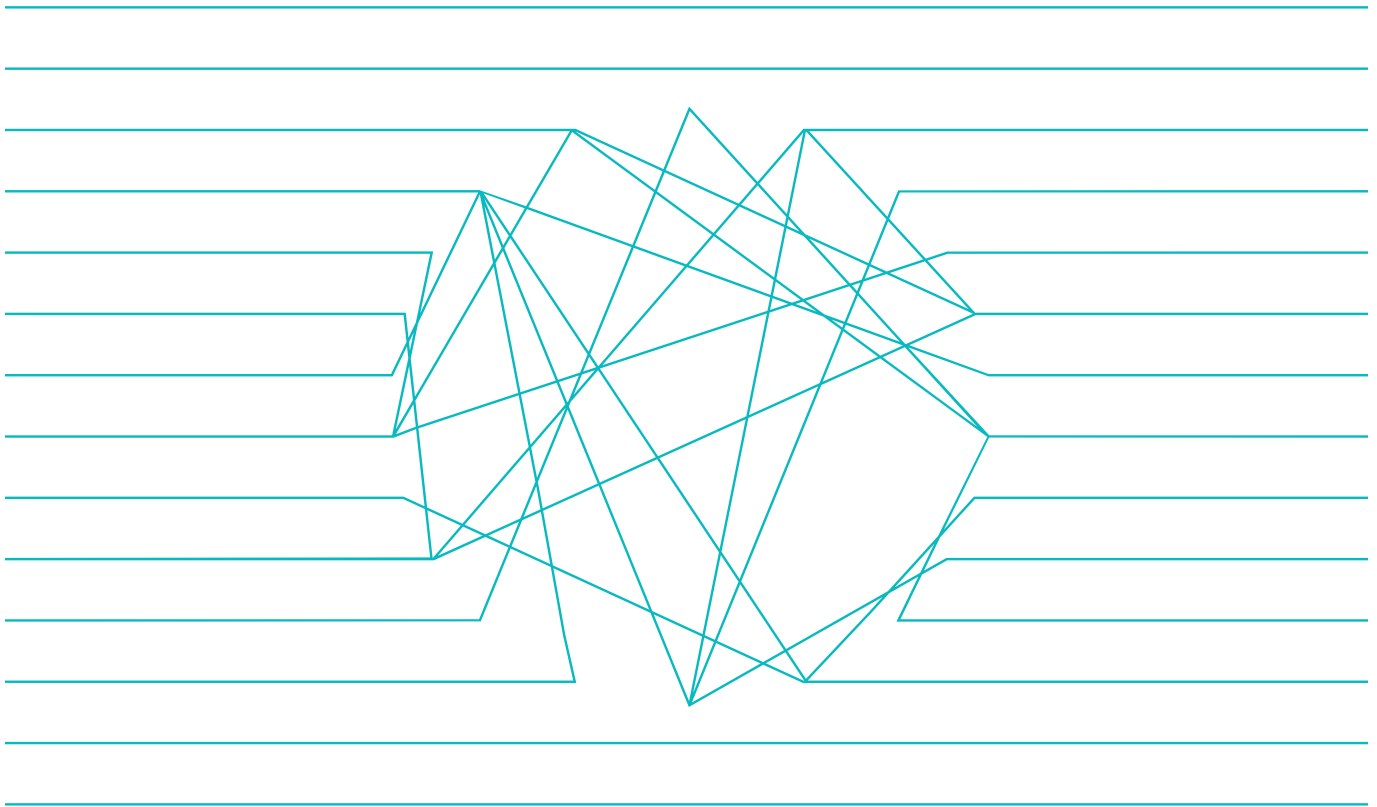# 2017

Connecting the
Genetic Health Information Network

Critical Steps To Realizing The Potential Of Precision Medicine

Version 1.0 | May, 2017

CONCERT
GENETICS

Table of Contents

Patients

Clinicians

Health Plans

Hospitals

Governing
Organizations

Labs

Researchers

Pharmaceuticals

01
The Challenges In Front Of Us

Why Hasn't Precision Medicine Arrived In Routine Clinical Care?

Precision medicine encapsulates an approach to disease treatment and prevention that takes into account variability in genes, environment, and lifestyle for each person. Proponents of precision medicine have identified it as a smarter and faster way to deliver care, with the promise to improve health, increase quality of care and lower costs. Heralded as a scientific successor to antibiotics, vaccines, x-rays, and organ transplants, precision medicine has been positioned as the next great fusion of technology and science, set to transform modern medicine and drastically improve health.

Two decades into the genetic revolution, we have discovered a reality that is more nuanced and humbling. Headline successes such as Trastuzumab and CRISPR sustain the prevailing winds of optimism, but it is increasingly difficult to justify the billions spent on research, drug development and clinical care. Despite massive investment, the data necessary to make a sustained and compelling case for clinical value is insufficient or inaccessible.

What Is The Genetic Health Information Network?

The Genetic Health Information Network exists today in an early form. It is not a technology platform, nor a single entity. Instead, the Network is comprised of patients, clinicians, hospitals, health plans, laboratories, governing organizations, pharmaceutical companies and researchers, and, critically, the channels of communication between them. Today the Network is inefficient, built largely on disparate systems and manual processes. However, through collaboration and concerted effort, all stakeholders can join together in enhancing the Network so it will meet the requirements for system-wide delivery of precision medicine.

What Prevents Effective Use Of Data Across The Genetic Health Information Network?

The Genetic Health Information Network today is disjointed, with stakeholders unable or unwilling to exchange data. Connecting the Genetic Health Information Network begins with understanding the root causes that have obstructed the system-wide exchange of data. Having performed a thorough analysis of the industry literature, we see four factors contributing to our current lack of evidence, and by extension, expanded clinical use, of precision medicine:

01

Inherent Complexity

Precision medicine relies on genetic profiling, which by its very nature, is highly complex. Determinations around who needs to be tested, what those results mean, and what should be done to change their treatment protocol, requires deep specialization. The processes involved, including test selection, laboratory processing, results interpretation, and treatment selection, are complex disciplines in which most practicing physicians are not trained. Clinician, hospital, and health plan systems were not designed to handle the data requirements of precision medicine.

02

Rapid Innovation

The pace of innovation in genetics is unprecedented within healthcare. The testing market is growing at a rate of 10 new tests every day, with over 70,000 tests on the market.[1] Linkages between mutations, disease risk, testing options, and therapeutics are constantly changing as more data is gathered and research accelerates. Treatment paradigms are also changing rapidly, with most drugs in clinical trials (a leading indicator of trends in emerging treatments) requiring a specific genetic mutation for patients to be eligible to participate. The pace of change strongly exceeds the capacity of our most highly trained experts.

03

Disparate Systems

The clinical application of precision medicine requires a variety of stakeholders to transmit information relevant to individual patients. Multiple systems responsible for individualized care cannot function effectively in isolation. Yet, systems to reduce complexity and connect data do not exist in the vast majority of care settings. This lack of interoperability makes it impossible to analyze data at the population level, limiting visibility into critically valuable patterns in complex interactions.

04

Absence of Integrated Standards

Few standards have been adopted that enable transparency across this market, which further disrupts the development of cross-platform systems and protocols. Traditional healthcare disorder and billing standards (ICD-10, SNOMED, HCPCS, CPT, etc.) were developed before the sequencing of the human genome. Genetics and related standards (HGNC, MeSH, COSMIC, DECIPHER, Orphanet, OMIM, UniProt, Ensembl, etc.) have been designed with limited exposure to the practical clinical environment. Importantly, there is limited ability to crosswalk between healthcare standards and genetics standards.

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[1] The Current Landscape of Genetic Testing – 2017 Update, Concert Genetics, March 2017

How Can We Improve The Genetic Health Information Network?

These factors raise the question, "How can we do better?" As believers in and champions of personalized medicine, we envision a world in which the Genetic Health Information Network is connected, transparent, and reliable, and that this efficient and highly functioning information network brings relevant data to the appropriate stakeholders. Connected and secure, the collective knowledgebase fosters the data-driven examination essential for the next wave of modern medical miracles.

We will never eliminate complexity — the complexity is as beautiful as it is core to our very being — however, we can elegantly enable order and objectivity to inform our path.

This Is
The Genetic Health
Information Network.

Here we envision a model for the future state of the Genetic Health Information Network, with infrastructure that will connect and bring value to all stakeholders within the industry. A system that will usher in the age of Precision Medicine.

02
Genetic Health Community

The Stakeholders, And The Problems They Face Today

There are eight key stakeholders in the genetic health community that are critical to solving the problems facing the genetics component of precision medicine. Taken together, these stakeholders and their interactions make up the Genetic Health Information Network.

Patients

Patients – increasingly "consumers" in the U.S. healthcare system—want first and foremost to be healthy. When unwell, patients want to understand their treatment options based on the best information available, including their genetic profile where relevant. Similarly, when healthy, the consumer or patient wants their genetic data to remain private, secure and readily available should they (or their physician) need it.

Only a small percentage of Americans will receive a genetic test in any given year. Like many medical procedures, this is not something the average person thinks about until it is brought up by a healthcare provider or they have a family member with a disorder-causing or high-risk mutation. As a result, patients rely heavily on clinicians to guide them to the most appropriate tests and to order tests which are germane to care. Further, in the era of high-deductible plans, there is increasing pressure on clinicians to help protect against large, unexpected medical bills.[1]

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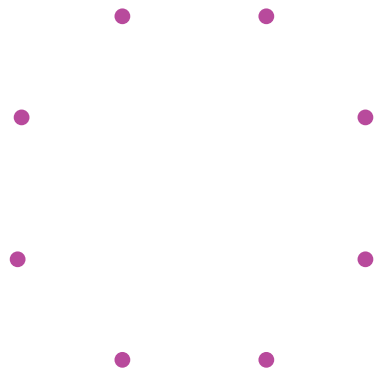
[1] In 2015, patients with private insurance were responsible for approximately 30% of the costs of genetic tests, or, more than $300 per test. The average American cannot afford this expense, but rarely are they informed of the costs before the test is ordered.

Clinicians

The challenge for clinicians in the era of personalized medicine is that the field has arisen so quickly that most have not been trained in genetics. This issue has contributed to the well-documented problem that 30% of genetic testing orders are misordered.[1,2] As the technology and testing capabilities continue to evolve at a rapid pace, it's unlikely that clinician education will keep up. Additionally, the burdens of prior authorization and financial counseling are falling to clinical staff more and more. Many genetic counselors spend increasingly more time talking to patients about insurance and reimbursement and less time providing counseling and education for their patients conditions.[3]

Hospitals

Hospitals organize medical staff and equipment, concentrate demand, and deal with the logistics surrounding coordination of care, enabling clinicians to better perform their jobs treating patients. Due to the rapid rise of genetic testing, most tests driving precision medicine are not offered at hospital laboratories, and are not present as an orderable unit in the EMR. This lack of a simple method to order tests leads to major logistical challenges for hospitals. Currently, most processes are manual; these include: ordering the test, leveraging experts to review orders, checking for insurance coverage, vendor selection, billing, and results entry into the EMR. Manual processes lead to error-prone, non-systematic decision making. Roughly 7% of test results received by the hospital are never returned to the patient, leading to gaps in care and financial waste.[4] Poor EMR functionality has been associated with even higher rates of failure to return results. Additionally, even if the right tests are ordered and useful results obtained, there are few technology tools that link molecular results back to specific treatment protocols.

1 Matthias P, et al, AJCP, 2016
2 Miller C et al, AJMG, 2014
3 Brown S et al, Abstract presented at the 2016 NSGC Annual Education Conference
4 Casalino LP, et al, Arch Intern Med, 2009

Health Plans

Health plans aim to provide individuals access to quality healthcare when they need it, and to manage scarce healthcare resources. To do so, plans need to ensure appropriate healthcare is provided for a reasonable price. Within genetics, plans are faced with high-growth – with constantly changing products and non-specific billing codes – which requires deep expertise. Plans struggle to determine which tests and emerging treatments are useful for patients, and how they should be reimbursed. Compounding this problem is the lack of clinical utility data for most testing products currently on the market.

Laboratories

Laboratories seek to develop and deliver high-quality tests useful in the diagnosis of disease. Historically, patent protection and deep expertise within certain labs for specific disease states led to concentration among a relatively small number of vendors. When gene patent protection was overturned in 2013, laboratories rushed into newly opened markets, such as BRCA1/2 testing, driving increased competition and vendor choice. However, these markets still lacked comparability and transparency across vendors, making it difficult for new vendors. Some laboratories make the case that these tests are commodities, while others assert their proprietary nature. Without the ability to compare quality metrics it's unclear which assertion is correct. Another major concern for laboratories is reimbursement uncertainty, made more difficult by a limited CPT code system and rapidly changing health plan medical policies.

Governing Organizations

Government policy makers and policy-focused interest groups are struggling to develop and implement data-driven policies. While mandates vary, these groups seek to ensure that genetic tests are safe, useful, and accessible. Frequently, they turn to expert panels and committees to provide the insight to make decisions. However, these groups have limited visibility into how tests are being used, coded and delivered to patients on a system-wide level. Data collection, if it occurs, happens over months or years. In the absence of current, comprehensive information, these groups are challenged to prioritize efforts and develop systems which reflect the current state of the market.

Pharmaceuticals

Pharmaceutical companies develop drugs to cure, treat, or prevent disease. Over the last decade, as medicine has entered the age of genetics, the genetic profiles of patients, their tumors and their microbes are significant predictors of the effectiveness of many drugs and of the likelihood that a patient will experience undesirable side effects. Further still, harnessing tools that identify the root cause of diseases has opened the potential to develop drugs for patients with exactly the same disease, not just the same symptoms. This shifts the source of market opportunities from large scale, "blockbuster" drugs to drugs designed for targeted populations.

This shift has led to a wave of drugs that are approved for patients with specific genetic variants and contra-indicated for patients with others. There are currently 32 drugs with FDA approved companion diagnostics.[1] However, challenges persist to the drug development process in the genetic-empowered world. Namely, the diagnostics that reveal a patient's genetic makeup remain expensive. Limitations in accessing (or creating) greater stores of integrated genetic and phenotypic data prevent more targeted clinical trials that could proceed by identifying target populations, the diseases they suffer from, and the genetic factors that define them. Beyond drug discovery, a major challenge to broader integration of these therapies is having timely access to the right genetic data and appropriate support for therapeutic decision making. For many therapies, waiting for a test result to come back or for a medical records department to track down an earlier result is not an option, and more efficient, but potentially less effective treatment options are chosen instead. As drug discovery shifts to targeted populations, and as our healthcare system shifts to reimbursement for quality and value, pharmaceutical companies will face challenges in delivering the most effective treatments to market.

1 https://www.fda.gov/Medical-DevicesroductsandMedical-Procedures/InVitroDiagnostics/ucm301431.htm

2 https://www.genome.gov/pages/about/planning/2011n-hgristrategicplan.pdf

Researchers

Over the last several decades, research in genetics and genomics has experienced a slow and deliberate shift from the laboratory bench to the clinic. In 2011, the National Human Genome Research Institute, a major government funder of genomics research, published a plan[2] to move the bulk of funded research accomplishments toward advancing the science of medicine and improving the effectiveness of healthcare. Unfortunately, there are real-world limitations on researchers operating within the Genetic Health Information Network, particularly as they move to do more pragmatic research studies and draw from real-world clinical data.

The central challenge of genetics research is gathering a large enough population with similar clinical features to draw a meaningful conclusion. With data siloed within private laboratory databases throughout the market, and a multitude of formats for recording clinical notes, there is no meaningful mechanism to access this information at population scale. This real-world barrier creates a huge limitation on advancing the research in precision medicine.

03
The Big Picture

5 Tenets Of An Effective Genetic Health Information Network

The healthcare system today is not designed to manage the complexity and unique characteristics of genetics and precision medicine. The status quo—where each stakeholder creates individualized workflows, codes, and solutions—limits our ability to create a comprehensive solution. Instead, we must change the system itself. If done thoughtfully, and with all stakeholders' interests in mind, we can create an elegant and long-lasting solution. To get there, we must agree to work together and fundamentally change the structure of the Genetic Health Information Network.

01

Patient-Centered

A network whose central goal is to place actionable genetic information within the patient's control.

02

Transparent

An open exchange or marketplace where those who serve and those who need service can securely and confidently interact and transact.

03

Frictionless Transfer Of Information

Standards and protocols that enable all stakeholders to securely exchange and translate information without delays, errors, or high transaction costs.

04

Learning System

A system that feeds back critical information so that effectiveness, safety, and cost, by individual circumstance, can be adequately measured and incorporated into routine clinical care.

05

Value Enhancing

A true self-enhancing network where the value to each stakeholder increases as membership grows and more interactions occur.
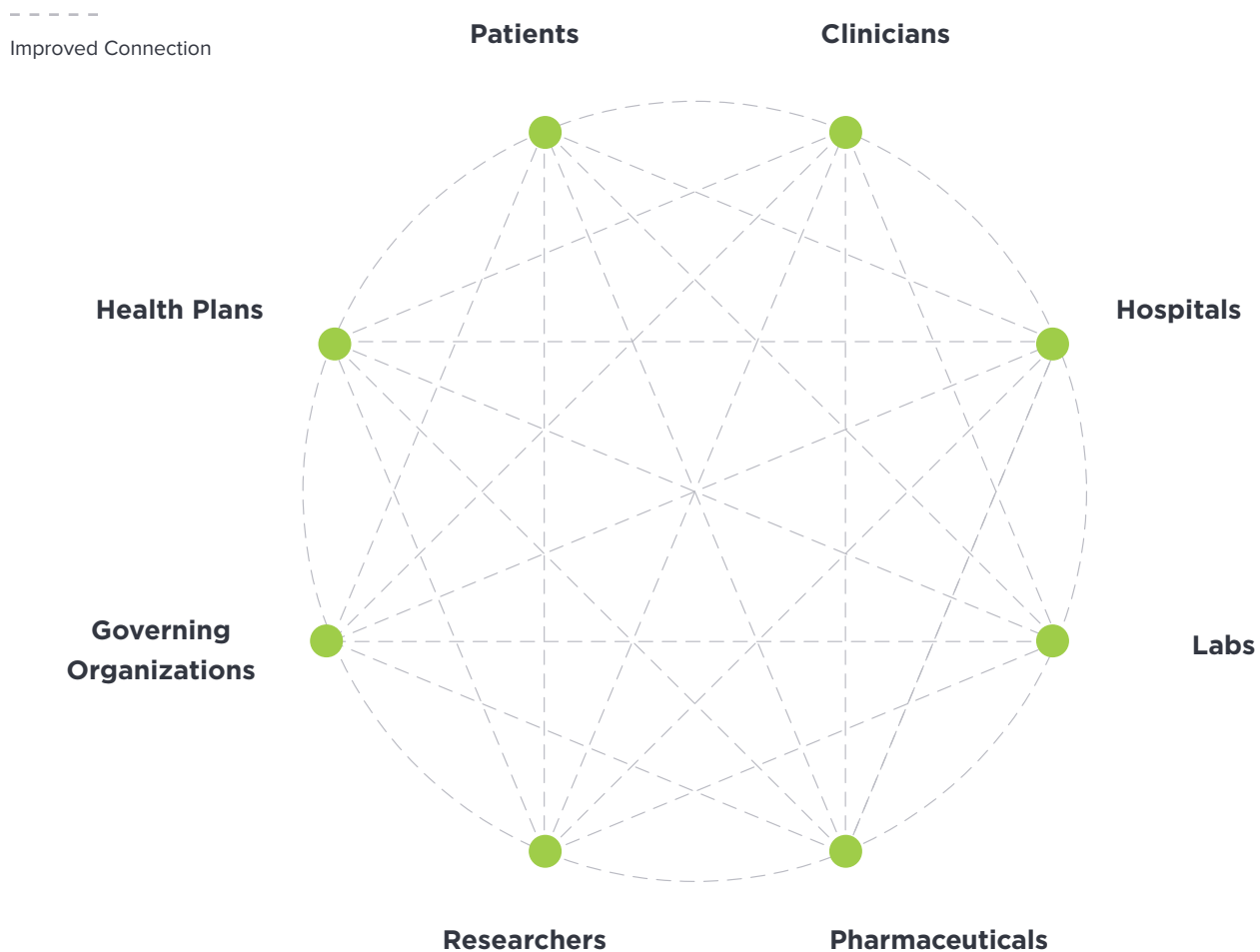
**The Key Tenets Of
The Genetic Health
Information Network**

04
Outline of Near-Term Emphasis

How Do We Begin To Realize This Vision?

The first step to deliver on the promise of precision medicine is to integrate existing genetic knowledge, tests, and other tools into routine clinical care delivery. All the systems and processes to enable effective ordering, resulting, record keeping, policies, billing, and payment must be established. Once these processes are in place, it will set the stage for determining the appropriate use of emerging therapeutics. On a practical level, here is what needs to happen in the next two years:

Improved Connection

Patients

Clinicians

Health Plans

Hospitals

Governing Organizations

Labs

Researchers

Pharmaceuticals

Patients

For the patient, the Genetic Health Information Network needs to ensure the right tests are being ordered, the best available interpretation is applied, and that the patient has more visibility into the financial costs of these tests. An initial focus should be to reduce the 30% of tests that are ordered inappropriately. We can do so in the near term by leveraging genetics experts for case review to ensure appropriate test ordering. With limited numbers of genetics experts, we should enable them to review cases via technology, which can make the process more efficient. Financial transparency can also be better achieved by intuitive, provider-facing systems that provide real-time authorizations and patient out-of-pocket cost estimation at the point of care.

Clinicians

For the clinician, the Network needs to make it easy to find and order the right test, and to retrieve results efficiently. Market-wide search-and-compare tools can simplify selecting tests quickly and accurately from the clinic. For hospital-based clinicians, formularies are emerging to reduce the clutter and confusion arising from the 70,000 tests currently on the market.[1] In order to increase the effectiveness of these formularies, they should be tied into the existing workflow wherever possible, and near-term, the network should begin with EMR-based formulary management. These formularies may be able to keep up with the pace of market change; results alerting should be a key feature.

Hospitals

For the hospital, we need to reduce financial risk around testing as well as integrate test ordering into their workflow. Many hospitals bear the brunt of the financial risk associated with test ordering, especially those that see a high volume of rare conditions. Prior authorization systems that are streamlined into the workflow could solve some of these issues, as could utilization management programs that engage expertise at key choice points. In both circumstances, logistical issues typically inhibit adoption. Having connected tools that streamline workflow, reduce manual data entry, and reduce financial risk, should accelerate adoption.

Health Plans

For the health plan, we need to provide transparency into what tests are being ordered and submitted for reimbursement. CPT coding within genetics functions for billing but it is inadequate to describe the complexity of the tests offered. Health plans need a method for matching CPT codes to the actual products offered by laboratories in order to understand what is being paid for. Only in this fashion can the plans make more informed decisions around coverage and policy development and communicate their decisions in a way that can be operationalized in the field.

Laboratories

For the laboratory, we need to put in place systems that enable labs to compete with each other on an even playing field. To increase transparency and value-based decisions, we need frameworks to evaluate (and systems to collect) data on quality and economic value, using standard nomenclature to compare tests across labs. With this, labs will be able to make data-driven decisions and communicate their value proposition clearly to the market. A short-term goal for the network is to draft and begin the implementation of a new, holistic, quality framework.

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[1] The Current Landscape of Genetic Testing – 2017 Update, Concert Genetics, March 2017

For All—We need to ease the burdens caused by inefficient systems, optimizing available time, money, and clinical expertise currently in the system.

Governing Organizations

For governing organizations, we need to provide information on how tests are being used and billed in the market. Today they face considerable information limitations, without sound market data on test volumes, billing practices, or clinical indications. By providing data on market trends, we can help these organizations continue to make healthcare more safe, effective, and accessible.

Pharmaceuticals

For pharma, we need to bridge genetic, phenotypic, and medical record data to overcome the challenges of identifying genetic associations with diseases and assessing drug effectiveness among patients with similar genetic traits. Initial steps may include aggregating reports from the growing number of integrated genetic-phenotypic databases (e.g. at academic medical centers). Another step may be to establish partnerships with reference laboratories and patient data sharing networks (e.g. Invitae's Patient Insight Network) to exchange data in a safe and appropriate way. Either way, new models must emerge for the identification of target populations for drug development.

Researchers

For researchers, we need to establish data sharing partnerships that provide access to real-world data and deliver practical value back to the participants who shared the data. For example, clearing a path to integrate test specification, order and claims data sets the stage for initial clinical utility and economic value studies that inform the medical policies and reimbursement decisions. In turn, this will give direction to test manufacturers about investment priorities.
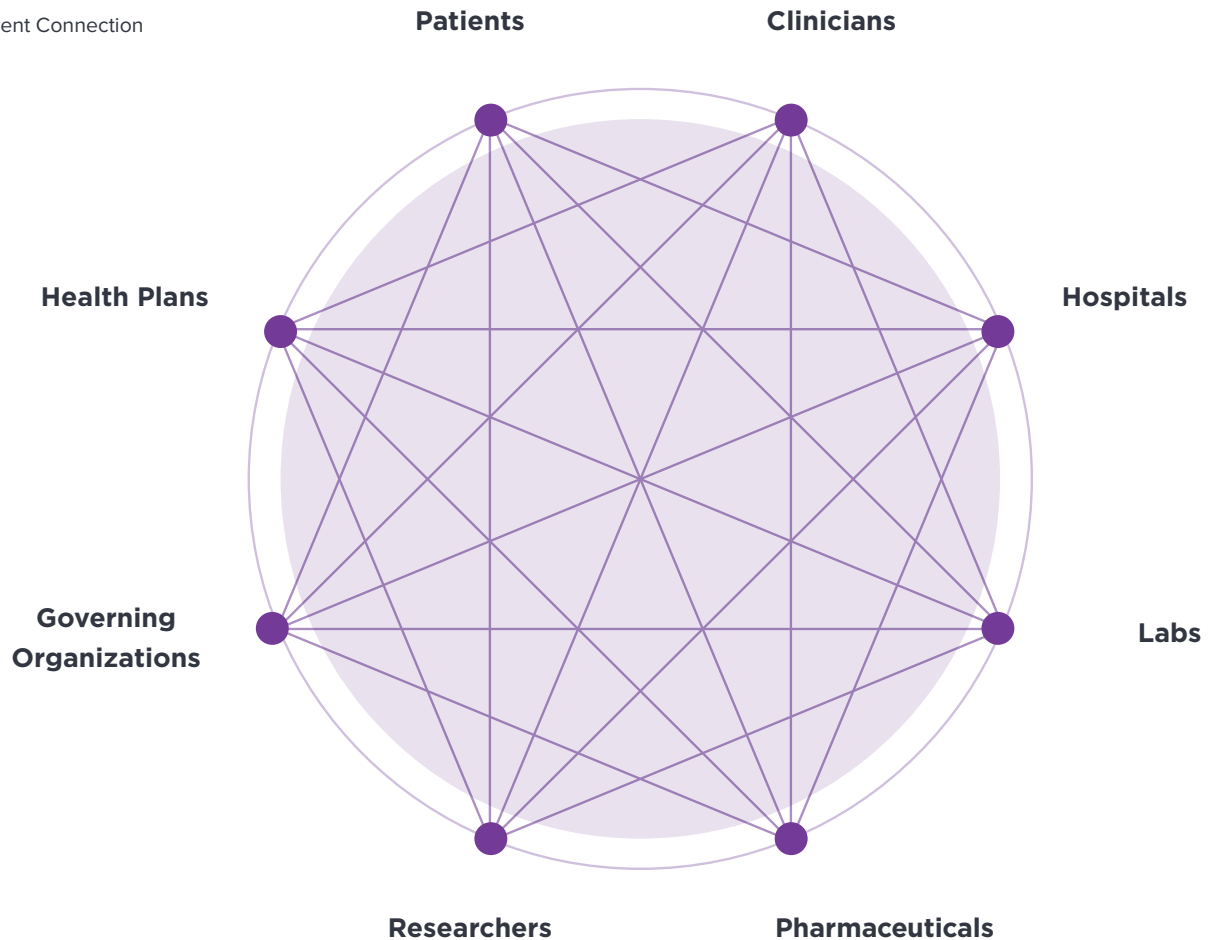
05
Portrait of Long-Term Solution

Ten Years Out, What Does This Network Look Like?

Over the next decade, the focus of the Genetic Health Information Network will shift to consumer and patient empowerment and the secure, trusted integration of genetic information into all aspects of health and healthcare. Genetic data will be used regularly to determine optimal treatment protocols and preventative measures across a wide variety of disease states.

● Shared Standards and Nomenclature

Efficient Connection

Patients   Clinicians   Hospitals   Labs   Pharmaceuticals   Researchers   Governing Organizations   Health Plans

Patients

For the patient, the Genetic Health Information Network will provide access and rights to their genetic information, and more treatments and preventative measures will be linked to this information. Patient genetic data will be stored indefinitely, and as clinical questions arise, this data will be interrogated digitally, rather than by re-sequencing. By providing a central storage system, with patients in control of who accesses their information, we will enable wide-scale research on an opt-in basis, without recurring sequencing expense. Patients will be in control of their data, and will have confidence that treatments are optimized, based on their genetic profile.

Clinicians

For the clinician, the Network will be providing the appropriate level of clinical decision support, enabling clinicians to practice medicine effectively in the age of genetic data. The system will flag patients in need of a genetic test based on data-driven guidelines, and provide access to additional genetics expertise where needed. Paperwork burdens will be drastically reduced, leveraging technology tools, integration points, and physician extenders. Finally, we will link patient history and diagnostic results to an expanding body of evidence-based treatment protocols. Simple, intuitive, decision support will direction decision-makers toward the right pharmaceutical agent, at the right dose, according to current and comprehensive data. From an economic standpoint, all of this will better enable clinicians to make well-informed decisions in the context of value-based payment models.

Hospitals

For the hospital, the confluence of precision medicine, value-based payment models, and provider system consolidation will provide the opportunity to serve as the anchor of population health. Hospital systems can enable precision medicine delivery at scale, facilitating innovative treatments and evidence-based prevention measures at acute care locations, outlying clinics, and even remotely. To make this possible, the Genetic Health Information Network will need to provide technology tools that integrate into the existing workflow, simplifying the precision medicine delivery process for clinicians and other front line health professionals, and that also tie to back office functions like billing. These tools will ensure hospitals will be appropriately reimbursed, and more importantly, enable the best service to be delivered for patients based on comprehensive data.

Health Plans

For the health plan, we will provide clinical utility and economic value data that will enable them to confidently identify effective interventions as they emerge, pay for them in appropriate clinical situations, and efficiently communicate these determinations to providers. Diagnostic testing becomes an entry point for evidence-based care pathways. As it becomes more mature and refined, this process will streamline the introduction of proven, innovative, precision treatments and preventative measures into the market, while simultaneously managing premium dollars for the benefit of all members.

Laboratories

For the laboratory, mature models for quality, value, and market demand will enable informed decisions on how to invest in test development. Labs will have a clear indication on where investments in quality versus price reduction will affect their volume. Further, the healthcare industry itself will be determining clinical utility of tests, and not requiring the laboratories to provide this information. As the learning system within the Genetic Health Information Network evolves, it will be the network itself that provides the clinical utility data, to be analyzed by leading research organizations, while the resulting data is fed back into the system to benefit all stakeholders. Finally, more efficient channels to market will enable labs to focus on developing excellent diagnostics rather than investing in costly marketing and sales programs.

Governing Organizations

For the governing organizations, we will provide integrated systems which allow them to access and analyze data as needed, and at critical policy development points, with minimal efficiency-loss to the market as a whole. Interventions to promote safety in the use of tests would quickly and effectively identify low quality or bogus tests, without slowing innovation. Policy recommendations would be set based upon clear utility criteria, with data drawn from an open, learning system. Where differing opinions and priorities exist, discussions are grounded in a common truth of data. Once decisions are made, they will be rapidly disseminated to EMRs, claims systems and research organizations.

For All—Precision medicine is an accepted and safe component of the healthcare system, driving better care and improving preventative medicine.

Pharmaceuticals

For pharma, we will develop and prove out models that safely accelerate the introduction of targeted therapies for niche populations. First, by integrating data such that the process of identifying appropriate target populations by both genetic and phenotypic characteristics is simpler. Then, by streamlining clinical trials to account for the inherent safety and efficacy benefits of pre-selecting truly appropriate recipients of these drugs. Further still, we must move the clinical trial process up, from an evaluation for safety and probability of effectiveness at the end of the process to "research trials" in which drug discovery is closely interwoven into the discovery and development process.[1]

Researchers

For researchers, we need to enable the data aggregation, secure access, and funding mechanisms that attract the brightest minds to the most pressing problems at the intersection of precision medicine and population health. On the data side, this means integrating intervention, outcome and economic data in ways that are safe, secure, and fair to the companies who collected the data and the patients represented by it. In study design, we must ensure the findings inform both clinical and economic decisions, with the ultimate goal of achieving an ever-clearer view of which interventions achieve maximum value for patients and the entities that deliver services to them. Finally, we must design funding mechanisms that leverage the enormous economic value of clinical utility studies and tap the resources of the organizations and entities that benefit most from them, including the test and drug developers who leverage this information to make strategic development decisions, and the government and commercial health plans who reimburse for the resulting services.

[1] Concept borrowed from The Innovator's Prescription by Clayton Christensen, Jerome Grossman, MD, and Jason Hwang, MD.

06
Summary

Stakeholder	Need	Near-Term	Long-Term
Patients	To maintain or regain health with support from health professionals who are appropriately leveraging the latest precision medicine tools and knowledge; To do so without undue financial burden	Systems that ensure the best test is selected—and the best available interpretation applied—to each patient's unique circumstance; Processes that avoid inappropriate or unnecessary orders	Access to genetic information, innovative treatments, and preventative measures that maximize health and vitality; Confidence in the security of their genetic data and control over who accesses it
Clinicians	To provide patients with high-quality care and guidance, and particularly in the age of precision medicine, to draw on new evidence, training, and support to deliver care informed by the genetic makeup of individual patients	User-friendly tools to select, order, and retrieve the results of genetic tests, integrated in the clinical workflow; Formularies and prior auth support to ensure test orders align with business processes	Access to the growing body of precision diagnostics, treatments, and evidence-based protocols to deliver high-value, individualized care to each of their patients; Systems that alleviate administrative burdens and adapt to value-based payment models
Hospitals	To effectively organize staff, facilities, equipment, and technology to support the delivery of precision medicine; To operate effectively within value-based payment arrangements	Tools that move test selection, ordering, utilization review, prior auth, and results retrieval into the clinical and operational workflow; Revenue cycle support that enables fair and timely payment	Systems and processes that enable precision medicine delivery at scale, facilitating innovative treatments and evidence-based prevention at acute care centers and outlying locations, all in a connected environment
Health Plans	To provide members with access to high-quality care by allocating scarce healthcare resources to high-value diagnostics, treatments and preventative measures	Transparency into genetic test orders, their clinical purpose, and the emerging data to assess their clinical and economic value; Systems to support providers in ordering and billing that aligns with policies and processes	Clinical and economic data to confidently identify effective interventions as they emerge and to pay for them in appropriate situations; Open and effective communication channels with providers and members
Laboratories	To develop and deliver high-value diagnostics into the market, and to be paid in a fair and timely way according to the clinical and economic value their tests deliver	Frameworks for clinical and economic data to better understand the value their tests provide—including a holistic quality framework—to guide strategic development investments; Streamlined systems for more predictable payment	Models for quality, value, and market demand to inform strategic investment; Channels to market that enable focus on high-value diagnostics rather than costly sales initiatives; Integrations with ordering platforms allowing for relevant data to support interpretation
Governing Organizations	To implement policies, programs and guidelines that make healthcare more safe, effective, accessible, and reliable for their constituents.	Information on emerging diagnostics and currently marketed tests; Insight into how they're being applied clinically, billed and paid, thus alleviating information imbalance and supporting effective governance	Integrated systems to access and analyze data at critical policy development points, with minimal efficiency loss to the market; More broadly, a common truth (e.g., data) to ground multi-stakeholder policy discussions
Pharma	To develop drugs to cure, treat and prevent disease, harnessing the emerging science to understand root causes of disease to develop effective targeted therapies	Databases that bridge the gap between genetic, phenotypic, and medical record data to accelerate the identification of genetic associations with diseases and the development of therapies	Models that rapidly introduce targeted therapies for niche populations safely, including regulatory and payment determination processes that leverage the streamlining made possible by genetic data
Researchers	To participate in the scientific discovery process to more efficiently and effectively evolve our understanding of human health, and to build a relevant evidence base for the health care system	Data sharing mechanisms, at least at small scale, that provide researchers access to real-world data, enabling studies that illuminate clinical utility and economic value for the rest of the market	Data aggregation standards and secure access that make relevant clinical questions more easily answerable, thus attracting the brightest minds to the most pressing problems in healthcare

Near-Term Emphasis

We need to ease the burdens caused by inefficient systems, optimizing available time, money, and clinical expertise currently in the system.

Long-Term Solution

Precision medicine is an accepted and safe component of the healthcare system, driving better care and improving preventative medicine.

Overarching Problems

Inherent Complexity

Precision medicine relies on genetic profiling, which by its very nature, is too complex for the existing systems on which healthcare operates.

Rapid Innovation

The evidence and clinical applications in genetics are constantly changing as more data is gathered. The pace of change greatly exceeds the current capacity to adapt.

Disparate Systems

In practice, precision medicine requires a variety of stakeholders to transmit information relevant to individual patients. Current systems don't meet those requirements.
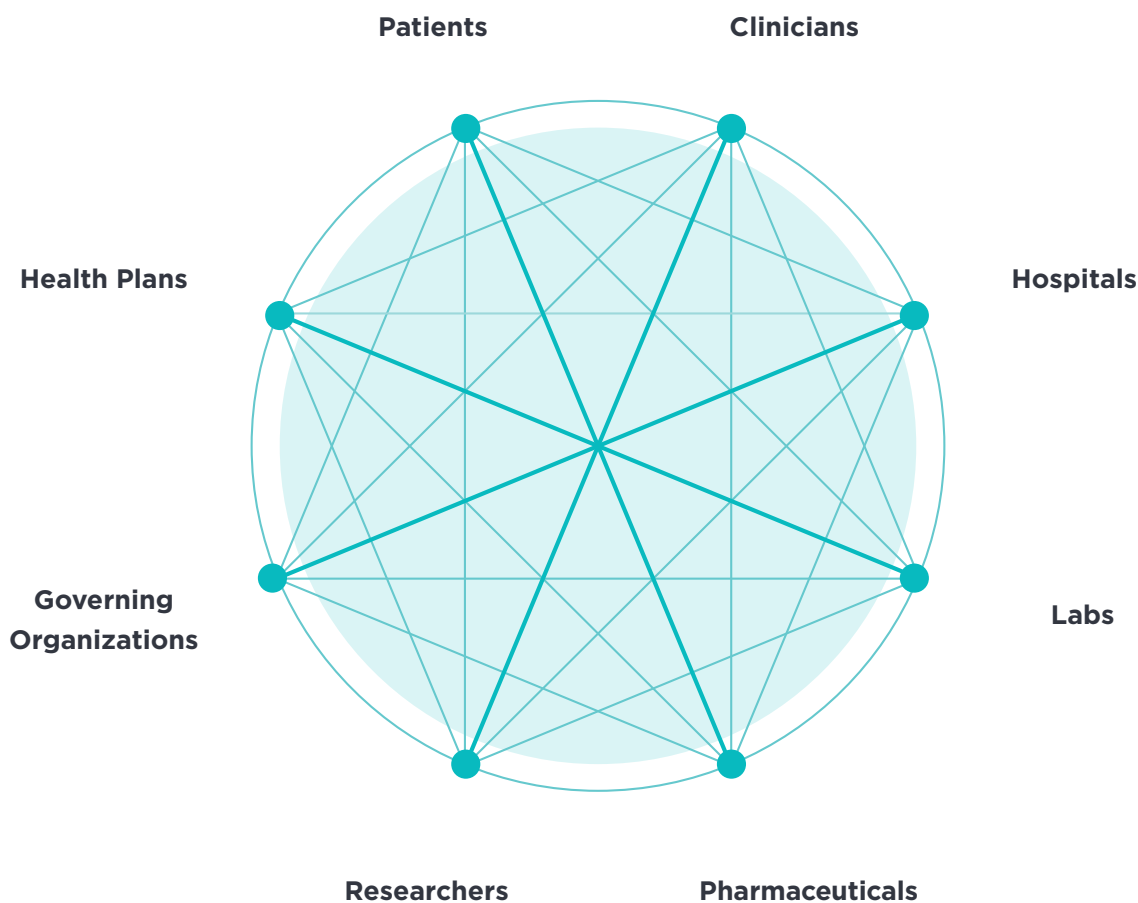
Absence of Integrated Standards

Healthcare disorder and billing standards were developed before the sequencing of the human genome. The system cannot deliver on precision medicine without standards that integrate.

07
Concluding Thoughts

For hundreds of years, medicine has been practiced using the law of averages. The promise of precision medicine is truly diagnosing and treating the patient as an individual. At Concert Genetics, we believe The Genetic Health Information Network must be overhauled to overcome the barriers inherent in transitioning an enormous legacy system to a new way of delivering care and value. Furthermore, we believe it will be a network-wide effort, and we eagerly welcome collaborators from across the network in joining together for this worthwhile effort.

Patients   Clinicians   Hospitals   Labs   Pharmaceuticals   Researchers   Governing Organizations   Health Plans

Concert Genetics is made up of a group of people who believe in a future where Precision Medicine is a reality, and healthcare works better for the patient.

We are optimistic that we can achieve this goal together, and stand committed to working with all stakeholders in the community to connect the Genetic Health Information Network. We would love to hear your thoughts, and invite you to join us in designing an elegant solution.

Want To Provide Input?
We Want To Hear It.

If you would like to work together toward a shared vision for the Genetic Health Information Network, or if you simply have input to share, we want to hear from you.

Email us at the address below to reach out. We will keep you in the loop about future efforts to connect key stakeholders from across The Genetic Health Information Network and to move together toward a shared vision where precision medicine is a reality.

connect@concertgenetics.com

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