

PRISM: A SHARED RESOURCE FOR GLOBAL DATA STANDARDS IN PATIENT REGISTRIES

Patient registries are an important first step in understanding the causes of rare diseases, for estimating their impact, and for developing new therapies. The value and utility of patient registries is largely contingent upon the use of high-quality questions and structured answer sets. The interoperability of registries or registry data – including the aggregation of patient data from registries in multiple countries – depends upon the use of data standards; yet, there is currently no clear specification for developing registry questions, nor are there banks of existing questions to support registry developers. This poster provides an update on the PRISM (Patient Registry Item Specifications and Metadata for Rare Disease) project, a library of standardized questions across a broad spectrum of rare diseases. PRISM can be used to support the development of new registries in all disease areas. If widely used, PRISM will enable the re-use of questions across registries, hence reducing the variation in registry data collection and facilitating a bottom-up standardization of patient registries. To date the PRISM library has over 2,200 questions relevant to many rare diseases. Additionally, the library includes existing standardized questions and is prepared to receive more content from experienced rare disease patient registries. In this way, PRISM can be a resource to the rare disease community and can be used to support discussion and projects aimed at global data standards in rare diseases. This poster also explores how the PRISM data model can support the translation of questions to support the development of multi-national rare disease registries and data sharing efforts.

- TITLES IN CAPITAL LETTERS, **Authors in bolds, Last name and Initials**, Institutions and e-mail in Arial normal size 11 letters. Provide text without free spaces, use international abbreviations or clarify them in the text and respect the space available in the form. The summary must clarify the objectives of the work, the used methods, the results and conclusions.
- The **deadline** for abstracts submission is **December 15th 2011**.