

Clinical Registries to Advance Focused Ultrasound

The Focused Ultrasound Foundation recognizes the importance of clinical data registries in modern therapeutic care. Clinical data registries provide many meaningful benefits that impact the lives of patients including:

- evaluating longitudinal outcomes
- defining and evaluating best practices
- developing treatment guidelines
- further supporting research and therapeutic development

Clinical data registries will increasingly become a critical part of the regulatory process, replacing, supplementing, or complementing traditional sources of evidence like randomized clinical trials. In some cases, they may also speed the path to reimbursement, by supporting insurers' health economics and outcomes thresholds. This support may include valuable evidence on both treatment durability and quality of life factors.

With this understanding, the Foundation supports and encourages the creation, use, and analysis of focused ultrasound clinical data registries. The Foundation's role in such activities includes convening stakeholders to define data requirements and standards; creating an ecosystem inventory / landscape analysis; and, connecting parties by business interest (e.g., manufacturers and research sites with registry vendors; and vendors with cloud computing providers, as appropriate).

All clinical data registry ecosystem members are encouraged to participate, including equipment manufacturers; clinical research sites and investigators; commercial treatment sites and clinicians; registry vendors; related software vendors such as electronic medical record and data analytics providers; and cloud computing vendors.

The Foundation welcomes inquiries and perspectives on this important topic, via email to registries@fusfoundation.org. With our partners, we aim to help find the best path forward for patients who entrust their data into this ecosystem, and we look forward to continuing to advance the capture and analysis of clinical data to highlight best practices across the global focused ultrasound community.