Trans-NIH CVI Workshop—Nov 17, 2023
Roadmap to Consensus and Building Awareness

Focus Group Discussions – 30 minutes for Discussion, 5 minutes each to report to plenary group

Topic	**Discussion leader**
Accommodations and Education	Christine Roman-Lantzy, PhD
Special Populations: Teenagers/Adults with CVI	Sharon Lehman, MD
Special Populations: CVI with multiple disabilities	Barry Kran, OD
Global Perspective on CVI	Linda Lawrence, MD
Caregiver Perspective – Securing services and diagnoses	Rachel Bennett, MEd
Building Awareness and Advocacy	Kristie Bjornson, PhD, PT

Focus Group Questions:

1) What are the problems/questions in this topic area that research or a registry can address? For example: delays in diagnosis; uncertainty regarding optimal interventions; lack of awareness? What are the key research questions to address these problems?

2) How will a CVI registry be useful for addressing research in this area? What specific elements would need to be incorporated to make the registry more useful for this topic? For example, quantifiable outcome metrics for functional vision and visual function.

3) How can this population/provider/perspective contribute to the CVI registry? Are there data or inputs unique to this population? What are the key clinical and demographic factors that would facilitate CVI research? How can we ensure the registry is appropriately diverse and captures social determinants of health?

4) A registry requires standardized data inputs. Identify differences in practices, metrics, and definitions applicable to this focus group topic. How might these differences interfere with large scale data collection or research use? How should registry data be validated and updated?

5) What are the gaps in building CVI awareness relevant to this topic/group? What are potential strategies to increase awareness? Who are the key partners/community members to involve?