

Genomic Consultation Research Working Group
February 16, 2023
Virtual
Meeting Summary

Welcome and Introductions

The goal of the working group was to examine approaches to implement recommendations of [GMXIV meeting](#) regarding genomic medicine consultation. Specifically, to 1) create a consult service or expert panel to help educate clinicians about genetic test orders, interpretation, and determining next steps, 2) develop a “learning community of practice” listserv to provide information and updates, potentially supplemented with a panel of experts, and 3) promote equity of implementation in low-resourced and underserved settings. Working group members were primarily those whose institutions are developing or have already developed provider-to-provider genomic consultation services.

Infrastructure

Working group members were asked to consider several elements that would need to be considered when developing the infrastructure of a provider-to-provider genomic consultation service.

Types of expertise needed

- Providers
 - Genetics
 - Primary care
 - Specialties such as oncology and OB/GYN
 - Pharmacists
- Staff
 - Triage staff within each specialty, such as schedulers or genetic counseling assistants
 - People who can provide insurance advice, such as genetic counselors
- Researchers
 - Implementation science
 - Qualitative research – user experience
 - Evaluators
 - Informatics
 - ELSI issues, health disparities; and social determinants of health
 - Return of results – both clinical and research results
 - Behavioral economist – someone who understand incentives and how to encourage behaviors
 - Pharmacogenetics
- Other
 - Payors – help streamline testing and ordering
 - Legal experts who can advise on liabilities that result from consults
 - Marketing

Target audiences

The target audiences of consultation services include primary care, family medicine, and specialty providers such as maternal fetal medicine and oncology. These audiences are not limited to physicians, but also include advanced practice providers (APPs) such as NPs and PAs.

User feedback

Qualitative data could be used to explore the user experience, the need for timeliness in returning consultations, and assessing if the patient/provider's questions were answered.

Equitable access

Because this is a provider-to-provider consultation service, equitable access needs to be considered on a provider level rather than a patient level. Thus, modalities like phone, virtual meetings, and online chats are ways all can engage. However, because some health systems have fewer resources, the consult service would need to be reasonably priced.

Consultation services are easier to provide when the consultant has access to the patient's medical record, either through a shared or accessible electronic medical record. Those unable to share medical records would be at a disadvantage.

A consultation service would need to provide practical information about how to access care. For example, if the patient is uninsured, how can testing be obtained? Which lab should be used for this concern for this patient with this history and this insurance coverage? Genetic counselors are resourceful and tend to know these types of practical information or how to figure it out.

A national service may not be able to adequately provide practical information as there are variations in the availability of resources for follow-up. There are also differing regulations and laws, such as licensure laws on who can provide genetic counseling. Even health insurance companies will have regional variations in coverage. Partnerships need to be built with state health organizations such as public health officers. It is also important to engage the regional genetic networks, HRSA, and the CDC.

When developing research on consultation services, it would be important to include sites like Federally Qualified Health Centers (FQHCs) so that researchers can make sure that they are focusing on development and evaluation in a variety of locations and settings.

Licensing and liability

There are state variations in licensure laws, particularly for genetic counselors. Some groups, such as genetic telehealth companies, have solved these issues by hiring staff with licenses that cover the country. A consultation service could similarly find licensed professionals to provide national coverage.

It was noted that a provider-to-provider consultation service would not be practicing medicine. Instead, it is providing "curbside consultations," which should alleviate some of the liability concerns. However, it is unknown if reimbursement for the consultations would come with higher levels of liability.

Sustainability

To create a sustainable consultation service, it is important to get data. Data needs to include the downstream burden on other providers. For example, it was noted that surgeons get higher reimbursement when they are in the operating room or seeing new patients. If less expensive providers can return results to patients rather than having surgeons do that, a program may pay for itself.

It is important to get qualitative data on the experience for the patients and the referring providers.

It is important to figure out how consultation services can bill. Historically, they have been uncompensated. However, they need to capture workload and seek reimbursement for their service. Genetic counselors especially need to be able to bill. However, reimbursement might lower equity.

For a consultation service to be sustainable, it needs to be easy. One often loses the providers who complete the consults because it is too hard. For example, the consult may not come with appropriate medical or family history. Given that reimbursement for consultations is approximately \$15, it may be difficult for some providers to justify spending much of time on consultations.

Feasibility of building a provider-to-provider consultation service

It may not be possible to create a provider-to-provider consultation service without patient involvement. For many providers, they are looking for someone who can tell them what to do and to counsel their patient. It may be impossible to create a consultation service without needing to reach out to some of these providers' patients directly. An alternative model that was suggested would be to have genetic counselor navigators who can go to clinics or have a region that they rotate through. They would know the local resources and barriers to care.

Some models that could be emulated are the newborn screening networks, poison control, and maternal teratogen advice lines. It may even be possible to utilize these already existing networks and add a genomics consultation service. Newborn screening, for example, has both national and state level infrastructure. Nationally, there is an advisory committee, then each state makes its own decisions. It may be possible to partner with the CDC to set up a national advisory board for genomic consultations.

Curating Advice for Recurring Questions

In this session, working group members discussed the possibility of creating a system where advice and information could be curated and disseminated. Some curation models that were suggested were ClinGen, NCCN guidelines, CPIC, and UpToDate.

Nurse triage lines might be a good model to examine. They are common and protocolized. A genetic counselor or a genetic counseling assistant could use phone scripts. They could handle easy, routine advice, then triage more specialized cases to other providers. Another possibility is to use an artificial intelligence chat, where information could be made available in a personalized way.

Curated information sources may not be helpful if a provider is not asking the correct questions. There may be ways to make information more tangible, such as adding case studies to the information. In addition to providing answers to frequent questions, decision trees may be helpful.

Limitations of curated advice

It is very difficult to keep information up-to-date; a rigorous, routine method of reviewing materials is needed. Developing another resource may not be a good use of time. It is already hard for people to know and keep up with all the resources that are currently available. Instead of creating a new resource, researchers could utilize existing frameworks, like UpToDate.

Another limitation of curated information is that it is difficult to use when looking for patient-specific information. It is difficult for providers to know if the general recommendations are appropriate for their patient. One option to address this concern was to have decision trees that might have several paths that lead to different answers. However, it is important to define the scope of the service. For example, providers shouldn't expect to obtain information on the specific VUS that their patient has; however, they can expect to obtain advice on what to do when they get a VUS.

Curated advice may not contain practical information, such as which lab to order from or need for pre-authorization from a specific insurance company. It also doesn't give advice on who should do the next steps, nor does it contain health system specific information. For example, if the advice is mammograms every 6 months, should primary care order those or do they get ordered in a breast clinic? There are already avenues to get some of this practical advice. For example, there is a phone number one can call to get an estimate of how much the out-of-pocket cost will be. It may be part of the Affordable Care Act. These types of resources could be connected to a consultation service.

A curated advice system isn't very good if no one uses it. It is necessary to get buy-in from the community. This means that a consultation service would need to be publicized and show benefit. A PR firm could be helpful.

Evaluating Impact

The impact of a consultation service should be assessed; ways to measure this are needed. This was considered in relation to the various participants in the service.

Experts providing consults

Providers who are answering consults want to know that their efforts have good results, such as cost reduction, patient satisfaction, and positive patient outcomes. They are also interested in job satisfaction. They want to receive consults with a variety of questions and have the routine questions automated. They want to practice at the top of their scope of practice. They want to be credited for the effort they put into consultations. Especially if the consultation isn't being billed or reimbursed, it needs to be factored into their job responsibilities, rather than coming out of "free time."

Measures of provider success should be under the provider's control. For example, it is frustrating when a provider is negatively rated on timeliness when delays are dependent on patients' initiative, such as making appointments. Everyone needs to agree on what success looks like, and accurately measure it.

Clinicians asking for the consultations

Researchers can measure clinicians' knowledge levels, comfort, and confidence with the care they are providing. Researchers can also measure clinician satisfaction, whether the consultations save time, and repeat use of the consultation service.

Patients

Researchers can measure total healthcare utilization and costs to see if the consultation service creates efficiencies. Alternatively, it is possible that the consultation service could result in additional testing, evaluation, and specialist visits. It would be important to measure how consultation services affect health and patient satisfaction.

Patients want to know what steps they need to take for themselves and for their families. Researchers can assess how the consultation service impacts communications with family members. They can also do a social network analysis to find out if there is an impact to family members or to others in the community.

A concern is that consultations may happen just once and not be repeated throughout a patient's care. Patients often fall through the cracks because they aren't managed over a longer period of time. Some patients need to be managed in a "genomic medical home." Would a consultation service prevent finding an appropriate genomic medical home?

Other outcomes and research questions

The working group members had several additional questions:

- Would a consult service have an impact on the spread of misinformation?
- In the case of patients with results with pleiotropic implications and those who need to be followed by multiple specialists, do consultation services impact connecting with these multiple providers?
- Can questions about polygenetic risk scores be handled in consultation services?
- How does one handle lots of information when they just wanted a little (unexpected results)?
- Is there an impact on health equity?
- How can consultation services fit into a larger, phased approach to fully integrating genomics into primary care and other non-genomic spaces?
- How can we make this sustainable? Sustainability needs to be a research question from day one.