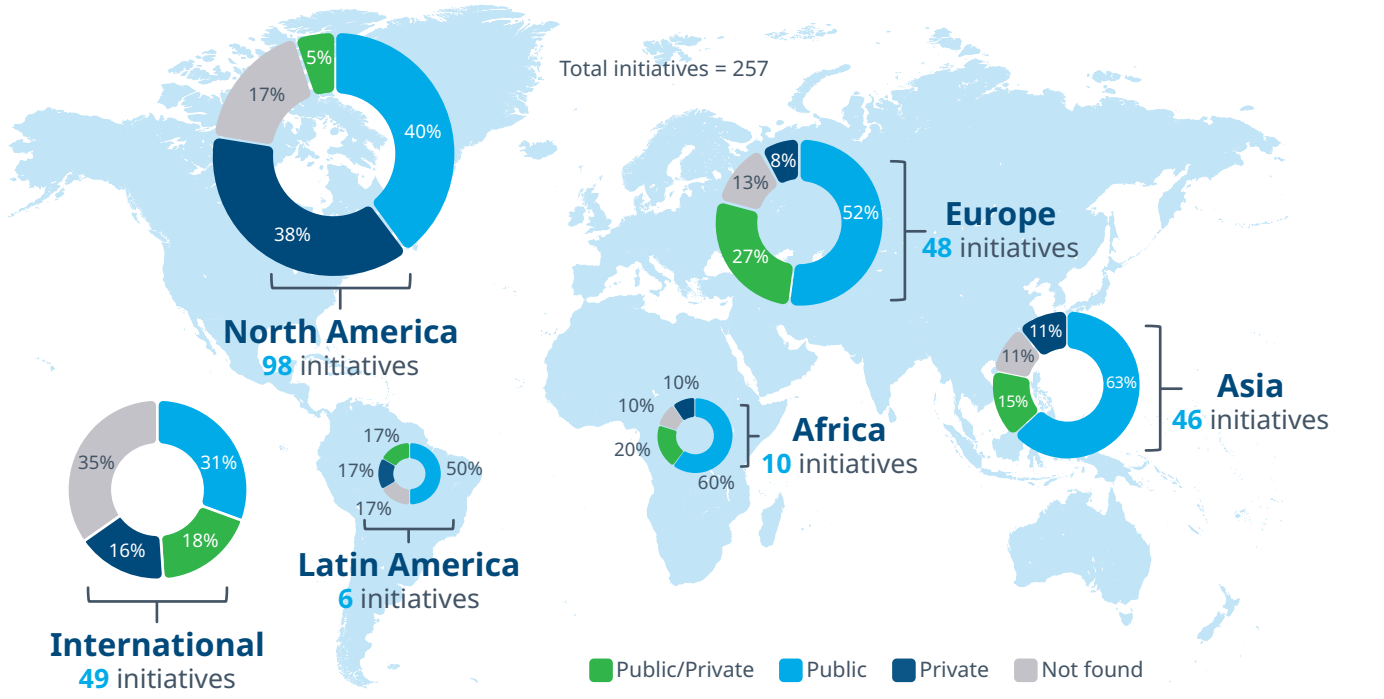
To enhance understanding of the genomic data landscape, IQVIA created the IQVIA Genomic Initiatives Database in 2020.[1] This resource was built from publicly available information on global efforts to generate and aggregate human genomic data. Now, five years on, the database has been comprehensively updated to reflect the dynamic developments shaping the field in 2025. We believe it represents the most extensive and up-to-date repository of genomic initiatives available today. This unique assessment aims to capture both current progress and future ambitions, empowering stakeholders to unlock the full potential of the genomic data surge in advancing human data science and medical research.

Global overview of initiatives

An updated analysis of the IQVIA Genomic Initiatives Database now identifies 257 initiatives with publicly available information, marking a rise of 37% from 187 initiatives in 2020. Notably, this difference reflects both the launch of new initiatives and the discontinuation of some existing ones, which have been excluded from the current update. These initiatives are geographically spread and vary in both origin and funding sources (Figure 3).

North America leads with 38% of all initiatives, followed by Europe (19%) and Asia (18%). Whilst most initiatives are publicly funded, patterns of funding type differ markedly across regions. The majority of initiatives in Europe and Asia are publicly funded, with only 8% and 11% of initiatives privately funded respectively. In contrast, 38% of initiatives in North America are privately funded, over twice the proportion of any other region. This trend can likely be attributed to the distinctive nature of the U.S. scientific and healthcare landscape, which is largely driven by private sector involvement and marked by a strong emphasis on commercialisation compared to other countries. Notably, private initiatives include those funded by both commercial and philanthropic sources.

Figure 3: Genomic initiatives by geographic origin and funding type



Notes: This map describes the source of initiatives in terms of region of origin and does not necessarily describe their scope. 'International' denotes initiatives which are either (1) international at conception or (2) those outside of North America, Europe, Asia, Africa and Latin America. Source: IQVIA Genomic Initiatives Database, July 2025; IQVIA EMEA Thought Leadership.

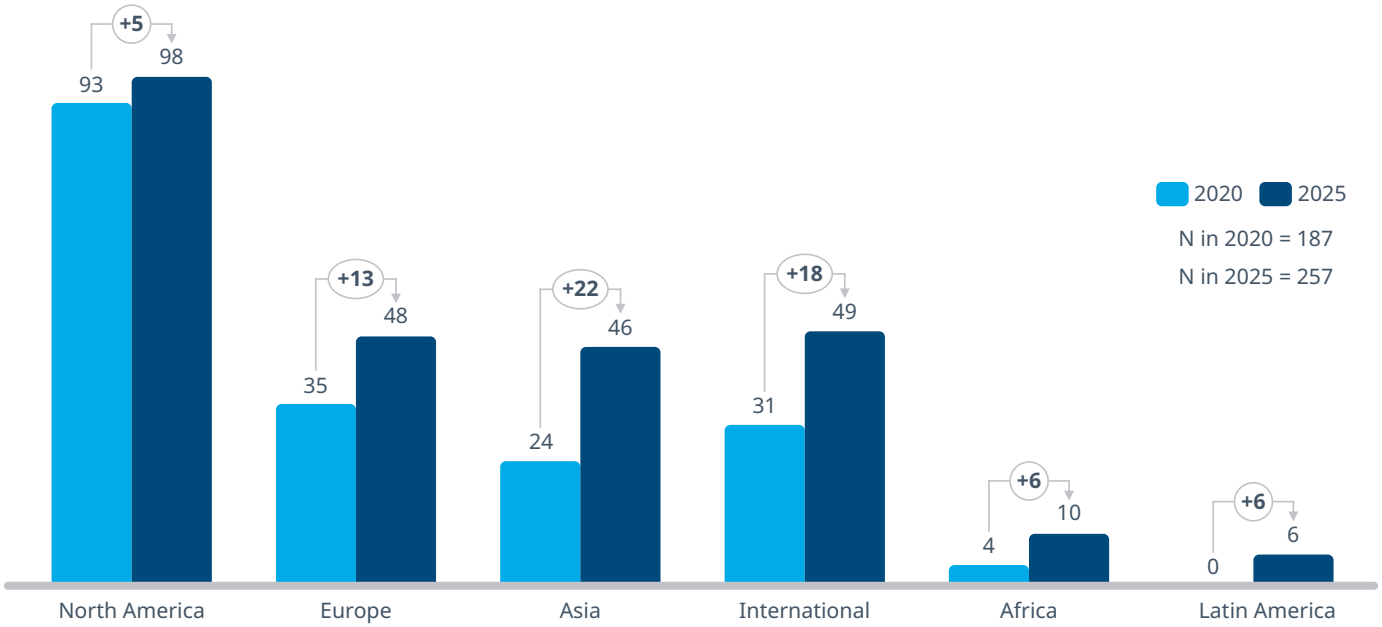
There has also been a discernible worldwide shift towards Public-Private Partnerships (PPPs), with these collaborative models most prevalent in Europe, where they fund 27% of initiatives. However, the most dramatic growth in such partnerships has occurred outside Europe, as the previous edition of this database recorded none beyond this region.

PPPs have become increasingly vital for unlocking the full potential of healthcare data, driving advancements in innovative therapies, personalised medicine and global health. Due to mounting financial pressures, public sectors increasingly lack the resources to fully capitalise on the data they possess, making collaboration with commercial entities essential.[14] Additionally, with increased reliance on bioinformatic computing software to discern insights from biological data, PPPs may be increasingly required to enable access to this costly computing power.[15] However, the involvement of profit-driven organisations can raise concerns around public trust and return of benefits to the public sector. Despite these challenges, it is clear that PPPs are the way forward for genomic initiatives in the near future.

Regional developments

A comparison between the 2020 and 2025 iterations of the IQVIA Genomic Initiatives Database reveals significant regional developments (Figure 4). North America continues to lead, with 98 initiatives recorded in 2025, a modest rise from 93 in 2020. In contrast, other regions have experienced substantial growth: Asia has seen an increase of 22 initiatives, while Europe has grown by 13. Notably, there has been vital growth in Africa and Latin America, as countries across these regions gain better access to genomic resources and technologies. This expansion is also likely driven by global health efforts aimed at reducing ethnic disparities in genomic research and improving genomic diversity.[16]

Figure 4: Genomic initiatives by geographic origin (2020 vs. 2025)



Notes: This graph describes the source of initiatives in terms of region of origin and does not necessarily describe their scope. 'International' denotes initiatives which are either (1) international at conception or (2) those outside of North America, Europe, Asia, Africa and Latin America. Source: IQVIA Genomic Initiatives Database, July 2025, February 2020; IQVIA EMEA Thought Leadership.

Additionally, as the COVID-19 pandemic necessitated global genomic surveillance and monitoring, many countries experienced dedicated funding to build and improve their genomic infrastructure, therefore paving the way for future genomic research and initiatives. However, the continued progress and launch of new initiatives in lower-and-middle income countries is heavily reliant on continued global health funding, which is currently threatened and thus poses a significant challenge for the future.

Landmark initiatives

To further illustrate the breadth of the genomic landscape, Figure 5 presents several landmark initiatives across different funding types with regards to current and target cohort sizes. Among these, Our Future Health is a leading UK-based initiative, with the ambitious goal of becoming the largest genomic cohort in the country with 5 million participants.[17] This project is dedicated to transforming how diseases are prevented, detected, and treated by collecting genetic data and patient-linked health records that reflect the diversity of the UK population.

Regarding diagnostics, the Newborn Genomes Programme (also known as The Generation Study) is a first of its kind initiative with aims to whole genome sequence 100,000 newborns to provide rapid diagnosis of treatable rare diseases in newborns, and provide a lifelong resource in the UK.[18] Led by Genomics England, this project follows previous initiatives such as the flagship 100,000 Genomes Project.[19] Research based on this dataset found that whole genome sequencing resulted in a new diagnosis for 25% of participants, highlighting the profound medical importance of genomic cohort studies.[20] Alongside the NHS Genomic Medicine Service, both Genomics England and Our Future Health are cited as key pillars within the UK Government's NHS 10-year health plan, emphasising their central role in shaping the future of genomic medicine.[21]

Within the EU, The Genome of Europe is a landmark cross-country initiative aiming to create a pan-European genomic reference database, comprised of 100,000 whole genomes across 27 countries.[22] This project is embedded within, and builds upon, the European 1+ Million Genomes (1+MG) initiative, seeking to drive personalised medicine through pioneering research and informed health policy making across Europe. Additionally, these initiatives are supported by the Beyond 1 Million Genomes project, which aims to support infrastructure development, guideline and policy creation, and training to facilitate the uptake of genomics across Europe.[23] Furthermore, these initiatives will be integrated within the European Health Data Space (EHDS), which seeks to promote the safe and secure sharing of health data (including genomic data) across Europe.

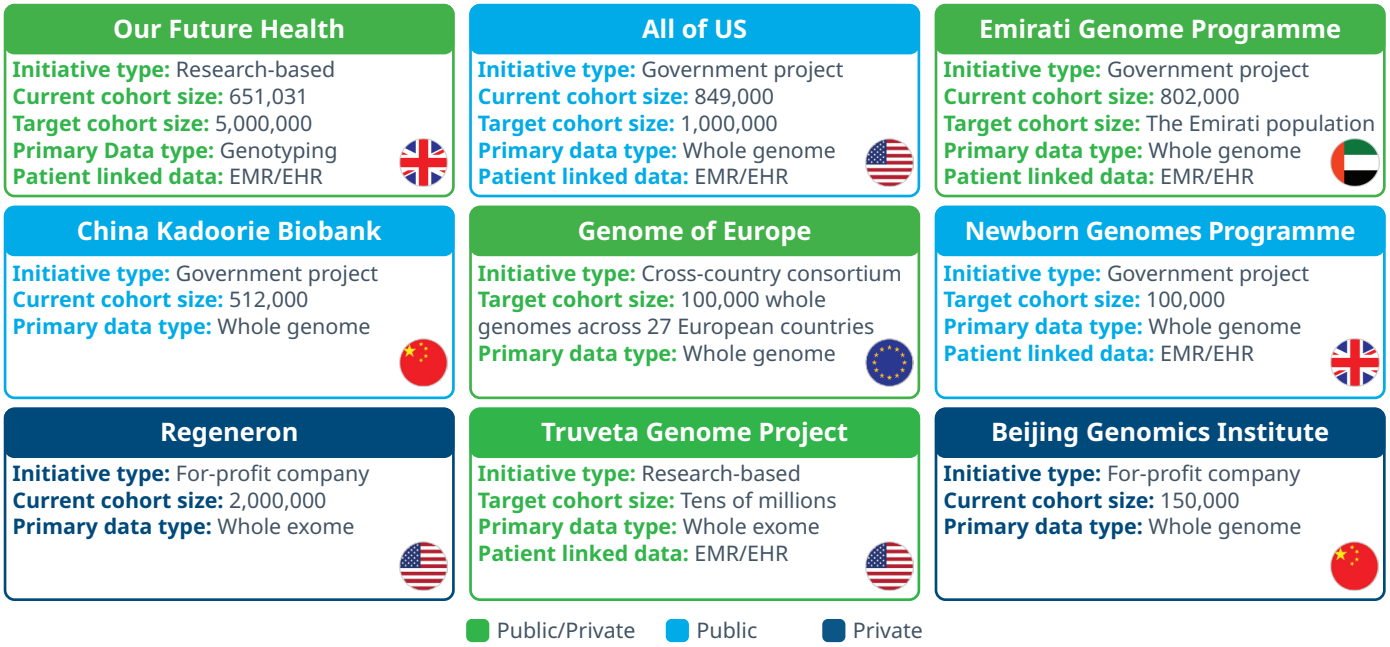
Across the U.S., there are several landmark initiatives including All of US, a precision medicine project, which aims to accelerate medical research and enable more personalised healthcare.[24] With plans to recruit 1 Million participants, this project is collecting genetic and patient-linked health records and therefore holds tremendous promise to transform human health in the years ahead. Additionally, The Truveta Genome Project, which was announced earlier this year, holds ambitions to sequence tens of millions of Americans and create the largest genomic cohort in the country.[25] With a focus on drug discovery and clinical trial optimisation, this project also highlights the importance of AI in accelerating biomedical research in the years ahead. As a partner of Truveta, Regeneron Genetics Center is another landmark initiative, having already sequenced over 2 million whole exomes.[26] These initiatives hope to harness extensive genomic databases to power therapeutic innovation, drug development and optimise clinical trials, thus potentially contributing to a new generation of medicines.

Many regions are under-represented in genomic databases, including that of Middle Eastern populations. Consequently, the Emirati Genome Programme is another milestone initiative, which seeks to invite every Emirati (approximately 10 million people) to build one of the largest genomic databases in the world.[27] This UAE-based initiative hopes to transform national healthcare and drive precision medicine, while integrating patient health records. It is hoped that this initiative will also attract commercial investment, including that of international pharmaceutical companies to leverage this data in the future.

Genomic diversity remains a profound challenge worldwide, with genomic research and databases largely dominated by individuals of European ancestry. Closing these disparities of under-represented populations will significantly benefit scientific research and global health.[16] Consequently, this reinforces the importance and necessity of initiatives dedicated to improving genomic diversity.

China has launched multiple landmark initiatives, such as The China Kadoorie Biobank, which crucially holds several different types of genomic data, enabling future integration of several data layers.[28] By holding tissue samples, biobanks enable longitudinal studies and the re-sequencing or processing of samples in the future, reinforcing their medical utility. Additionally, the Beijing Genomics Institute (BGI) is a world-leading initiative, helping to drive precision medicine through integrated next-generation sequencing and bioinformatic platforms worldwide.[29] Alongside the success of these initiatives, China's strategic plans for the future highlight the importance of genomics and genomic data, indicating future expansion and proliferation of national genomic initiatives.[30]

Figure 5: Examples of landmark genomic initiatives

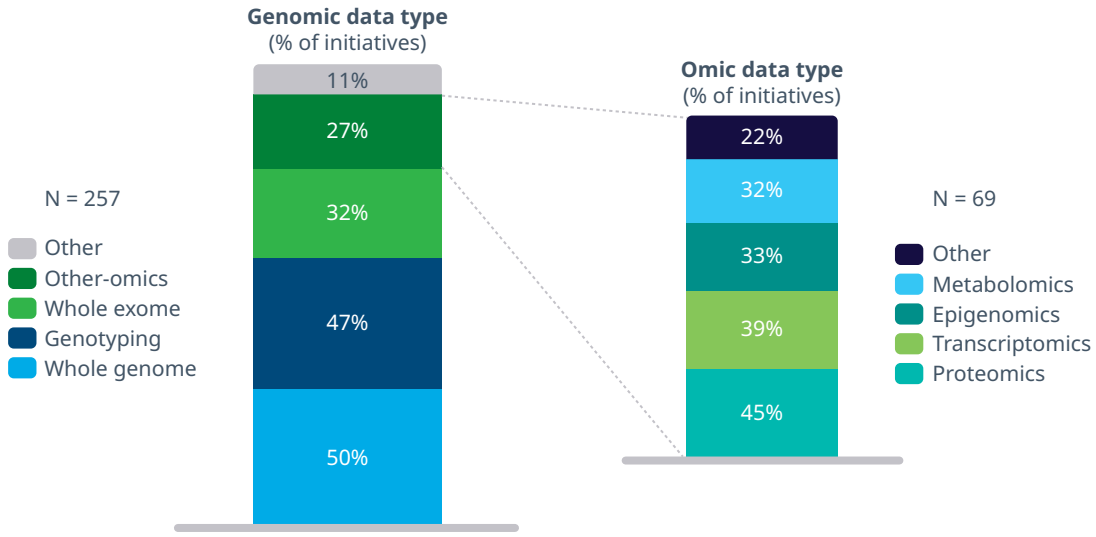


Notes: Only the primary or highest level of genomic data collected for each initiative is shown; only the primary or highest form of patient linked data is shown; flags display geographic country of origin; Source: IQVIA Genomic Initiatives Database, July 2025; IQVIA EMEA Thought Leadership.

Genomic data types

Crucially, we are in the midst of an omics revolution, with genomic studies rapidly expanding to integrate a variety of other omics technologies to reveal unprecedented insights into human health. This transformation is clearly reflected in our database, which now catalogues these diverse omic data types in greater detail than in 2020, enabling a deeper understanding of the evolving landscape of technologies used (Figure 6). Whole genome sequencing leads the field, with 50% of initiatives collecting WGS data, closely followed by genotyping at 47%. Notably, 27% of initiatives have collected or processed additional omic data types, led by proteomics and transcriptomics, highlighting the increasing significance and adoption of these technologies.

Figure 6: Genomic initiatives by data type



Source: IQVIA Genomic Initiatives Database, July 2025; IQVIA EMEA Thought Leadership.

Critically, there were 23 initiatives we considered as "multi-omic", which collect or process all genomic data types studied. As a result, these may be considered the most powerful for certain purposes due to their breadth of data, and potential to integrate and link multiple layers of data to power research. In particular, multi-omic approaches are key to drug discovery through more comprehensive target identification, advancing basic scientific research, as well as disease diagnosis. Example initiatives defined as multi-omic include the UK Biobank and the Cancer Genome Atlas Program.

However, the collection or processing of several genomic data types does not necessarily enhance the utility of these initiatives compared to others.

For example, an initiative seeking to study a well-characterised monogenic condition (caused by mutations in a single gene), genotyping may be the optimal technique due to high accuracy of detection, reliability and cost-efficiency. Additionally, for clinically focused initiatives, quick and accurate diagnoses are the priority. Alternatively, for complex polygenic diseases (caused by mutations in several genes and environmental factors) such as cardiovascular disease and obesity, several different data types may be required. As a result, the data types chosen are largely determined by each specific initiative's aims, remit, and capacity. Consequently, this prevents a one-size fits all approach with regards to the data type selected for collection.

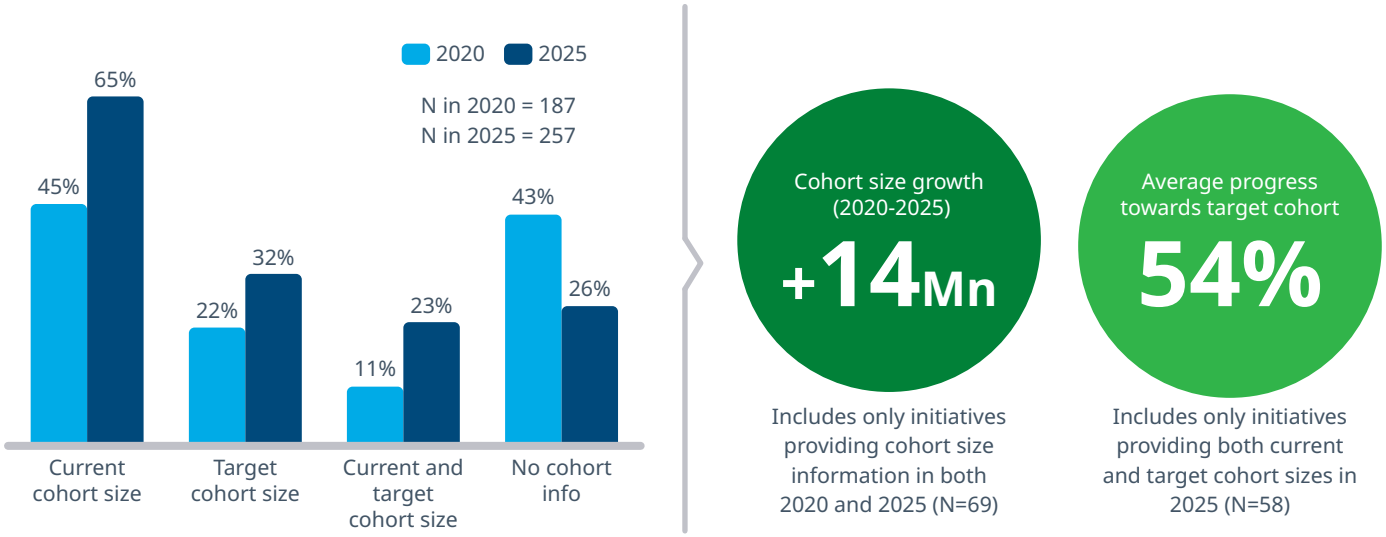
To provide further clarity on the core data types investigated, their respective advantages and limitations are outlined below:[1]

- Whole-Genome Sequencing (WGS) provides the most comprehensive view of the genome, identifying both coding and non-coding variants, which is crucial for complex disease research, though it is costly and data-intensive.
- Whole-Exome Sequencing (WES) targets the coding regions where most disease-causing mutations occur, making it more affordable and interpretable than WGS, but it misses important non-coding variants.
- Genotyping is highly accurate and cost-effective for detecting known variants in large groups, ideal for monogenic diseases, but cannot identify new or rare mutations.
- Other omics, such as proteomics and transcriptomics, enable a broader understanding of disease by integrating multiple data types, though they can involve high technical complexity, greater costs, and analytical challenges.

Cohort size reporting and progress

As we turn to look at cohort size information and progress, there have been landmark developments over the last 5 years (Figure 7). There was a marked increase in the percentage of initiatives reporting current cohort size (+20%), target cohort size (+10%) and both current and target sizes (+12%). This highlights the enhanced transparency and public reporting of genomic initiatives and their associated goals and progress. Since the COVID-19 pandemic, there has been a push for medical transparency, with detailed cohort reporting becoming increasingly common requirements by funding bodies, medical journals and healthcare organisations.

Figure 7: Genomic initiatives cohort size reporting and progress



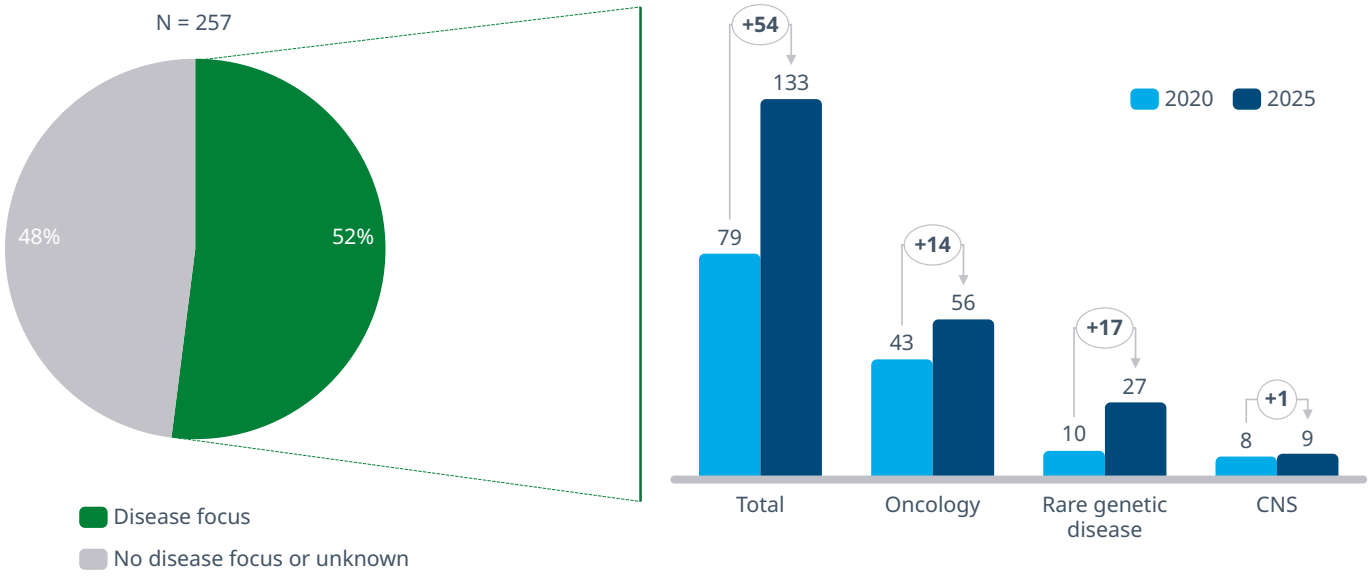
Source: IQVIA Genomic Initiatives Database, July 2025, February 2020; IQVIA EMEA Thought Leadership.

Moreover, the cohort size across genomic initiatives (providing cohort information in both 2020 and 2025) has increased by over 14.6 million since 2020. This growth reinforces the mounting importance of genomic studies and participant recruitment in this field. Additionally, by comparing the current and target cohort sizes as of 2025, this revealed average progress of 54% across initiatives, an increase from 45% in the 2020 report. Only 20 initiatives in 2020 reported both current and target cohort sizes, however this increased to 58 in 2025. Therefore, this difference of progress may be partly driven by reduced reporting and transparency in 2020, and an increase in target ambition.

Disease area focus

Utilising our database, we also examined initiatives by disease area focus (Figure 8). Over half of all initiatives explicitly mention a disease area focus, with a substantial increase from 2020. These are led by oncology with 56 initiatives, including projects focused upon breast, ovarian, and lung cancers. However, rare genetic disease-focused initiatives experienced the greatest growth over the last 5 years (+17 initiatives). This may be due to factors such as cost, cohort size required, and disease dynamics.

Figure 8: Genomic initiatives by disease area focus



Source: IQVIA Genomic Initiatives Database, July 2025, February 2020; IQVIA EMEA Thought Leadership.

For example, rare genetic diseases are often inherited in well-characterised patterns and are stable (mutations are consistent throughout cells). Comparatively, cancers are extremely complex, dynamic and involve several genetic and environmental drivers, and initiatives may therefore be more costly and require very large cohorts. Additionally, oncology-focused initiatives may be accompanied by several logistical challenges, with cancer patients often requiring multiple rounds of re-sequencing due to tumour evolution and progression. Consequently, data becomes older quicker, thereby reducing data longevity and raising costs.

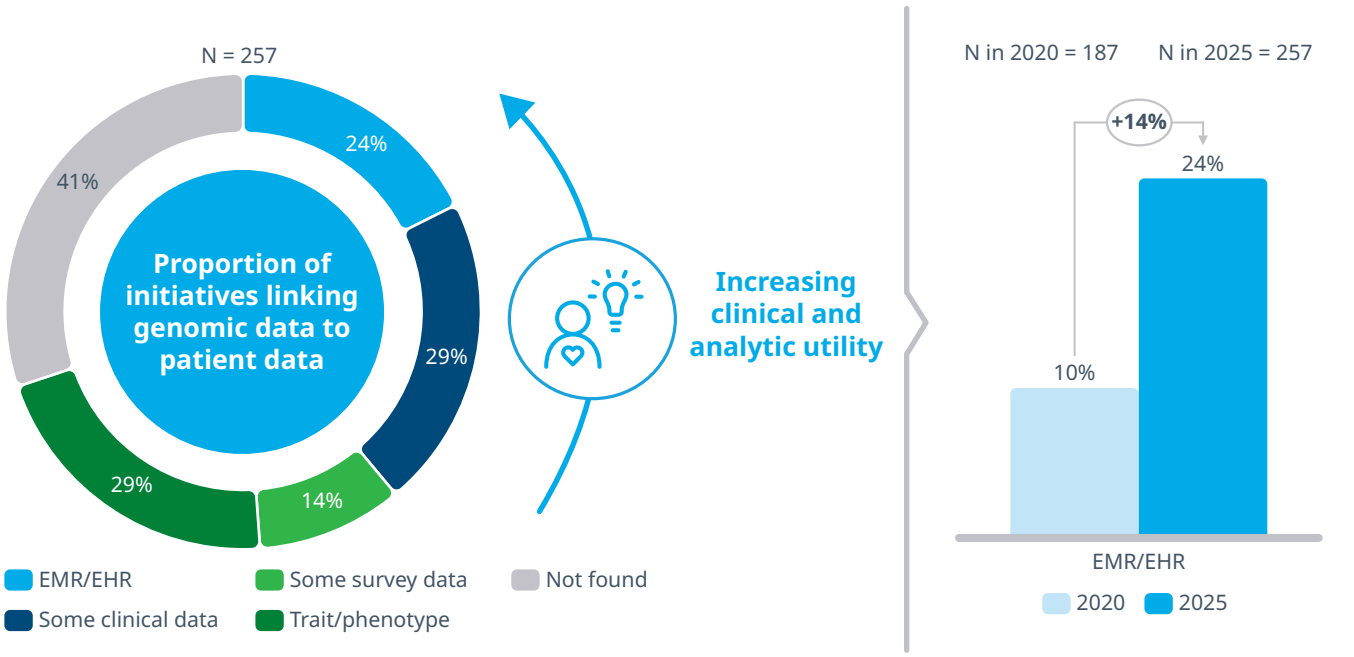
Beyond these disease areas shown, our database also highlighted initiatives focused on common chronic diseases, cardiology, paediatrics, psychiatry and mental health, representing greater variety compared to 2020. A particular focal point of the healthcare and pharmaceutical industry at the moment is that of obesity, which is an extremely fast-moving space. With significant attention and investment in this field, it is likely that this will in turn drive a proliferation of genomic cohort studies, seeking to investigate the complex interplay of genetic, lifestyle, and environmental factors of obesity in years to come. Likewise, mental health and psychiatric disorders have ascended in visibility and prevalence over recent years, thus prompting the growing interest and necessity for dedicated genomic initiatives and studies. As a result, these dynamics indicate an ongoing shift towards addressing complex, multifactorial diseases beyond the realms of oncology.

Patient linked data

Furthermore, it is increasingly important to link patient information with genomic data in order to enhance the translatability of research findings. Genomic and omic data alone are biologically rich but context-poor. To give some examples, linking these findings with healthcare data allows researchers to associate genomic profiles with health conditions, symptoms and clinical presentation of disease. Moreover, when patient linked information is linked longitudinally, this crucially enables researchers to study disease progression, aging and response to treatment. Subsequently, patient linked information is paramount and enables crucial real-world data studies.

The importance and utility of patient linked data across genomic initiatives is illustrated in Figure 9. Our updated database reveals that 59% of initiatives link some form of patient information, up from 44% in 2020. Crucially, there was a 14% increase in the proportion of initiatives linking Electronic Health Records (EMR/EHRs) since 2020, which now represent almost a quarter of all initiatives at 24%. These records are the most valuable type of patient information, and thus initiatives linking this type of information will likely play a vital role in advancing human health.

Figure 9: Genomic initiatives by patient linked data



Source: IQVIA Genomic Initiatives Database, July 2025, February 2020; IQVIA EMEA Thought Leadership.

Despite these advances in patient linked data, information regarding participant consent and data access within genomic initiatives remains largely elusive. This issue is especially apparent among privately funded projects, which often disclose only minimal or generalised details about consent procedures and data privacy practices. It is important to note, however, that much of this sensitive information is likely intentionally restricted to participants themselves and is seldom made widely accessible to the public outside of the cohort itself. However, with many key parameters of genomic initiatives now more consistently reported, it is hoped that details regarding data access, consent models, and privacy policies may soon become more readily available. Enhanced transparency here would likely promote collaboration and strengthen public and participant trust.

The application of genomic data

The subsequent output of genomic initiatives can have profound transferable impacts upon patient care, pharmaceutical research and development, and global health. Additionally, genomic technologies are extremely versatile and can thus be harnessed across almost all sectors of human healthcare. Subsequently, the primary applications of genomic initiatives will be discussed here, with specific examples from the IQVIA Genomic Initiatives database.

Drug development

The application of genomic data in drug development has revolutionised the pharmaceutical landscape by enabling a more targeted and efficient approach to therapeutic discovery. By elucidating the genetic underpinnings of diseases, researchers can precisely identify genes, proteins, or molecular pathways that are implicated in disease initiation and development. These insights facilitate the development of targeted therapeutics, therefore enhancing treatment efficacy and reducing the likelihood of eliciting off-target effects. Drug candidates which have been supported by human genetic data are 63% more likely to be approved than those without.[31,32] Consequently, this reinforces the importance of pharmaceutical and biopharma companies to leverage human genomic data.

Regeneron Genetics Centre is an example initiative which leverages data from over 2 million whole exomes with linked health data to inform and advance Regeneron's drug discovery and development programs.[26] Similarly, AstraZeneca's company-wide genomic initiative harnesses genetic-health linked data from over 1.4 million individuals worldwide to power their drug discovery pipeline. In addition to the integration of multi-omic data, AstraZeneca utilises genome editing tools such as CRISPR screens to further validate drug candidates.[33]

Pharmacogenomics

Pharmacogenomics examines how an individual's genome influences their response to medications. Genetic differences can determine whether a drug is highly effective or, conversely, ineffective for certain patients. In fact, it is estimated that only 30-60% of treatments are effective in patients due to this variability.[34] Integrating pharmacogenomic insights into clinical practice could enable clinicians to select the optimal medication and dosage for each patient, reducing the risk of adverse reactions and maximising therapeutic benefit. Recent surveys indicate that while 98% of physicians believe pharmacogenomic testing could improve predictions of how patients will respond to medications, only 10% feel they currently possess sufficient knowledge and resources in this area.[35] This highlights the growing importance of advancing pharmacogenomics in clinical practice.

The Cancer Dependency Map (DepMap) is a leading initiative within this field and is primarily funded by The Broad Institute.[36] In addition to extensive human genetic data types and over 2,000 cell lines studied, this consortium crucially holds thousands of drug screen outputs. This database is biannually updated, and enables researchers to study patient stratification, drug repurposing and investigate oncology pharmacogenomics. Alternatively, the Ubiquitous Pharmacogenomics consortium (U-PGx) is another landmark initiative seeking to study the impact of pharmacogenomics upon patient outcomes throughout Europe.[35]

Personalised medicine

Personalised medicine seeks to stratify patient populations with regards to disease risk, classification, progression, and treatment response such that medical care can be tailored to the individual. Global personalised medicine initiatives coupled with those from individual countries are gaining momentum expeditiously. The overarching goal of personalised medicine is to move from reactive to proactive care, improving outcomes through more precise, predictive, and preventive healthcare strategies. One such strategy is biomarker investigation, which refers to the study of biological indicators of disease used to inform diagnosis, prediction, monitoring and treatment. These biomarkers can encompass genomic, proteomic, metabolomic and imaging indicators, thus highlighting the importance of generating and collecting multi-modal data types across initiatives.

A personalised medicine initiative example includes TOPMed (trans-omics for precision medicine).[37] This project advances personalised medicine by integrating whole genome sequencing with a wide range of multi-omic data, in addition to comprehensive environmental, behavioural, imaging and lifestyle information. This holistic approach provides researchers with extensive genotypic and phenotypic data, helping to drive studies of personalised treatments, diagnostic tools and prognostic pathways. The Taiwan Precision Medicine Initiative (TPMI) is another landmark initiative in this space and combines both genomic and patient data to study the Han Chinese population longitudinally. By enabling studies on disease risk and pharmacogenomics over time, it is hoped that results from this project will contribute to population-based personalised medicine models.[38]

Global health

The application of genomic data in human disease epidemiology has significantly enhanced our understanding of disease distribution, risk factors, and population-level health dynamics. By analysing genomic variation across diverse populations, researchers can identify genetic determinants of disease susceptibility, resistance, and progression. For example, Genome-Wide Association Studies (GWAS),

have uncovered thousands of genetic loci associated with complex diseases such as diabetes, cardiovascular disorders, and autoimmune conditions. These insights can enable the identification of at-risk populations, inform public health strategies and develop Polygenic Risk Scores (PRS). PRSs provide a quantitative measure of an individual's genetic risk for a condition by aggregating the combined effects of individual genetic variants. These scores can estimate the likelihood of developing certain diseases and are regarded as important diagnostic tools. This approach has been highlighted by countries such as the UK, where polygenic risk scores feature in the NHS 10-year health plan and will be generated for all participants of Our Future Health.[21]

Example global health initiatives include Brazil Gen-t, a landmark national project designed to enhance understanding of genetic diversity and disease risk in the Brazilian population.[39] By sequencing and analysing the genomes of tens of thousands of people from diverse backgrounds, this enables the identification of population-specific risk factors for both common and rare diseases, and supports the development of more effective, locally tailored public health interventions and screening programmes. Similarly, the Human Heredity and Health in Africa (H3Africa) consortium is dedicated to genomic research throughout Africa and supports several population-based studies of both communicable and non-communicable diseases across 30 African countries.[40] Crucially, this consortium also further develops the genomic infrastructure in Africa, in addition to genomic training and resource building.

Lifestyle and wellness

In recent years, there has been a marked shift towards lifestyle and wellness worldwide, reflecting a broader cultural movement that continues to gain momentum. As part of this movement, genomic data is being utilised to inform personalised health and offer lifestyle recommendations. This has largely been facilitated by the ease and cost-efficiency of direct-to-consumer genetic testing kits, which claim to provide insights into various traits such as nutrient metabolism, exercise response, sleep patterns and disease predispositions. The rapidly moving field of obesity and significant public interest in associated treatments could drive significant growth of nutrigenomic and metagenomic-based companies, providing tailored reports on metabolism, the microbiome, nutrition and diet optimisation in the future. However, the scientific robustness of some of these trait associations remains under scrutiny, highlighting the requirement for further genomic research in this field.

Example direct-to-consumer initiatives within this space include Nebula Genomics, which is a genetic testing company, utilising whole genome sequencing data to provide individuals with detailed reports on their health from $249.[41] In addition to information on disease predispositions, these kits claim to provide detailed information on how one's DNA influences their appearance and hormones, behaviour and perception, body and athleticism, personalised nutrition and diet optimisation, among several other traits. Similarly, 23andme uses genotyping data to produce lifestyle and wellness reports on topics such as caffeine consumption, sleep movement and lactose intolerance, in addition to several health and ancestry reports.[42] However, many of these direct-to-consumer genetic testing kits are not supported by scientifically rigorous studies, posing challenges with regards to misinformation, misunderstanding and false positives.

Global data governance and challenges

Genomic data is uniquely sensitive compared to other medical data because it is inherently identifiable, permanent, and reveals information not only about the individual but also about their biological relatives. Unlike traditional medical records, which can change over time and are often anonymised, genomic data is a lifelong identifier that cannot be altered and requires particularly robust security end privacy measures, which can include de-identification of genetic variant level data. It also has powerful predictive capabilities, potentially indicating future health risks, which raises concerns about discrimination and misuse by insurers or employers. These characteristics make genomic data particularly challenging to protect and govern, requiring stricter ethical, legal, and technical safeguards than other types of health information. Beyond these data protection challenges, funding pressures, competition, and ethical considerations add considerable complexity to the global landscape of genomic initiatives.

Data governance frameworks

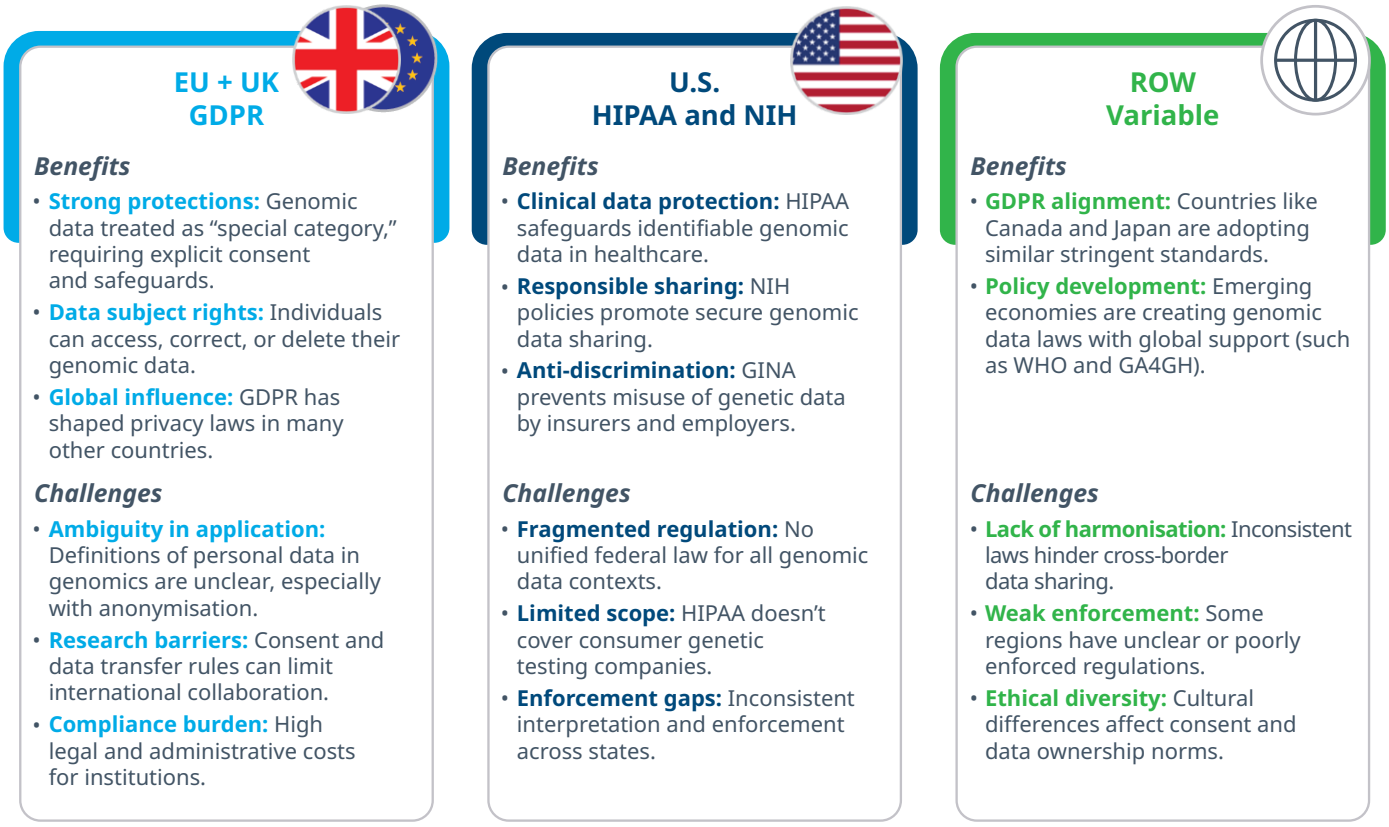
In order to harness genomic insights to drive research and development, various data governance frameworks exist, providing guidelines concerning the access, use and sharing of sensitive data. However, despite a collective understanding that genomic data should be protected and secured, these guidelines vary considerably across the world, with several different practices, legal and ethical frameworks, and organisational models. This divergence of policies and lack of a singular shared data framework can often pose challenges regarding global collaboration. The most foundational framework to protect genomic data is that of tiered data access, split into the following categories: [43]

- Open Access refers to data that is publicly available for anyone to access and download. This data is anonymised and not considered sensitive, making it suitable for promoting scientific collaboration and accelerating research and innovation.
- Controlled Access requires researchers to apply for data access and download pending review and authorisation. The data in this category may be re-identifiable and therefore necessitates sensitive data protection.
- Trusted Research Environments (TRE) keep data within a secure, monitored platform, where data can be safely accessed and analysed without downloading it, ensuring greater protection against misuse, breaches or re-identification risks.

These systems are employed to protect privacy, prevent participant identification, comply with regulation, and retain rights to hold and commercialise insights derived from the data. Dependent upon each genomic initiative's individual aims and funding type, the data access model employed varies.

Beyond individual data access models, the vast majority of genomic initiatives must adhere to legal frameworks, which can vary considerably by region and country (Figure 11). The most prominent legal frameworks include the General Data Protection Regulation (GDPR) in the EU/UK and the Health Insurance Portability and Accountability Act (HIPAA) with the National Institutes of Health (NIH) in the U.S.[44,45] In contrast, genomic data protection legislation is extremely variable in the rest of the world. While many countries are modelled on GDPR and are thus similar to these stringent data protection requirements, several countries do not have as rigorous privacy rules in place. These diverging legal frameworks, including differences in privacy laws, consent requirements and data governance, significantly hinder global data sharing and collaboration. Additionally, countries such as China increasingly prohibit the export of their citizen's genomic data, posing further challenges with regards to global genomic diversity studies. This further complicates integration of datasets across borders, which may fragment and hinder future research progress.

Figure 10: Genomic data protection laws by region



Source: General Data Protection (GDPR), Health Insurance Portability and Accountability Act HIPAA; National Institute of Health (NIH); IQVIA EMEA Thought Leadership.

In order to address some of these challenges, organisational standards exist, which set a global precedent and detailed recommendations for genomic data use across borders. Two primary standards include the World Health Organisation (including the Technical Advisory Group on Genomics, TAG-G) and the Global Alliance for Genomics and Health (GA4GH).[46,47] These organisations provide detailed framework and guidance for human genome data collection, access, use, and sharing, and can help direct initiatives and organisations with clear responsibilities that should be upheld to ensure rigorous genomic research and data privacy.

Funding challenges

Despite the landmark progress of genomic initiatives discussed in this paper, critical funding challenges threaten the future of these and risk derailing biomedical advancements. Principally, many of these challenges are due to severe budget cuts, institutional re-organisation, and the de-funding of global health, which are particularly pronounced in the United States.

Earlier this year, the Trump administration announced plans to cut the NIH budget by 44% (over $20 billion) in the 2026 fiscal year.[48] Funding over 60,000 research grants, the NIH is the largest public funder of biomedical research in the world and would thus have considerable knock-on effects upon the field of genomics.[49] A key branch of the NIH, known as the National Library of Medicine (NLM), hosts the Sequence Read Archive and GenBank, two of the largest repositories of genetic sequences worldwide. Budget cuts and NIH re-organisations could therefore detrimentally impact these critical tools.[50] As globally leading resources, any impacts upon these archives could have severe repercussions throughout the world, impacting many of the genomic initiatives discussed here.

Due to severe disruptions, 75% of U.S. scientists are considering re-locating to Europe and Canada, according to a Nature poll of 1,600 readers.[51] Consequently, with the scaling back of genomic funding (both direct and indirect) and the re-location of scientists from the U.S., it is crucial that other regions

must contribute to addressing this shortfall, and by doing so begin to close the regional gap of genomic initiatives. Since our database shows that currently nearly 40% of all genomic initiatives are located in North America, budget cuts in the U.S. would severely affect the global landscape of genomic initiatives.

Another significant impact upon the global landscape of genomic initiatives is that of the de-funding of global health, notably including the announced U.S. withdrawal from the World Health Organisation (WHO). As a founding member of the WHO, the U.S. contributes an estimated 15% of the organisation's total funding and is considerably the largest donor member.[52] The U.S. withdrawal from the WHO would therefore trigger profound impacts to the detriment of global health. Specifically, genomic research and initiatives in lower-and-middle income countries are often heavily reliant on funding by global health bodies such as the WHO. Consequently, global health funding cuts threaten to erode recent progress of genomic initiatives throughout these regions. Whilst, at the time of writing, this decision may be reversed, it is evident that new global health funding strategies are required to support the continued work of biomedical research and by extension, genomic initiatives worldwide during significant economic and political shifts within the scientific community.

Competition and nationalism

Further to funding pressures and concerns, genomic data is increasingly viewed as a National Strategic Resource (NSR), posing profound challenges to international collaboration and data sharing. The worldwide collection, access, and sharing of medical information (including genomic data) often termed "open science" is a cornerstone of human health advances and developments. Over recent decades, this worldwide approach has enabled and driven countless biomedical advances, global health initiatives and most recently the global surveillance of SARS-CoV-2 throughout the COVID-19 pandemic.

Despite the clear advantages of international genomic collaboration, as showcased throughout the pandemic, mounting evidence indicates that major global powers such as the EU, U.S., and China are undergoing a fundamental transformation in how they regulate and share human genomic data.

Human genomic data and the associated supporting technologies and infrastructure are increasingly considered National Strategic Resources (NSRs) by policymakers in these regions. Consequently, managing and safeguarding genomic data is now seen not just as essential for biomedical research and therapeutic innovation, but also as a critical matter of national security, national autonomy and economic security.[53]

Typically, strategic resources are leveraged to further national strategic aims and aid competition. Even though reciprocal sharing of genomic data offers widespread benefits, some countries may still choose to restrict access for foreign institutions, researchers, or commercial organisations. By doing so, they typically aim to secure a strategic advantage through having exclusive information access. Data exclusion from foreign governments may also be driven by biosecurity concerns to prevent the wrongful exploitation of genomic data. In summary, these policy shifts risk placing national priorities above the shared goal of advancing human health, thus destabilising global collaboration and the sharing of genomic data, which is integral to genomic initiative progress.

Ethical considerations

When an individual shares their genomic data, they are, by extension also sharing the genomic data of their biological relatives, often without the knowledge and consent of these relatives. In most scenarios, individuals will be sharing up to 50% of their parent, sibling or child's genomic data through their own participation. However, in the case of identical twins this rises to ~100%, irrespective of whether both individuals have agreed to participate. Whilst genomic

data is most often anonymised or de-identified, there have been instances where cross-referencing with genealogical databases has enabled the re-identification of individuals.[54] This highlights the profound privacy and consent challenges inherent in genomic data sharing and reinforces the requirement for robust data protection frameworks.

These challenges are further exemplified by large-scale initiatives such as the Newborn Genomes Project (The Generation Study), which aims to sequence the genomes of 100,000 infants.[20] Since newborns cannot consent, the decision falls to parents, posing complex ethical considerations given that an individual's genome is a lifelong identifier and highly sensitive. There is also concern about discovering adult-onset conditions or unknown variants which could cause undue anxiety and stress for the family.

Consumer genetic testing initiatives are also associated with various ethical challenges encompassing data privacy concerns, report accuracy, and the lack of support from medical professionals. This lack of medical support poses significant ethical challenges, especially when individuals receive potentially distressing, misleading, or complex health information. Potentially the most publicly known consumer genetic testing company is 23andme, which has been surrounded by controversy over recent years. Earlier this year, 23andme filed for bankruptcy and is due to be sold, raising significant data privacy concerns for the 15 million participants who have shared their genomic data with the company.[55] Ethical challenges such as these are likely to contribute to public distrust with regards to genomic initiatives, reinforcing the need for further public education on the profound medical benefits enabled by genomic research.

Future perspectives and conclusions

As the field of genomics continues to evolve with the genesis of new technologies and further sequencing cost reduction, genomic research has the potential to be more widely accessible globally than ever before. Consequently, it will be increasingly paramount to study the global landscape of genomic initiatives, as discussed here, using insights from the IQVIA Genomic Initiatives Database. Trends examined in this paper can be leveraged by stakeholders to contextualise their own genomic programs on a regional or global level or plan the creation of new ones.

With the rapid evolution of AI-powered technologies, this holds great promise to revolutionise genomic data analysis, enhancing the translation of genomic initiative findings into real-world applications. Moreover, these tools will increasingly facilitate the integration and analysis of complex multi-modal data, powering unparalleled comprehensive insights into human health. Consequently, initiatives generating and aggregating human genomic data will be increasingly vital in years to come.

Alongside technological and research innovation, it is expected that genomic initiatives will continue to grow in number worldwide. This will be further supported by the increased recognition of genomic data and its importance for human health. Crucially, studies and reports in recent years have reinforced the importance of global representation in genomic databases, with European populations still grossly over-represented and Asian and African populations significantly under-represented. While there remains a long way to go to close this genomic representation gap across ethnicities, developments over the last 5 years indicates substantial progress.

However, all genomic initiative progress is conducive to sufficient funding, developed genomic infrastructure and efficient global collaboration. As of 2025, these fundamental pillars of genomic research are threatened by budget cuts, staff shortages, institutional re-organisation, increased nationalism and competition, global health de-funding and public distrust. Many of these challenges are especially pronounced in the United States. As the U.S. is the global leader in terms of genomic funding (including global health funds) and by number of

initiatives, challenges posed by the political and economic environment in the U.S. could have drastic repercussions upon the rest of the world.

During this incredibly fast moving and dynamic environment, especially in the U.S., the importance of other regions and countries making up this shortfall and playing a larger role in global genomic research is critical to the continued progress of this field and genomic initiatives. These challenges highlight the pressing need for public-private partnerships that combine funding, resources, and expertise to establish sustainable and impactful genomic programmes. Achieving this requires a concerted, collaborative approach that unites the strengths of technology, infrastructure, academia, life sciences, and healthcare sectors. By pooling resources and capabilities, these collective efforts lay a strong foundation for genomic initiatives that can propel medical research and human health forward, nurturing resilient innovation anchored in diverse and complementary expertise.

Due to these technological, economic and political challenges, regular updates to the IQVIA Genomic Initiatives Database and frequent re-examining of the global landscape of genomic initiatives is especially critical for the continued monitoring and surveillance of genomic progress.

Through this comprehensive overview of global genomic initiatives, this work aims to promote greater transparency, equity, and collaboration in the advancement of genomic medicine and healthcare. By highlighting emerging trends, disparities, and opportunities, this landscaping paper situates current genomic initiatives within the broader political and economic context. It is further intended as a benchmarking resource, enabling stakeholders to assess current genomic initiatives or inform the development of future ones. Above all, by tracking progress in this rapidly evolving field, this paper encourages the open exchange of genomic knowledge and supports the strategic planning and evaluation necessary for continued innovation.

Methodology discussion

The IQVIA Genomic Initiatives Database was developed and updated using publicly available information. Therefore, initiatives may exist for which there is no publicly available information and are outside the scope of this project. Additionally, publicly available information may not be up to date in some cases or fragmented. Moreover, the landscape of genomic initiatives is an extremely fast-moving field and as such new initiatives may have been announced or launched by the time of writing that are not captured here. It is also possible that certain initiatives for which publicly available information exists were inadvertently missed during data collection. Accordingly, there may be gaps in the database.

The genomic initiatives represented in this database span a diverse array of organisations: private companies targeting consumers, organisations operating at a national or global level with a primary focus on medical research (both public and private), public-private partnerships, and various other entities. Our project scope primarily focused on initiatives that are either actively generating genomic data (sequencing new genomes or analysing other genomic data) or providing tissue samples that can be analysed across multiple studies in the future (such as biobanks). Some initiatives do not conduct sequencing or analysis themselves but instead offer platforms that aggregate existing genomic data, facilitating improved access and analysis. Others follow a hybrid model, combining their own sequencing or processing activities with the provision of analysis platforms for existing data. We have intentionally excluded projects that do not contribute any new genomic data from our database. It is important to note that there remains a possibility of some double-counting in our database, particularly if genomic data produced by one initiative is also included in another.

The database was initially created in 2020 and then most recently updated in the first half of 2025. Across the data, we have collected information on 257 initiatives which meet our criteria of being genomic initiatives by either wholly or partially generating genomic data or aggregating genomic data. For all initiatives, we aimed to collect information across 24 parameters or characteristics. These include but are not limited to initiative description, funding type, organisation type, genomic data type, cohort size, patient linked data, consent process, geography of initiative and therapy area focus.

Genomic data type was split into the following categories: whole genome sequencing, whole exome sequencing, genotyping and other omics. Within other omics, this was further categorised into proteomics, metabolomics, transcriptomics and epigenomics. Cohort size information collected refers to the current and target sample size of each initiative. Many initiatives, especially private organisations, do not report current or target cohort size information. Comparatively, some initiatives have stated extremely ambitious targets, such as sampling whole populations, or have stated vague goals with no clear deadline. Consequently, cohort information, especially target cohort size, is associated with several caveats and dependencies. Patient linked data was categorised into EMR/EHR, clinical data, trait/phenotype data and survey data. For therapy area focus parameters, both primary and secondary diseases were recorded. For the purposes of our analysis, we defined the primary disease focus of each initiative as the first disease area listed on the initiative's website.

Complete data across all characteristics was not available for every genomic initiative. As more projects launch in the future, we anticipate that more comprehensive information will become accessible for a wider array of initiatives alongside an increased focus on reporting transparency. The IQVIA Genomic Initiatives Database represents a particular moment in time. Given the fast-moving field of genomics and frequent initiative updates and launch of new ones, it will be necessary to continue updating this database to maintain accuracy and reflect the current dynamic landscape.

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