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Discussion

Creating a global rare disease patient registry linked to a rare diseases biorepository database: Rare Disease-HUB (RD-HUB)

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### Abstract

A movement to create a global patient registry for as many as 7,000 rare diseases was launched at a workshop, "Advancing Rare Disease Research: The Intersection of Patient Registries, Biospecimen Repositories, and Clinical Data."

[http://rarediseases.info.nih.gov/PATIENT\\_REGISTRIES\\_WORKSHOP/](http://rarediseases.info.nih.gov/PATIENT_REGISTRIES_WORKSHOP/). The workshop was sponsored by the Office of Rare Diseases Research (ORDR). The focus was the building of an infrastructure for an internet-based global registry linking to biorepositories. Such a registry would serve the patients, investigators, and drug companies. To aid researchers the participants suggested the creation of a centralized database of biorepositories for rare biospecimens (RD-HUB) <http://biospecimens.ordr.info.nih.gov/> that could be linked to the registry. Over

two days of presentations and breakout sessions, several hundred attendees discussed government rules and regulations concerning privacy and patients' rights and the nature and scope of data to be entered into a central registry as well as concerns about how to validate patient and clinician-entered data to ensure data accuracy. Mechanisms for aggregating data from existing registries were also discussed. The attendees identified registry best practices, model coding systems, international systems for recruiting patients into clinical trials and novel ways of using the internet directly to invite participation in research. They also speculated about who would bear ultimate responsibility for the informatics in the registry and who would have access to the information. Hurdles associated with biospecimen collection and how to overcome them were detailed. The development of the recommendations was, in itself, an indication of the commitment of the rare disease community as never before.



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## Keywords

Rare diseases; Patient registry; Disease registry; Rare disease; Patient advocacy; Biospecimen; Biospecimen repositories; Clinical data; Electronic health record

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