2022 ASPECT Patient Engagement Summit Roundtable Discussion

Prevent Blindness
ASPECT Patient
Engagement Program

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Purpose

An estimated 7 million Americans currently live with blindness or significant visual impairment.[1] In addition to the impact of the population aging, the rising prevalence of visual impairment is partly driven by the ubiquity of barriers to care, such as high cost of treatment, lack of insurance coverage,[2] poor health literacy,[3] limited transportation, poor accessibility of services,[4] short duration of clinic visits,[5] and lack of self-advocacy.[6] In May 2022, Prevent Blindness hosted a roundtable discussion aimed at increasing discourse and awareness around barriers and facilitators of eye care access and eye care engagement for individuals with vision disorders or impairment.

Methods

On Wednesday May 11, 2022, Prevent Blindness hosted the roundtable discussion at the inaugural ASPECT Patient Engagement summit in Washington DC, which was entitled "**Addressing the Gaps in Health Care Delivery and Patient-Provider Communication for Those with Vision Loss.**" Participants from the first three ASPECT cohorts (Fall 2020, Summer 2021, and Fall 2021) were divided into three groups (12-14 per group), with each group responding to one of three prompts:

1. What barriers get in the way of you being able to fully access eye care?

2. What resources can help you to better engage in eye care?

3. What types of relationships/support can help you better engage in eye care?

Roundtable participants

Participants (N = 40) included a diverse sample of patients, caregivers, eye care providers, psychologists, social workers, peer counselors, researchers, eye health educators, medical students, and public health professionals. A range of eye conditions were represented, including retinitis pigmentosa, Stargardt disease, macular degeneration, myopic macular degeneration, glaucoma, diabetic retinopathy, thyroid eye disease, lattice degeneration, albinism, and myopia. Over 16 states were represented. Approximately half (48%) of participants were from minority racial or ethnic groups which are often under-represented in research and policy making.

Barriers

Identified barriers to eye care access included limited transportation, fragmentation of services, inadequate clinic signage and lighting, limited low-vision accessibility options, inadequate patient-provider communication, insufficient disease-specific education, limited mental health support, high cost of treatment, and lack of workplace accommodations.

Resources

Key resources for improving eye care access and engagement included accessible clinic forms, staff training for cultural and disability sensitivity, a mechanism for including individuals with vision impairment on design committees for clinic and office spaces, avenues for improved communication between clinic offices, and inclusion of patient navigators who provide education and mental health support.

Relationships

Roundtable participants identified relationships with eye care providers and staff, co-workers and employers, mental health professionals, patient support groups, family, friends, and self as being most helpful for improving access to and engagement in eye care.

Recommendations

1. Relaxed time restrictions for handicap services, standardized pricing for medical transportation, improved disability training for transportation staff.

2. Brighter lighting, larger signage, screen readers, office design accommodating use of canes, inclusion of individuals with visual impairment on design committees.

3. Greater availability of mental health professionals and patient support groups, disability and cultural sensitivity training for clinical staff.

4. Follow-up calls and after-care support, more warmth, empathy, and personability among physicians and clinical staff, staff disability sensitivity training.

5. Clear explanation of clinical tests and results, preferred communication formats, resources for education, clinical trials, and rehabilitation, and home monitoring.

6. Patient navigators, listing sheets for eye care specialists, EHR systems for accommodating patients with disabilities, interoperability across eye care specialists.

"Often there is small print on intake forms with no option to complete the forms ahead of time or online. It can be anxiety producing to complete paper forms quickly"

"It can be easy to become discouraged. It might help to set expectations for outcomes"

"Staff not showing that they care enough about the patient, treating patients as just a part of the job, disability may not always be obvious"

-Roundtable participants on barriers to eye care access

Feedback

ASPECT summit and roundtable participants indicated that the experience elevated the importance of relationships, provided tools for managing visual impairment, and motivated them to be more active in advocacy.

A prominent theme was the value of community as several participants indicated that they were now more likely to connect with others with visual impairment and be inspired by each other's experiences.

Recommendations for future summits included involving more advocates who are politically active, providing more opportunities for networking, and offering more natural host environments that allow participants to benefit from the healing powers of nature.

Call to action

Every advocate that is empowered, dollar that is raised, and interest that is piqued in order to increase awareness about vision and the importance of equitable access can create sizeable and meaningful changes in the lives of patients. This work is invaluable to the improvement of the population's health. There is a pressing need for continued advocacy for investment in patient-centered care and vision research, particularly as the prevalence of vision impairment in the US is projected to increase by 150% by 2050.[7]

References

1) Flaxman, A. D., J. S. Wittenborn, T. Robalik, R. Gulia, R. B. Gerzoff, E. A. Lundeen, J. Saaddine, D. B. Rein. 2021. 'Prevalence of Visual Acuity Loss or Blindness in the US: A Bayesian Meta-analysis', *JAMA Ophthalmol*, 139: 717-23. **2)** Wagner, L. D., and D. B. Rein. 2013. 'Attributes associated with eye care use in the United States: a meta-analysis', *Ophthalmology*, 120: 1497-501. **3)** Dreer, L. E., C. Girkin, S. L. Mansberger. 2012. 'Determinants of medication adherence to topical glaucoma therapy', *J Glaucoma*, 21: 234-40. **4)** Zaback, T., S. Lam, J. Randall, T. Field, and M. V. Brinks. 2020. 'Access to Eye Care Before and After Vision Loss: A Qualitative Study Investigating Eye Care Among Persons Who Have Become Blind', *Qual Rep*, 25: 1473-88. **5)** Buller, A. J., B. Connell, and A. F. Spencer. 2005. 'Compliance: clear communication's critical', *Br J Ophthalmol*, 89: 1370. **6)** de Vries McClintock, H. F., F. K. Barg, S. P. Katz, M. G. Stineman, A. Krueger, P. M. Colletti, T. Boellstorff, and H. R. Bogner. 2016. 'Health care experiences and perceptions among people with and without disabilities', *Disabil Health J*, 9: 74-82. **7)** Varma R, Vajaranant TS, Burkemper B, Wu S, Torres M, Hsu C, Choudhury F, McKean-Cowdin R. Visual Impairment and Blindness in Adults in the United States: Demographic and Geographic Variations From 2015 to 2050. *JAMA Ophthalmol*. 2016 Jul 1;134(7):802-9.