Archived Policy Statement

HIT Policy Committee: Meaningful Use Workgroup

Public Comments by Genetic Alliance
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July 29, 2010

Genetic Alliance is the world's leading nonprofit health advocacy organization committed to transforming health through genetics. Our open network of over 10,000 organizations connects members of parent and family groups, community organizations, disease advocacy organizations, professional societies, educational institutions, corporations, and government agencies, including state public health departments and federal institutions, to create novel partnerships. We actively engage in improving access to information for individuals, families, and communities, while supporting the translation of research into services.

Genetic Alliance is pleased by the commitment of the Meaningful Use Workgroup to fully understand the impact of meaningful use in the context of population health. We believe that the combined work of the HIT Standards Committee and HIT Policy Committee have laid out an achievable and appropriate framework in moving forward.

Genetic Alliance suggests that the Committee include newborn screening (NBS) as an area of focus for meaningful use for 2013. I am glad that it came up already today.

The NBS system is a federally supported, state mandated public health initiative that includes screening, diagnosis and follow up care for those detected to have an early onset condition (including hearing deficiencies, metabolic disorders and other genetic/inherited conditions). This system experiences considerable disparities in standards of collection, storage, and transmission of information by each state. Annually, over 4 million babies are screened by state newborn screening labs and despite the large portion of the population that is served, standards have yet to be harmonized between these state systems. To remedy this, Genetic Alliance suggests that the Office of the National Coordinator consider incorporating NBS as a focus area. Experts such as the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children's HIT working group (administered by the Health Resources and Services Administration) is currently planning for the integration of the new regulations into these public health programs. The creation of the Newborn Screening Coding and Terminology Guide, developed by the National Library of Medicine (NLM), as the vocabulary standard for the inclusion of newborn screening data into electronic health records is another initiative that positions this public health program to be the next testing ground for meaningful use measures and their compatibility with the mission and capacity of public health agencies. This NLM vocabulary guide will allow for the inclusion of NBS results into EHRs and for the standardized reporting to state departments of health. By including NBS specific language in meaningful use for 2013, electronic health record systems will be able to meaningfully capture

and collect data about normal and out of range newborn screenings in a way that will facilitate the information being used for clinical decision support and secondary research purposes in future stages. A child's EHR could and should begin with one of the first pieces of clinical information – the newborn screening results.
Information entered as free text poses a risk that those fields maybe left out of a record if the transmitting or receiving electronic medical record system does not have a reciprocal field. Furthermore, information kept as free text will not be as easily indexed by electronic medical systems and for this reason it will be less likely that the whole records will be meaningfully used by provider and payer systems. The NBS system, since it exists in all 50 states and territories, should be an excellent model system for electronic health information exchange in the service arena. This is a unique opportunity for both public and personal health – the first health information exchange in a mandated services system that needs integration across several entities.

Genetic Alliance acknowledges the task that is ahead of the HITPC and pledges its support for the committee and its processes. We commend this opportunity for public comment and look forward working with leaders of both the committee and working group to make sure this important topic is included in future discussions about meaningful use and its long-term benefit to the general population.

[1] National Newborn Screening Information System (NNSIS) http://www2.uthscsa.edu/nnsis/
[2] Newborn Screening Coding and Terminology Guide. National Library of Medicine.http://newbornscreeningcodes.nlm.nih.gov/