NHGRI Genomic Medicine Working Group
Discussion on GM XIV: Genomic Learning Healthcare Systems

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GM XIV Recommendations and Next Steps

One possible next step is to create a coalition of genomic learning healthcare systems (gLHS). The NHGRI could fund a coordinating center (CC) that would bring together gLHS to share their best practices as well as challenges. There are several potential difficulties. The gLHS landscape is heterogeneous, and there may also be experimentation (exacerbating the heterogeneity) as this is a new field. In that case, there may be fewer commonalities than expected. Relevance to diverse populations on both a population and a health system level will be difficult given the lack of diversity among current gLHS. Finally, liability is local, so implementation is local—solving issues of liability will likely be a challenge.

However, there are also several opportunities. The coalition could use systematic assessment and design thinking and come forward with a methodology that would assess the gLHS to inform the development of an implementation guide. Clinical informatic aspects, including CDS, could also be shared among gLHS. Implementing small pilot projects with clear, measurable outcomes which have to do with extracting best practices and/or shared goals might work best.

The current healthcare environment may not be conducive to this project as health organizations are already struggling and may view this as a low priority. However, there are enough organizations that are working on gLHS to determine potential research questions and begin to address them in preparation for implementation. If NHGRI can determine what the best practices are in a systematic way, the gLHS landscape might be quite different five years from now and NHGRI should be ready.

Another possible next step that could be pursued is the creation of an e-Consult service/forum. A few systems have implemented an e-consultation approach. One method is to have a webinar or an email group that meets regularly. Additionally, tumor boards might be an example to draw from. Having a resource that patients could access, especially in regard to services such as Invitae, would be helpful. The question of liability needs to be further explored. There are many potential problems, and many issues differ depending on the state. While experts could be drawn from ClinGen, giving reimbursement raises further issues with liability and conflict of interest.

After discussion, it was noted that instead of focusing on either gLHS or e-Consult services, it might be worth looking at Implementation models were also noted to be an important focus, both in relation to gLHS and e-Consult services and outside of them. Bringing together both facilitators of existing gLHS and implementation scientists could be worthwhile. Implementation research could be built on an LHS, although it doesn't have to be, including in some pilot projects. Pursuing the e-Consult project through an implementation science lens and learning how to do it better may make it more easily distributable. Using the gLHS system to implement an eConsult service is another possibility.