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**Prevent Blindness Response to National Eye Institute's
Request for Information on the Strategic Plan 2021**

We thank the National Eye Institute for seeking information from the patient advocacy community, in addition to others, on your draft [Strategic Plan](#). As an organization whose mission is steeped in improving vision and eye health via a population health approach, Prevent Blindness specifically commends NEI on the following considerations within the Draft Strategic Plan:

1. Inclusion of “Preventing Vision Loss and Enhancing Well-Being” as one of three research domains, with its areas of emphasis including “individual quality of life” and “public health and disparities research.”
2. Establishment of two important new offices – the Office of Vision Health and Population Sciences, and the Office of Data Science and Health Informatics.
3. Shifting the approach of the plan from focus areas on only parts of the eye, to now include the new “Areas of Emphasis” (AOE). The addition of the AOE’s indicates a new, more complex and aware perspective on vision research. It is our hope that this new approach will propagate sharing of best practices and key learnings from each of the AOE’s to the subcategories of areas of the eye.
4. Exploration of the impact of COVID-19 on the vision community, both short- and long-term, including the impact on individual eye health, as well as changes in eye care behaviors such as telehealth.
5. Commitment to understanding the connection between aging, eye diseases, and low vision.
6. Investment in data science, and NEI’s interest in strategically positioning resources to stay ahead of the data curve.
7. Prioritization of representation of diverse populations in NEI clinical research studies, and encouragement of datasets that represent the diversity of populations.
8. Investment in advancing investigations around portable, low-cost instruments that can assist in clinical screenings, potentially allowing for increased access in underserved communities.
9. Commitment to exploring research that encompasses comorbidities and integrated care management, including mental health.
10. Support of additional vision questions/components to national surveys, specifically the NHIS and NHANES.
11. Commitment to community engagement and public outreach, including mention of opportunities for interactions with non-governmental and philanthropic organizations.
12. Promotion of health equity by expanding diversity in the research workforce and environment.

The draft Strategic Plan notes a commitment to community engagement and public outreach, including interactions with non-governmental and philanthropic organizations. Prevent Blindness welcomes continued opportunities to partner with NEI. Potential opportunities include:

- NEI’s efforts to more broadly embrace population sciences referenced in the 2016 National Academies of Sciences, Engineering, and Medicine (NASEM) report – [“Making Eye Health a Population Health Imperative.”](#) This same NASEM report was the impetus for the establishment



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of the [Center for Vision and Population Health at Prevent Blindness \(CVPH\)](#), which was created to advance key recommendations of the NASEM report, and to carry out the critical role of convening national experts on vision health, research, patient perspectives, and public health while collaborating with community, state, and national stakeholders. Prevent Blindness and NEI should together pursue opportunities to align the work of our CVPH with NEI's Office of Vision Health and Population Sciences, as well as its Office of Data Sciences and Health Informatics.

- One way that Prevent Blindness and the CVPH advance our efforts to broaden the dialogue around population health is by convening our annual [Focus on Eye Health National Summit](#). It may be worth discussing formalized opportunities to utilize this established venue to annually report out on the advances of the Office of Vision Health and Population Sciences and the Office of Data Sciences and Health Informatics.
- Our [National Center for Children's Vision and Eye Health at Prevent Blindness \(NCCVEH\)](#) works to integrate population health-based interventions for vision into existing systems of healthcare and education. There may be opportunities for the NCCVEH to collaborate with the NEI Office of Vision Health and Population Sciences to advance the understanding of the role of healthy vision on child development, learning readiness, academic success, and long-term health and quality of life outcomes. The NCCVEH is focused on improving eye health through collaboration, dissemination of evidence-based best practices, improving children's vision and eye health surveillance, and empowering families, communities, and broader systems of care to act on eye health.

Other general comments:

- One of the goals stated by NEI, when publicly announcing the formation of the Office of Vision Health and Population Sciences, was to coordinate existing activities within and across NIH and provide a focal point for new trans-agency programs to launch and remediate disparities in eye health. There's further inclusion in the Strategic Plan of enhancing impact through leveraging partnerships. And yet, while there is mention of other federal partnerships, nowhere in the plan is the CDC's [Vision Health Initiative](#) included. When expanding population health activities, it seems like a missed opportunity to not engage with existing vision health efforts at the CDC.
- On page 17 of the Strategic Plan, there is a reference to wider availability of hand-held OCT's. We feel it is worth investing in research that assesses how the use of such devices in broader health and community settings (in community health centers for instance) may impact diagnosis and monitoring.
- On page 18, there is mention of new diagnostic devices for the early detection of glaucoma that can allow eye care providers to noninvasively measure glaucoma progression and manage care. It is worth exploring this technology's use in non-eye care settings, such as primary health care (including federally funded community health centers and other community locations) may impact diagnosis and care coordination.
- At Prevent Blindness, we appreciate the recognition by the NEI that, while cataracts are easily treatable. Unfortunately, there are still a significant number of people in the U.S. who do not



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have access to surgical correction due to compounding Social Determinants of Health (SDoH.) Perhaps the new Office of Vision Health and Population Sciences can further research the role that SDoH play in accessing care for cataracts as well as other proven treatments and share the lessons learned with collaborating partners to reduce inequities in vision health.

Line-specific comments:

- Line 333: Prevent Blindness encourages the NEI to take a stronger look at the role of environmental influences on eye health across the lifespan, including, but not limited to, formation of myopia, dry eye, cataract, and presbyopia, and not limiting environmental impact research to the aging eye.
- Line 364: NEI recognizes disparities in incidence of glaucoma in certain populations. This recognition leads to another opportunity to collaborate with the CDC's Vision Health Initiative as they manage a glaucoma grant program seeking evidence-based community-level interventions to identify pharmaceutical and population health strategies leading to the reduction of glaucoma in targeted populations.
- Line 444: As the Strategic Plan describes the impact of vision loss and blindness, the narrative should also mention that mental health issues and cognitive decline are often co-morbid conditions associated with vision loss. The NEI should support research that seeks to understand the impact of vision loss to mental health.
- Line 828: Kudos on calling for more research to better understand the causes of myopia. We encourage the NEI to include research to advance treatments that slow or prevent myopia progression, as well as research into the SDoH that drive disparities in myopia impact.
- Line 833: Do not limit cognitive issues to Alzheimer's disease alone. Encourage research that explores the broader interaction between cognitive decline and vision and mental health and vision and the role that external factors such as social isolation and loneliness due to vision loss further contribute to cognitive decline. Approaches to addressing this issue in a more comprehensive way are further defined in line 2055 of the NEI strategic plan: "Measure how vision loss and mental health are related, including how factors such as age of onset, cultural differences, living conditions, and individual coping strategies can be used. Develop tactics to improve engagement with social support networks and how to optimize the use of vision rehabilitation services to improve mental wellness."
- Line 1958-1962: Ensure that efforts taken to develop and evaluate evidence-based practices for rehabilitation of ocular- and brain-based visual impairments are done in collaboration with all professionals critical to the rehabilitation system. Beyond those already listed in the plan, this should include certified low vision therapists, certified orientation and mobility specialists, and certified vision rehabilitation therapists.
- Line 1963: We commend the focus on patient experience in driving improvements in research related to vision rehabilitation; especially the evaluation of "navigator" programs to connect individuals newly diagnosed or in a different phase of vision loss with appropriate resources. This is an area that is sorely missing and largely the reason that only 12% of people with VI/B access rehabilitative services. Additionally, we feel the NEI should consider the SDoH in these



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cases- as access to rehabilitative services is largely dependent upon being able to pay for enhanced insurance coverage or to pay directly out of pocket. This leads to significant inequities in access to rehabilitation for populations of people already faced with health inequities. Additionally, this is an area for NEI to fund population health research to determine the best way to promote patient care coordination beyond the clinical setting to coordinate with community services, and to consider the data that can be collected from these initiatives.

- Line 1983: Regarding identifying the comorbidities (especially in older adults) with vision impairment, this area has been well-explored already. If there are specific goals as to what should be accomplished, this should be clarified here.
- Line 2007: In regards to establishing the efficacy, accessibility, affordability, and acceptability of telehealth; the discontinuation of support for telemedicine by payors will result in modifications to these objectives to some extent.
- Line 2067-2076: This is an important paragraph to outline public health concerns related to vision, though no citations were included to support the statements. Please include citations.
- Line 2096: It is important to include the CDC's Vision Health Initiative and specifically discuss the [Vision and Eye Health Surveillance System](#), especially as that system is harnessing data beyond population health studies and surveys. Including the VEHS would be beneficial in NEI's strategic plan and propagating a collaborative approach.
- Line 2194: The NEI could promote research data sharing by creating a data repository for population-based study data to be shared among vision researchers. One such repository to model after could be the NACDA repository at (<https://www.icpsr.umich.edu/web/pages/NACDA/index.html>)
- Line 2252: We encourage the inclusion of other professions such as nursing, public health, education, primary health care, occupational and rehabilitative therapy, and psychology.
- Line 2282: Prevent Blindness appreciates the efforts that the NEI is taking to promote the inclusion of researchers with visual and other disabilities in the efforts to promote increased diversity among researchers. At present, there is no reliable data collected on the proportion of available research and academic positions that are filled with disabled individuals, though studies have shown the rates of disabled faculty at large universities to be as low as 1.5% of all available positions. Proactive approaches that would support the inclusion of persons with disability might include:
 - Conduct surveillance of the current rates of inclusion of disabled persons in research and academic positions.
 - Implement an environmental scan of policies and practices that promote inclusion of disabled students and staff in research and promote best-practices broadly.
 - Collaborate with individuals from the disabled researcher community to determine the tools needed for them to work to the best of their ability.
 - Provide guidance, recommendations, and technical assistance for NIH-funded researchers in appropriate study design and best practices for recruitment to ensure compliance with laws, regulations, and policies regarding the inclusion of disabled individuals on research teams.



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- Restructure undergraduate and graduate programs to be more accommodating, such as implementing accessible features in their undergraduate STEM courses and labs.
- Establish mentorship programs involving faculty members and visually impaired students to create interest in furthering a career in research.
- Provide access to more national and local funding geared towards researchers with visual impairments, encouraging them to pursue their passion and lead projects.
- Provide training on inclusion of individuals with visual disabilities in a research setting to staff in charge of hiring and employee development.
- Monitor and evaluate inclusion practices for persons with disabilities and progress towards goals.
- Establish partnerships with nongovernmental groups to showcase research led by individuals with disabilities and other underrepresented populations to promote inclusion, best practices, and to foster interest in research in younger members of those populations.

Again, Prevent Blindness appreciates the opportunity to review and comment on NEI's draft Strategic Plan. The expansion of scope, approach, and collaboration expressed in this draft is both encouraging and exciting. We look forward to identifying collaborative opportunities for us to work with NEI to help bring this plan to reality. Please reach out to Prevent Blindness as we can be of further assistance.