Pediatric Terminology Conference

The importance of research into prevention and cure of childhood diseases cannot be understated. Anything that can be done to speed that process should be a priority. One way to make this process more effective and efficient is to standardize where possible. Standardization of pediatric terminology was the focus of “Bridging the Terminology Gap in Pediatrics: Developing an Action Plan to Support the Continuum from Clinic to Research” – a conference held on Friday, 21 September 2012 at the Natcher Conference Center on the NIH main campus in Bethesda, MD.

The goal of the meeting was to bring together a broad constituency of pediatric researchers to organize a governance structure and organizational model to work collectively within and across domains to address issues of terminology harmonization with the objective of linking clinical care and research terminologies to support data sharing and integration. The meeting initially focused on pediatric terminology efforts and real-world experiences, including use cases, successes, and challenges. The meeting then focused on developing a pediatric research terminology framework that aligns with clinical care terminologies.

CDISC representative, Frank Newby, Executive VP, Development, provided details on best practices to develop controlled terminology standards including establishing a well-defined process, controlling scope to develop an agreed list of data elements, engaging sufficient subject matter experts and other volunteers including NCI EVS personnel (see complementary article on NCI EVS in the eNews), employing a project manager, creating robust definitions for each data element then bundling the resulting output into documentation for public review. Once all public comments have been taken into consideration the package of terminology passed onto our partner at the National Cancer Institute and is loaded into their Enterprise Vocabulary Services (EVS) application. The package of terminology is then made freely available for public use.

The final component of the meeting was to determine a set of next steps and short-term goals to begin organizing a governance structure and prioritization mechanism so that the work of developing a robust set of pediatric terminology could continue. There was great energy around this work given the promise it holds to aid in the development of new medicines and devices which will improve the health of children!