A deeper coverage of the blog post -

Patient-centered genomics-based care requires real genomics-based care coordination

MOVING FORWARD #3

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A Comprehensive Review and Perspective Report

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Introduction

The integration of genomics into patient care can be complex and requires coordination between various medical practitioners.

By analyzing an individual's genomic data, healthcare providers from across the care spectrum can identify genetic risk factors for certain diseases and tailor treatment plans accordingly. By having access to a patient's complete genomic profile, the healthcare team will make more informed and unified decisions about their care, leading to better outcomes.

This is where technology can play a crucial role in improving genetic-based care coordination. This goal is contingent on high-quality data that is easily accessible and applicable in the patient care setting. Despite advancements in electronic health record (EHR) systems, work remains to be done to optimize their ability to support genomically informed care and, as a result, for genomic information to be systematically used in care coordination.

EHR systems used by the care team should access the patient's genomic data repository, store genetic and genomic test result data, and utilize clinical decision support functionality to review the most effective treatment options. The system (both clinical and technical) should then share all of this information among the other healthcare providers throughout the patient's continuum of care, improving the communication and genetic-based coordination of care.

However, the initial integration of genomics into healthcare has not been completely solved. (See an earlier blog post on Genomics as standard of care - The top 15 issues and barriers slowing clinical adoption). But when that milestone is achieved, care coordination becomes the next major goal.

What is needed

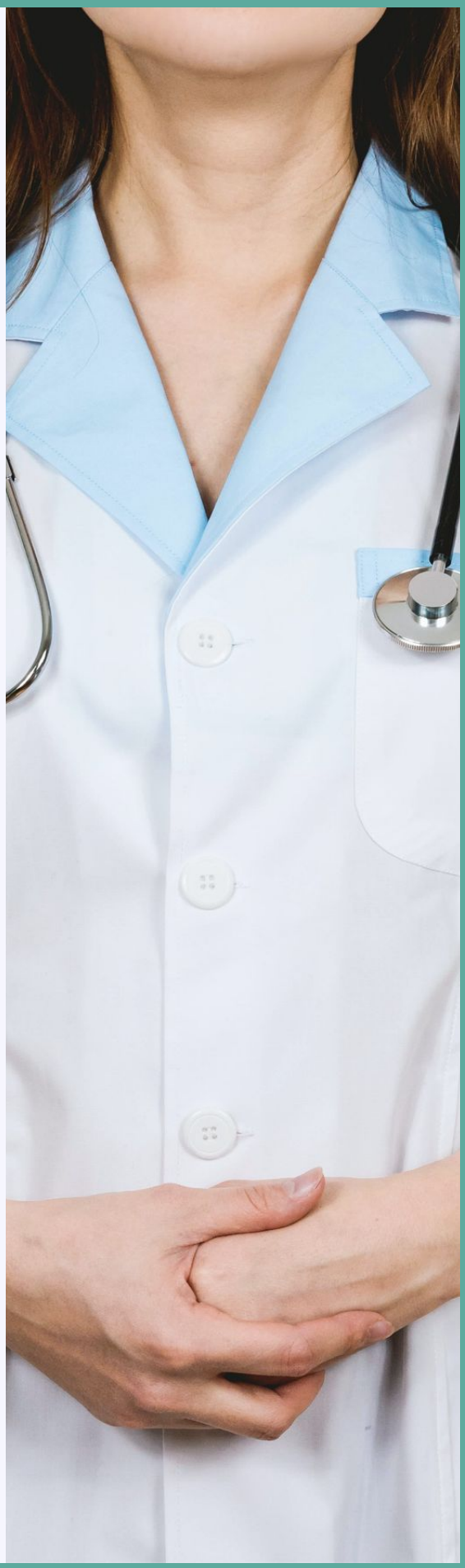
All healthcare delivery organizations claim they offer patient-centered care. But what is that exactly? Is it just an approach that tries to focus on the needs, preferences, and values of the individual patient?

Does it prioritize open communication, collaboration, and respect for the patient as a whole person to empower the patient to play an active role in their own care? Yes, but this should not be the entire definition. If the goal of patient-centered care is to improve health outcomes and enhance the patient experience, how is this even possible when the data is not patient-centered but rather healthcare system and provider centered, as it is today?

Now let's look at this question from a genomics as standard-of-care perspective. Genetic-based patient-centered care is a healthcare delivery approach that takes into account the patient's clinical, genetic, and family health history information and uses it to inform the development of personalized health plans, determining the most appropriate diagnostic tests, treatments, and preventive measures. This includes communicating and collaborating with all members of a patient's healthcare team, including primary care physicians, specialists, genetic counselors, nurses, and other health service providers.

Genetic-based care coordination involves organizing the molecular knowledge of the patient (tests, clinical interpretation, etc.) to ensure that multiple treatment plans from multiple care providers work as one, with no duplications or gaps in the patient's care. This coordination will then allow us to look even further toward cascade testing for family-based genomics care.

Sadly, current medical record system designs do not support this. EHR and other clinical applications need to be rebuilt from the ground up. A patient healthcare record should be owned and directed by the patient. Their genomic data record should also follow this same model. (More on patient genomics data repositories in a future perspective paper and blog post.) Currently, there is no consensus on the best approach to genomic data ownership or on a standardized model of consent. However, it is clear that the academic model of opt-in and opt-out will not scale. Technology may need to be rethought and redesigned to achieve true patient-centered genetic-based healthcare.



My experience

After 18 years in this industry, health care systems still do not have patient-facing websites that describe genetic-based services and how information would be coordinated among current and future care providers.

Many doctors order genetic testing, but others still want more evidence of the clinical utility. Test results are not received as discrete and computable data in the EHR, but rather in PDFs, which are hidden in file folders on screens tailored to specific specialties. Specialist results are not known to primary care, and vice versa. And with the lack of clinical coordination, they are also not available for emergency care, physical therapy, nutrition, or other ancillary services.

The most clinically appropriate test is not always chosen. We did a study some years ago and found that duplicate genetic tests were ordered 3–5% of the time. The cost savings here alone are worth the coordination efforts. Patients still do not have access to their test results and data. Two years ago, we had to ask a market-leading pharmaco-genomic testing lab for report data that we stored in a major EHR system. We then created our own PGx review screen for clinicians. It is true, however, that some gaps are being filled by integrated third-party solutions in EHR's.

The Call to Action

⇒ The healthcare system should have formal policies for data access to the patient's full genomic record by all of their care providers.
⇒ The patient summary screen in the EHR should contain all the clinically actionable genetic variants, their interpretations, and subsequent clinical decisions prescribed by any and all providers.
⇒ If a specialist physician orders a test, the primary care doctor is alerted of the results, and vice versa.

The Action statements above are only a few of the capabilities needed, others include:

- genetic tests performed are reported with results and clinical interpretations in a computable format,
- the system has the ability to collect and utilize genetic and family health history risk assessments and polygenic risk scores,
- the effectiveness of genetic-related treatments are studied for knowledge improvement,
- when indicated, cascade testing is available for the benefit of all family members,
- and, a patient's multi-omic profile is created to leverage even more 'precision' medicine.

We really want to see these actions happen. Your input and ideas will determine the next steps and development of each action strategy. Progress will be tracked in future posts. This blog is not designed for passive readers. If you agree with these actions, let's work together to make it happen. We will pursue these and future Call-to-Actions over time until we can verify that they have been achieved. Stay tuned!

To join this Call-to-Action, and email ideas,
efforts, and results to
moveforward@genomics.network

Genetic and genomic data comes from several sources

Depending on the service provided and the expertise of the healthcare practitioner in charge, multiple and diverse clinical scenarios generate genetic data with varying degrees of complexity. Genetic and genomic data will come from several sources that need to be coordinated. Advanced data applications need to be in place, of course, but let’s look at care coordination from the healthcare provider's perspective.

Primary Care Physicians

Primary care doctors play a crucial role in coordinating genetic-based care with other healthcare providers. They are often the first point of contact for patients and are responsible for identifying potential genetic disorders, referring patients for genetic testing, and interpreting test results that other caregivers of that patient might use. Patients in the primary care setting range from those with preexisting diseases or who have just developed symptoms, to those who are otherwise healthy and are seeking out preventative treatment for familial disorders and other traits that may run in their family.

Besides communication and collaboration, primary care physicians must also stay up to date with advances in genetic-based care and be familiar with available resources and support systems for the patient. This includes being aware of genetic testing options and educating patients and their families about the risks, benefits, and limitations of genetic testing, as well as the results of any tests performed. In addition to coordinating with specialty providers (e.g. pharmacogenomic testing), primary care doctors must play a front-line role in helping patients understand and manage the psychological and emotional impact of genetic information.

Referring the patient for testing and care by other clinical providers demands maintaining a lifetime medical record for that patient. To accomplish this, primary care doctors must collaborate with specialty physicians, genetic counselors, and other healthcare professionals to ensure that patients receive comprehensive and integrated care. Coordinated care means everyone is responsible for helping patients navigate the complex healthcare system to access the resources they need to manage their condition effectively.

Specialty Care Physicians

Specialty doctors will also play a key role in coordinating genetic-based care. They are responsible for providing expert medical care to patients with specific conditions. One of the key challenges in coordinating genetic-based care is ensuring that all healthcare providers have access to the same information and understand the significance of genetic test results. Specialty doctors must work closely with primary care doctors, genetic counselors, and other healthcare professionals to make sure that all relevant information is shared and that a comprehensive care plan is seamlessly administered to the patient.

In a specialty situation, the generation of genetic data is frequently amplified. Germline testing is used for risk assessment, diagnosis, and treatment guidance. In oncology, somatic testing is used to optimize therapeutic choice. When a primary care physician suspects a patient has a genetic issue or decides that the patient might benefit from the expertise of a genetic counselor or medical geneticist, that will typically include a specialist physician. As symptoms and differential diagnoses are investigated and a genetic-related disease is discovered, the processes of collecting a family history, performing a risk analysis, ordering and interpreting tests, and devising management plans can generate a great deal of data that needs to be coordinated. Specialty doctors will monitor patients over time to assess their response to treatment and adjust their care as needed, especially when information on a gene whose clinical significance was previously unknown.

Specialty Care Physicians, continued

Just like primary care physicians, specialists must also keep up with advances in genetic testing and treatment options. Specialty doctors must be knowledgeable about the latest developments in their field and be able to incorporate new information into their patient care plans as needed. They must also be familiar with available support systems for patients, such as patient disease advocacy groups, and be able to refer patients as needed. Specialty providers can give their patients the best genetic-based care possible by working together with other doctors and keeping each other informed.

Not to be forgotten, in order to keep the care process moving forward in a timely manner, insurance companies may need to review and approve treatment plans in advance. Out-of-pocket costs for the patient need to be assessed. Supporting efficient and optimal care management processes will require fast access to the necessary information for all providers who need it.

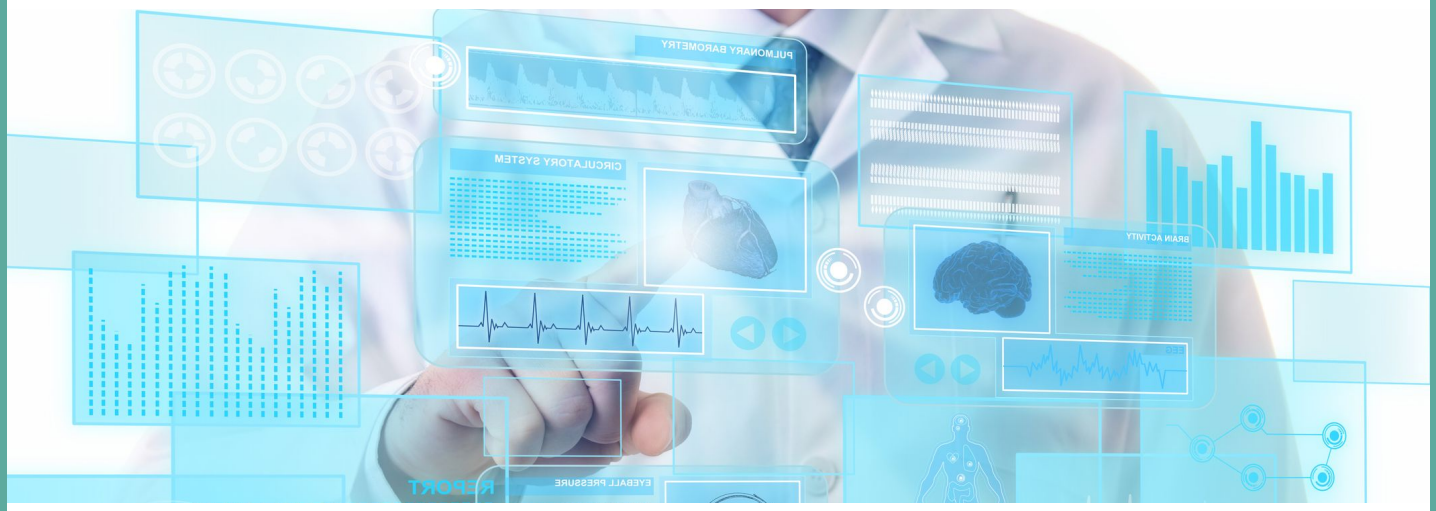
Genetic Counseling

There will be a greater need for genetic counselors as routine genetic and genomic testing, data analysis, and clinical interpretation become the norm in healthcare. This procedure begins with a referral from a doctor (either a primary care or a specialist physician). The doctor has already decided that genetic testing is necessary for the patient, or they are consulting with the counselor to evaluate whether testing is clinically recommended. One of the most useful tasks counselors do is collect and analyze a family medical history in order to determine risk and propose appropriate tests. The ability to handle and integrate this data across patients, patient families, and healthcare professionals is improving, but requires better solutions from EHR systems to integrate with the very capable third-party family health history platforms.

The genetic counselor then coordinates the ordering of tests and discusses the lab results with the patient and the doctor. Counselors play a vital role in patient care by providing information, assisting with decision-making, and facilitating other processes related to patient management and follow-up, including seeing additional family members for what is called 'cascade' testing. Genetic variants found in relatives confirm the diagnosis and treatment plan for the patient. At the end of the process, the counselor gives feedback to the doctor. This initiates a model for interdisciplinary teams and care coordination. Just as true for the previous clinical scenarios, an integrated data system and provider-specific decision support are required for the effective management of this process.

The expanded team of healthcare providers who will access the data in the continuum of care

Beyond the traditional primary and secondary care providers, we should also acknowledge the vital role that many tertiary and ancillary providers play in genetics-based care. These caregivers will need access to the same patient data as physicians, although they are unlikely to perform genetic or genomic tests themselves. However, they provide ongoing support and care to help patients manage the effects of their condition, or in many cases, learn to live with their condition.



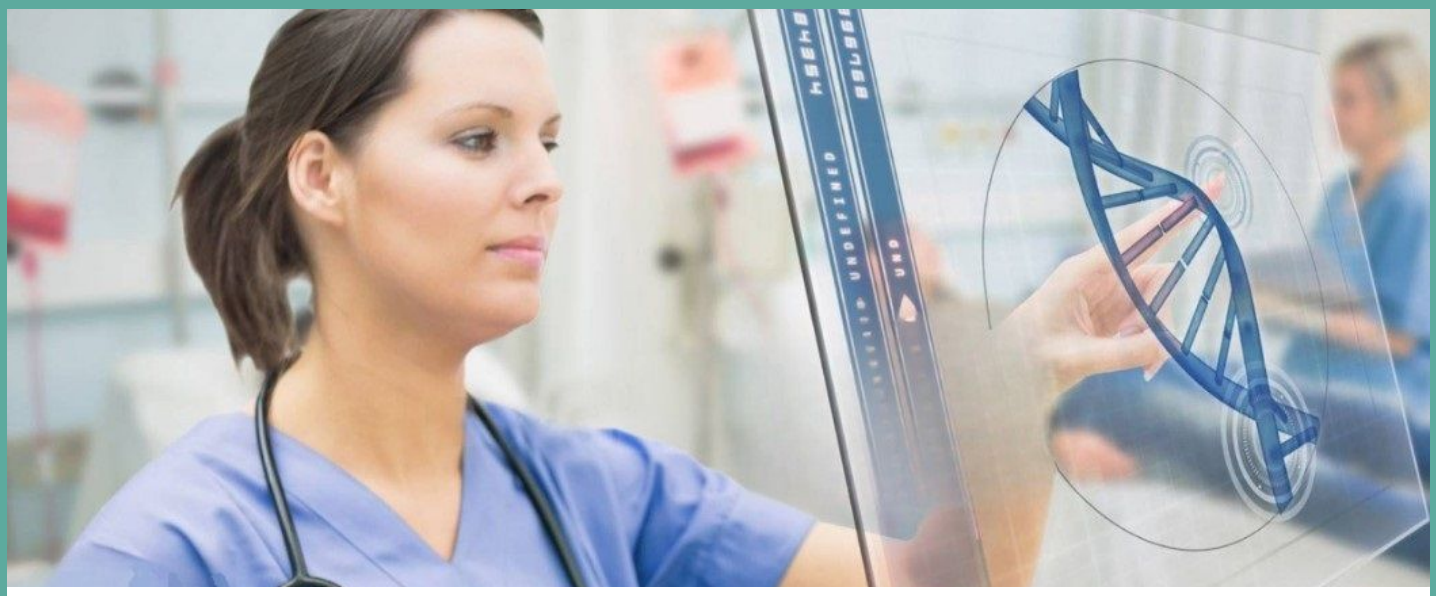
Laboratory and Pathology

Although they collaborate with numerous other fields, pathologists play a vital role in the diagnosis of many disorders thanks to their ability to conduct cytogenetic and molecular testing, as in the case of soft-tissue tumor studies. The medical directors of laboratories do more than just sign off on test findings, they also contribute to the creative process of developing new types of genetic tests.

In addition, laboratories contribute to variant databases, which aid in the ongoing discovery of variant knowledgebases with therapeutic relevance. The development of procedures by which laboratory workers keep doctors updated on the reclassification of variations of unknown importance (e.g., benign or pathogenic) is ongoing. The future will bring faster sequencing and quicker interpretive reports back to the clinic.

Pharmacy

The outcomes of pharmacogenomic testing can inform the development of individualized treatment plans for patients with drug therapies targeted to their specific conditions. Pharmacists, in collaboration with other medical experts, can assist in the interpretation of test results and provide clinical recommendations for communicating those results to providers and patients. Pharmacists actively promote and take part in studies, collaborative efforts, and networks that help guide and speed up the integration of pharmacogenomics into clinical practice.



Nursing, Nurse navigators

The genetic component in many diseases can be altered by environmental, lifestyle, and other variables, along with the medications used to treat them. The entire field of nursing has a stake in keeping tabs on and making sense of these details. Nurses have a unique understanding of the diagnostic and treatment process from the perspectives of 1) the patient, family, and community, 2) expertise in communication and coalition building as patient advocates, 3) familiarity with genetic and genomic technologies and information, and most importantly, 4) the public's trust in their front-line care. To help nurses better understand genetics and genomics, the American Nurses Association has produced a set of core competencies. This paper descibes a roadmap to accerlate genomics integration across nursing.

Nurse navigators play a critical role in coordinating genetic-based care as they assist patients and families in navigating the complex healthcare system related to genetic conditions. They work closely with genetic counselors, healthcare providers, and insurance companies to ensure that patients complete the ordered tests and treatments in a timely and effective manner.

In addition, nurse navigators may assist with the management of symptoms and side effects of treatment, as well as communication with healthcare providers and support services. They may also provide resources and referrals for patients and families, such as support groups and financial assistance programs. Also, they help make sure that patients get follow-up care that is centered on the patient, such as medication adherence, regular monitoring and screening tests.

Hospitalists, critical and emergency care

Diseases that run in families can be devastating and even fatal over time. Some of these conditions may cause emergency visits or long stays in the hospital. As an example, the identification of a subset of children with severe asthma who present to the emergency room is one application of identifying clinically relevant biomarkers in the patient's medical record. For another, hereditary changes in the adrenergic system's capacity to function can have an impact on the patient's susceptibility to post-traumatic pain.

Physical Therapy

Evidence from the scientific literature suggests that hereditary factors play a role in the development of many of the dysmorphic disorders that physical therapists treat in clinical practice. It appears that genes affect not only susceptibility to disease but also injury course, prognosis, and response to rehabilitative efforts.

Nutrition, Nutritional genomics

Nutritional genomics can help identify personalized dietary interventions based on an individual's genetic makeup. By knowing a patient's genetic variations, the nutritionist can create targeted plans that optimize eating choices. Nutritional genomics can also inform healthcare providers about how certain nutrients may interact with medications or impact specific health conditions.

Researchers

Doctors and patients must work together with clinical research to accelerate the search for treatments. Patient data donations will increase if individuals have all of their structured genetic information in a single location. Sync for Science is a data-sharing platform developed as a resource for the All of Us national genomics study, and it's just one example of a new program that allows individuals to give clinical data from their EHR. Healthcare providers may educate patients on these opportunities.

Care managers, including payers and other third parties

For insurers to make educated decisions about how much to pay for their insured's medical services, they must first have a firm grasp of the benefits and limitations of genetic testing methodologies, interpretations, outcomes, and patient care. Determinations of the financial value of testing and treatment coverage by the health plan and other benefit or quality managers are improved by an evaluation of the validity and utility of clinical genetic and genomic testing.

Healthcare Providers and Clinical Decision Support

When all healthcare providers with access to the EHR view the same interpreted data and the same recommendations, genetic-based clinical decision support (CDS) becomes a key component in care coordination. CDS ensures that clinical actions by one provider will generate notifications to other providers. When test results are available, CDS will combine that new data with clinical and FHH information to bring evidence-based clinical guidance targeted to the medical focus of each provider.

For example, if a patient presents with abdominal pain and blood in the stool, and a family history indicates they may be at risk for hereditary colorectal cancer, pre-authorization could be completed in advance by CDS, which then triggers a genetic test panel order screening several genetic cancer variants. A comprehensive risk analysis of colorectal cancer will determine the best team of caregivers.

However, the multi-gene panel has generated a database of information on other genes that can be referenced in the future. Therefore, the cognitive load of remembering which genes have been evaluated in the past and are relevant to future clinical scenarios for that patient should be assisted by CDS. Incorporating genetic information into a practical, streamlined CDS-informed process has the potential to speed up diagnosis, shorten the time it takes to plan both therapeutic and non-therapeutic care, and better inform and engage all members responsible and accountable for ensuring that the patient-centered care plan is followed.

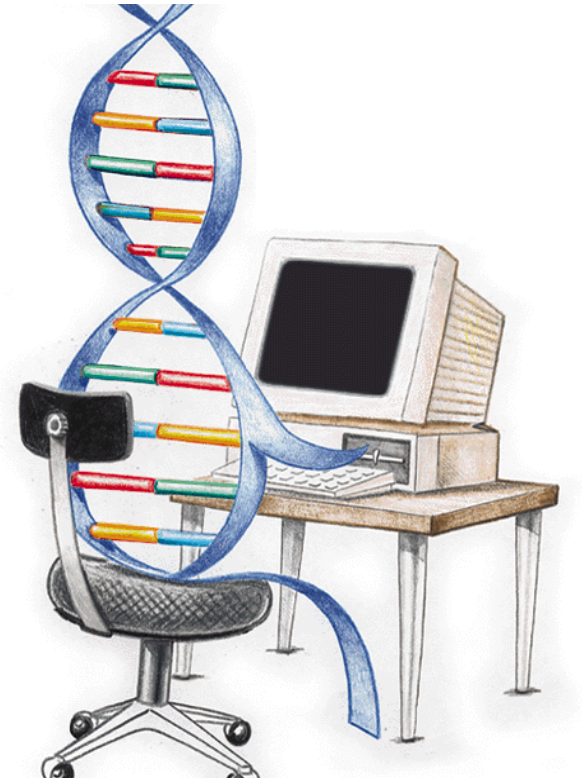
What this is leading to is CDS functionality that spans across care providers, alerting each care team member to what the other is doing, and informing their own part of the care continuum. Of course, artificial intelligence will drive this new clinical ability, which will be the topic of a future blog.

Genetic testing and clinical decision support

Integration of CDS into an EHR helps improve the integration of these diverse data sources and their use in care. Health care providers can benefit from CDS because it equips them with knowledge and information tailored to each individual patient, which is then intelligently filtered or delivered to them at the right time.

CDS tools include automated reminders and alerts, case-specific clinical guidelines, targeted reports and summaries of patient data, and dictionaries and encyclopedias that are appropriate for the situation.

With the use of EHR and CDS tools, care coordination can be improved through the automatic distribution of messages to all relevant parties at the initiation of certain events, such as the ordering of tests, the receipt of test findings, or the need to test other family members.



Direct-to-consumer genetic testing services

We cannot ignore direct-to-consumer (DTC) generated data as a possible source of patient genetic data in their medical record. This is feasible because many DTC companies conduct their testing in CLIA-certified laboratories. (CLIA certification is required so that the lab data can be used in clinical care settings.) Most DTC services have excellent reports written by experienced MDs. We should look at it as an educational and preventive health opportunity. A small percentage of the population, but a large number of people, may find clinically significant results. When available to the doctor, this test report may begin early screening that otherwise would go undetected until after the disease has progressed, and when there are limited treatment options. (There will be more on direct-to-consumer testing services in a future blog post.) Also, keep in mind that ancestry testing actually collects more genetic information than is necessary for only ancestral analysis.

Genetic-Based Care Coordination From the Patient Perspective

Care coordination is important for patients in general because it makes sure they get seamless, high-quality care. From a patient's point of view, care coordination is the deliberate organization of a patient's care activities between two or more providers, with the goal of getting better care. With genetic-based care coordination, patients believe they will experience the promise of precision medicine, with better health outcomes and a higher level of satisfaction with their overall sense of well-being.

If implemented correctly, care coordination should help to reduce the risk of medical errors, duplicative tests and treatments, and adverse drug interactions. Too often, patients with complicated medical conditions or who are seeing more than one doctor have gaps in their care. The coordinated efforts of the healthcare team should reduce the burden on patients, who are often overwhelmed by the demands of managing their care and what the costs might be.

Proving the value of genetic services

Consumers of medical care in the coming value-based era will give serious thought to the tradeoffs between the price of health services and the benefits they provide. Cost-benefit analysis is especially important when it comes to genetic services, where testing and interpretation could be expensive, but results can provide knowledge that helps the patient and their loved ones for their lifetime. Some of the possible benefits of genetic testing for patients include helping with the diagnosis or identification of disease risk so that preventive care can be given, and providing information that will help choose drug therapies that are more likely to be effective and less likely to cause side effects. This benefit is fully realized when healthcare providers understand the lifestyle needs and socio-economic realities of patients so that they can make informed treatment choices.

Optimal healthcare experiences depend on a lot of things, and each patient's needs and circumstances are different. For both short-term and long-term care, it is important to collect and store longitudinal data from every care episode by every care provider. Patients who have more information about their health and how to change their lifestyles tend to have more positive experiences overall. It helps that patients have access to their complete medical, genetic, and family health history information no matter where they are receiving services.

From the Family Perspective

Genetic-based healthcare has the potential to greatly benefit families by providing them with a deeper understanding of their health risks and inheritance patterns. Genomic data has applications beyond the individual patient. When one member of a family carries a genetic variant, it's possible that other members of that family also possess that variant. When a patient's family is identified as carrying a genetic mutation that significantly raises the risk for breast cancer, for instance, invitations for early screening can be extended to all relatives who have yet to seek a clinical assessment.

Consequently, learning the hereditary cause of a patient's illness might help prevent more cases in that family. If a family has a history of a particular genetic disease, genetic testing can identify carriers of the disease and help them take steps to reduce the risk of transmitting it to future generations. After one family member is found to have a clinically important heritable variant, family care coordination should make it possible for other family members to get cascade testing. All new test results should then loop back into the information about the family.

From the Perspective of the Patient Lifespan

With patient-centered care, the hope is that patients actively participate in their own medical treatment throughout their lives. In the interdisciplinary field of genetic medicine, coordination of care is also crucial for patients throughout their lifespan.

Beyond having direct effects on the patients, their families, and the service providers directly involved in their care, heritable conditions have far-reaching implications also for employers, public and private payers, public health decision-makers, policymakers, educational institutions, and others.

For individuals with genetic diseases to get the care they need throughout their lives, care coordination services must be improved and made more permanent. The physical, psychological, and social demands of individuals living with conditions that have a genetic foundation vary greatly over one's lifetime. Patients diagnosed with or at risk for genetic diseases frequently have worries regarding the costs and insurance coverage of genetic services. They also have concerns about reproductive risks, quality of life and life years, and the effect on earning potential.

The following chapter contains a quick look at genomic events that happen at different times in a person's life, and the possible care coordination and support service needs that may be experienced as a result.

Prenatal and newborn

Genetic-based healthcare provides families with the opportunity to make informed reproductive decisions. For example, carrier testing can identify individuals who carry a genetic mutation that could be passed on to their children. This information can help couples make choices about having children and allow them to seek medical advice and support if needed. Genetic testing can also help diagnose genetic conditions in newborns and provide families with the necessary information to plan for their child's future care. All of these issues point to the importance of medical geneticists working with obstetrics and pediatrics in genetic-based care coordination for both mothers and their children.

Risk factors like the mother's age, race, illnesses in siblings and other family members, and problems or loss of a previous pregnancy are used to decide which tests should be done during pregnancy to look for genetic conditions. Parents who find out through testing that their unborn child has a genetic disorder should be able to get help and counseling as they review options about the future of their pregnancy and the care of their child. A pre-implantation genetic diagnosis is an option for couples who are carriers of genetic diseases. It involves testing embryos made through in vitro fertilization for the condition(s) of interest before they are implanted.

In the United States, babies are screened for dozens of genetic disorders using metabolic testing within the first few days of life. These are often uncommon diseases and disorders, although they can be treated effectively if caught early in the child's development. When a genetic issue is suspected and confirmed in a newborn, it is important to coordinate care so that the infant receives treatment and the family has access to resources as the child moves through critical developmental stages. In special cases, taking care of a new baby means coordinating social services, helping the family make changes at home, setting up specialized transportation, or getting long-lasting medical equipment.

Childhood and adolescence

The symptoms of some genetic disorders, such as those that affect intelligence and social skills, may first appear during childhood. Rare genetic abnormalities and childhood malignancies, both of which are more difficult to diagnose, are encountered at this point as well. When children are diagnosed with genetic disorders at a young age, it frequently triggers for the family a period of intense and emotionally painful involvement with the health care system. Depending on the patient's location, genetic testing of family members, and consultations with numerous specialists, this may necessitate long-distance travel, disrupt work and family routines, and incur substantial costs.

Adolescents typically require genetic services for the early detection of disorders such as hypertrophic cardiomyopathy and long-QT syndrome. Other well-known disorders are diabetes, asthma, childhood cancers, cystic fibrosis, and muscular dystrophy, as well as several syndromes like Down, Turner, Marfan, and Fragile X. Many parts of the world have to focus on sickle cell anemia and hemophilia. Adolescents may need to undergo screening for hereditary cancer syndromes if they run in the family, and those who are older may be interested in genetic testing for adult-onset illnesses like Huntington's and other neurological disorders.

Teenagers with genetic diseases may find it hard to switch from child health care to adult care, so they may benefit from transitional support services. Even if they are mature enough to live independently, they may require help making the adjustment from living at home with their parents.

Young adult to elderly years

Typically, when dealing with young adults, genetic services center on helping them plan a family. Those who are at risk are often screened for carrier status. Once again, testing for the genomic basis of cancer and other illnesses that don't show symptoms until adulthood may also be done at this time. The testing also identifies subsequent treatment strategies. Pharmacogenomic testing may be one of them, helping choose the best drug and dose for a person, which could reduce the chance of side effects.

Although genetic testing is not yet routinely used to identify complicated illnesses like cardiovascular disease and mental health disorders, risk can be discovered through the study of family history. Adult patients often benefit from genetic counseling to better grasp the implications of their test results in terms of risk, potential health difficulties, reviewing options, and what information to share with family members.

As people enter their later years, they are more likely to start making use of healthcare services. Many people in this age range have neurodegenerative diseases like Parkinson's, Alzheimer's, and other dementias, heart problems like stroke and heart attack, and cancers that show up later in life. However, many people in this age group take many drugs, putting them at increased risk for drug interactions and adverse effects, and a patient's genomic profile for these and other disorders is not routinely available in this population. Elderly patients' families and caregivers frequently need assistance in order to meet the person's needs, especially if a long life is in the genes.

The Survey

Genetics care coordination survey – asking for your input

To gather further insights into some of the genetics-based care coordination issues you are aware of, we have developed a quick two-minute survey. The questions will investigate various areas where clinical coordination may or may not be operating well.

A survey report reviewing the responses will be posted after a significant number of responses are received. This will generate further ideas for your feedback and our discussion. It will also provide data for future posts on building a genomics program, an ecosystem, and other post topics.

No sign-in is required, and no emails will be collected.

2-minute survey

Conclusion

Genetic-based care coordination has the potential to revolutionize the way we approach health care for individuals with genetic disorders. By using genetic information as part of the care plan, doctors can better handle the complicated medical needs of these patients and improve their outcomes. With the increasing availability of genetic testing and the growing understanding of the genomic basis of disease, genetic-based care coordination will likely become an important part of the healthcare landscape in the coming years. However, the integration of genomics into healthcare requires coordination between various healthcare providers and is supported by the use of technology. While there are challenges to overcome, the benefits of using genomics in patient care are clear and will likely lead to improved patient outcomes.

For genetic-based care coordination to reach its full potential, genetic information needs to be better integrated into electronic health records, standard protocols for sharing genetic information need to be made, and healthcare providers need to be trained in how to understand and use genetic information in patient care. Nevertheless, by working together, healthcare providers, including physicians, nurses, counselors, therapists, labs and pharmacy, patients, researchers and case managers, can overcome these challenges and pave the way for a future where genetic information is routinely used to optimize the care of individuals and families.