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Systematic Review of Community-Engaged Research in Ophthalmology

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Abstract

Introduction—Community-engaged research (CEnR) allows researchers and community organizations to partner together to improve health outcomes and to decrease health disparities. While prevalent in other fields of medicine, it is rarely used in ophthalmology.

Areas covered—A comprehensive search of Ovid MEDLINE, NLM Pubmed, Ovid Embase, Scopus and the Cochrane Library for the Medical Subject Headings (MeSH) “Community-based participatory research” and text word variations including *participatory research, community engagement, community research, partnered research, community-institutional relations, CENR, CBPR* in addition to *variations on ophthalmology, eye diseases, vision disorders and eye injuries* yielded 451 unique references. Two ophthalmologists (KN, PANC) reviewed the titles and abstracts and identified 37 relevant studies. Expert consultation yielded an additional reference. After reviewing the full texts and excluding non-English texts, 18 articles met the necessary criteria. The eighteen articles all utilized at least one of the nine principles of CEnR.

Expert commentary—Ophthalmology is perfectly positioned to benefit from CEnR. Increased community engagement in ophthalmic research would expand the reach of our work and address some of the most difficult problems in vision disparities and outcomes.

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1. Introduction

Community-engaged research (CEnR) brings community members and researchers together to solve health problems. While there are many research studies that are based in communities, CEnR requires a specific degree of stakeholder commitment to working together to address health issues. *Community engagement* is defined as “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people”[1]. This process seeks to empower all parties involved to push towards more comprehensive, inclusive, and executable solutions to improve health through collaborative planning and processes.

In 1947, the Constitution of the World Health Organization (WHO) presented the idea that the environments people live in impact their health [2]. This served as the foundation for the Social Ecological Theory, which describes the interaction between a person, that person's community, and the environment in which that person lives [3-5]. Using this theory as a foundation, the CDC developed the Social-Ecological Model of health (Figure 1) [6]. This model begins by discussing *individual* risk factors for disease based on that person's sociodemographic and biologic characteristics. The next level identifies how *interpersonal relationships* can both negatively and positively impact health. It then expands to include how one's *community* impacts health status, and lastly, how the *societal* influence around that particular community impacts health. This model serves as a framework to ensure that health promotion interventions address all levels of a person's risk factors for poor health from the level of the individual level to the level of society as a whole.

According to the CDC, “acknowledging diversity in background, experience, culture, income, and education and examining how society produces privilege, racism, and inequalities in power” is at the core of community engagement [7]. In 2011, the CDC described a continuum of increasing levels of community involvement that may facilitate longstanding, productive academic-community relationships (Figure 2)[7]. The interactions described begin as *outreach* to the communities and progress toward *consultation*. After *consultation*, increased involvement develops and groups become *collaborative*. The highest level of community involvement is *shared leadership* during which ventures are developed together, from the creation of the research question to the evaluation of the final results.

In 2011, the CDC published the *Principles for Community Engagement*[7], which outlines nine principles to CEnR (Table 1). The first principle requires the research group interested in engaging the community to be clear about the goals of the work and about the population. The second principle advocates the use of qualitative and quantitative methods to learn more about the community the research team wishes to engage. Principle 3 involves building trust and relationships with the community and with the formal and informal leadership of the community. The next principle describes the self-determination of the community as the responsibility of the community and reminds those interested in engaging that empowerment comes from within. Principle 5 entails building partnerships with the community. Principle 6 requires the recognition of the diversity of the community in the planning, design, and implementation of engagement. Principle 7 requires the recognition and the utilization of

community assets along with the expansion of the community's capacity. Principle 8 describes the release of control of interventions to the community and the flexibility that comes with seeing the community as a dynamic entity. Lastly, principle 9 is defined as the long-term commitment to improving the community's health through partnership.

Not only have the WHO and the CDC emphasized how important considering a person's environment is to their overall health status, but research has also demonstrated this important connection. Schulz and colleagues explored the social determinants of diabetes in Detroit, citing stressful life conditions, the built environment, the social environment, and educational opportunities as social determinants of health and mediators between the risk of diabetes and race[8]. Geraghty and colleagues found a significant association between higher hemoglobin A1c and living in lower income neighborhoods, when examining the distance patients with diabetes travelled to primary care visits[9]. In European studies, social deprivation has been associated with decreased screening uptake in diabetic retinopathy and an increase in sight-threatening diabetic eye disease [10]. These are just a few examples of how physical spaces and social support impact the health of those who live in a particular community. There has been a historical disconnect between researchers and the communities they study[11]. Engaging communities as a whole in research may bridge that interpersonal gap, allowing mutually beneficial partnerships to emerge.

Because there are numerous disparities in vision health outcomes among underserved communities[12-14], there is a need to improve the way in which public health interventions in ophthalmology are developed and implemented. Solutions developed by research should be accessible to the communities that they were created to benefit. In a recent report, the National Academies of Science, Engineering, and Medicine implores health experts to improve eye health from a population health perspective. They recommend that communities be included both in the identification of community-level barriers to vision health and the promotion of vision health screening services[12]. CEnR includes the community in the research process at various stages, which brings the community and researchers together to create implementable solutions. This systematic review identifies studies in ophthalmology that utilize tenets of CEnR to address issues in eye health.

2. Methods

In this systematic review of CEnR research in ophthalmology, we included all studies that utilized community engagement. We defined community engagement according to the nine principles established by the CDC in 2011[7]. We included primary research studies that utilized any of the nine principles defined (Table 1). We excluded commentaries, meta-analyses, and reviews. We also excluded any studies that were not available in English.

On September 14, 2016, an experienced medical librarian performed a comprehensive search of multiple databases: Ovid MEDLINE (1946-September Week 2 2016), NLM PubMed for unindexed material, Ovid Embase (1974-2016 September 14), Scopus, and Cochrane Library. To formulate the search, we began with the Yale MeSH Analyzer (<http://mesh.med.yale.edu/>) using key articles to produce relevant controlled vocabulary and keyword terms. We also read abstracts and full-text of key articles to generate concepts and

synonyms. In each database we ran scoping searches and used an iterative process to translate and refine the searches. The key articles were also used for validating the success of the searches and the search strategies were peer-reviewed by a second librarian. Only English language articles were eligible. No date or other filters were applied. The Medical Subject Heading (MeSH) “Community-based participatory research” was only introduced in MEDLINE in 2009 so we combined controlled vocabulary (MeSH terms, Emtree) and with textword variations in combination, including *participatory research, community engagement, community research, partnered research, community-institutional relations, CENR, CBPR and variations on ophthalmology, eye diseases, vision disorders and eye injuries*. All search strategies are available from the authors.

The final search retrieved a total of 799 references. We pooled and de-duplicated those references in EndNote, which resulted in 451 unique records. Two separate screeners (KHN, PANC) evaluated the titles, abstracts, and full text of the eligible articles against the inclusion and exclusion criteria using Covidence. The screeners resolved conflicts by consensus. Review of the articles ensured a comprehensive, complete search. Based on title and abstract, the search identified thirty-seven relevant articles. After consultation with an expert in the field, the authors added an additional reference. After reading the full text of the articles, authors excluded two studies because the texts were not available in English. Authors also excluded sixteen studies because they did not include any of the nine principles of community engagement. Eighteen articles met the inclusion criteria and are included in this analysis.

3. Results

All eighteen of the manuscripts demonstrated knowledge about the community being studied (Table 2). Seventeen of the eighteen studies clearly described the target population and the goals of the effort. Boudville and colleagues detailed both of these principles as they evaluated access to eye care in a primary care setting in Aboriginal communities[15]. Their qualitative, mixed method study used knowledge of the community to further elucidate the role of primary care providers in eye health. The researchers described the population and sought answers from the community through focus group interviews. Burnett and colleagues also discussed these principles[16]. Their study of subjects attending ophthalmic outreach clinics in Papua New Guinea used a questionnaire-based approach to further understand barriers to eye care services. They used an iterative in-person process to develop their questionnaire to capture the opinions of community members and leaders for a better understanding of the communities in which they were working. Owsley and colleagues demonstrated the same principles when they facilitated focus groups for older African-Americans in Alabama[17]. An experienced facilitator helped uncover barriers to eye care in seventeen focus groups. Semi-structured interviews with questions tailored to this population described to uncover barriers to eye care in this community. Elam and colleagues evaluated barriers to care in African-Americans in Virginia and North Carolina in a similar fashion[18]. All of these studies described the characteristics of the participants and sought input from the community in characterizing the population's eye care needs.

Ten of the evaluated studies described trust and relationship building during the community engagement process. For example, Anderson and colleagues leveraged established relationships with community leaders and partnerships with carefully chosen organizations to conduct community-based eye disease screening in Detroit, Michigan [19]. In this case, authors detailed that it was especially prudent that the investigators were introduced to new community organizations by partners who had longstanding relationships with both the researchers and community organization leaders.

Owsley and colleagues also described trust building in their program: *In Communities Helping African Americans Receive General Eye Care (InCHARGE)*. They detailed a community-specific message promoting eye health to elderly African-Americans[20]. The researchers were familiar with the community and worked to build trust. They also partnered with the community to facilitate the pre/post design where they tailored messages that were community-specific, and highlighted the diversity within African-American communities.

Quigley and colleagues utilized technicians and community health workers to screen East Baltimore residents for eye disease[21]. They trained and employed seven full-time neighborhood health-workers in visual acuity assessment and visual field testing. In addition, they also trained and certified 150 volunteers. This research group detailed intimate knowledge of the community and the building of trust and relationships. Through their longstanding commitment to building trust and working with this particular population, they screened over 5300 participants.

Rhodes and colleagues designed *the Eye Care Quality and Accessibility Improvement in the Community (EQUALITY)*, a glaucoma education program[22]. Researchers partnered with an eye clinic in the community to trial this education program and assessed its impact using questionnaires administered to participants during their visits. The program was designed after focus groups in the community demonstrated areas of opportunity for education[23]. This group of researchers clearly describe the population, knowledge about the community, trust-building, and reliance on the community partnership to design the intervention and to evaluate the administration of the program.

Ronanki and colleagues surveyed the Srikakulam district in India about corneal donation[24]. They used a largely semi-structured questionnaire to interview 350 participants. Participants included multiple different stakeholders: health assistant students, high school teachers, social service workers, and family members of those who had previously donated their corneas. This research team described knowledge of the community and building trust by engaging community stakeholders.

Winters and colleagues hired a community liaison to promote a vision health program in a senior apartment community[25]. This specific partnership required clarity about the population to be evaluated, knowledge of the community, and trust building between researchers and the population.

Dreer and colleagues were one of two groups to demonstrate the principle of community self-determination in the research process[23]. Self-determination is control or ownership over one's destiny. Self-determination must come from within the community and cannot be

given to a community by anyone from the outside. In Dreer's research, the community-based advisory board created a culturally-specific health promotion program. It engaged community members with glaucoma to create educational materials for other glaucoma patients within their own community.

Eleven studies partnered with the community. Hark and colleagues detailed this in the development of their glaucoma screening program in Philadelphia[26]. The Philadelphia Glaucoma Detection and Treatment Project worked with over 40 community partners. These partner organizations each identified a site coordinator to work with their team. They describe how their team work allowed them to create culturally-appropriate materials for specific sites, which resulted in over 1500 scheduled glaucoma detection evaluations in the community setting. These partnerships facilitated the creation of community-specific materials and expanded their reach. In addition, Hark and colleagues also engaged a clearly defined population to be engaged and detailed knowledge of the community with whom they were working.

Marella and colleagues evaluated low vision services in Papua New Guinea[27]. They described knowledge of the community and partnered with the community to explore the needs of those with low vision and the public perception of those with low vision. They interviewed 50 stakeholders including eye care practitioners, special education teachers, rehabilitation service providers, disability-related service providers, those from the low vision community, and their family members.

A qualitative study explored the stakeholders involved in correcting refractive error and presbyopia in an indigenous population in Australia[28]. Anjou and colleagues used qualitative methods to examine barriers to eye care. They partnered with the community and multiple stakeholders including representatives from private practices, hospitals, the government, and non-governmental organizations. They described building trusting relationships in order to create partnerships.

Ives and colleagues executed a Community-based Participatory Research (CBPR) Photovoice project[29]. In order to execute this project, the researchers had to be clear about the population, have knowledge of the community, have a trusting partnership with the community, and a unique respect of the cultural aspects specific to this population. Their *Vision Voice* program was developed out of a long-standing academic-community coalition. They detail the facilitation of the community member narratives that expressed their experience with diabetes and vision loss.

Earle-Richardson and colleagues employed CBPR to decrease eye irritation among migrant farm workers[30]. This was the only research that created sustainable results and one of three to demonstrate long-term commitment to a community. The academic and community partners of the Hudson Valley region met and determined that eye irritation was a serious priority [31]. The migrant farm worker community ranked possible interventions to improve eye health. This informed how the researchers created a three-part intervention consisting of eye drops, protective eyewear, and an in-person presentation on eye health. Symptoms were evaluated among the migrant farm workers before and after the intervention using a survey.

The intervention resulted in a significant decrease in eye pain ($P=0.009$). They described the population and the goals of the effort, detailed knowledge about the community being studied, utilized partnerships built on trust to sustain the intervention, and discussed the importance of recognizing and respecting the community.

Lugue and colleagues utilized community-based prevention marketing to create the *Partnership for Citrus Worker Health*, an eye safety peer-to-peer education program[32]. Community health aides facilitated the iterative process of creating the educational program using an analysis of field operations, focus groups, and written questionnaires. Researchers described going beyond knowledge of the population studied and their community to build trust. They not only detailed partnerships with the community and the acknowledgement of the diversity within the community, but also, the development of strong, long-term relationship by regularly evaluating and improving the program.

Williams and colleagues utilized the Participatory-Action-Research methodology to create solutions to improve accessibility to physical places for visually impaired community members and to adapt slide presentations for people with low vision[33]. The study described the transformative moments that came from the monthly meetings of this organization that included five dedicated visually impaired participants with diabetes. They detailed how research control was based in the community. They worked together to build something that belonged to the community members and were required to be flexible enough to meet the community's changing needs. The finished product greatly assisted in improving diabetic education for the Diabetes Association of Greater Cleveland.

4. Discussion

CEnR begins with “meaningful community participation [that] extends beyond physical involvement to include generation of ideas, contributions to decision making, and sharing of responsibility”[7]. Relationships with communities must be developed and nurtured to allow for the partnership to be consistent with the cultural framework of the particular community [34]. The strengths that currently exist in a community should be acknowledged. Communities should be evaluated not in terms of their problems, but in light of what is available to them and how they are able to use what they have [35,36]. Empowerment theory stresses that no external entity should assume that it can give a community the power to act in its own self-interest. Rather, those working to engage the community should, when appropriate, offer tools and resources to aid the community in its own empowerment journey [7]. We identified 18 studies in the ophthalmic literature that utilized various aspects of CEnR in their work. The most commonly used tenets of CEnR were clarity about the goals of the study and population to be engaged and knowledge about the community being studied.

Ten of the eighteen studies we identified made building trust and relationships through the community engagement process a priority. Given the history of human rights violations in health-related research within disenfranchised communities, overcoming mistrust of academic researchers remains an important barrier to conducting meaningful research in underserved communities [35,37,38]. To overcome these historic barriers, relationships must

be nurtured from the very beginning as trust is an essential aspect of these partnerships [35] [39][40]. This trust may be built by demonstrating competence in working with diverse cultures including a diversity of class, gender, ethnicity, age, and sexual orientation [41]. Because trust is such a central issue, many partnerships continue to monitor issues of trust and influence throughout all of the stages of development of the project. They continually review and re-assess issues of governance and decision making to ensure that both the academic and community members feel like equal partners in the research endeavor [42].

In 2010, the National Institutes of Health Director's Council of Public Representatives created a framework for CEnR to serve as a guide to educate the research community[43]. A CEnR relationship begins with a thorough understanding of CEnR by each party. The framework values an equitable, empowering, longstanding partnership that fosters effective communication. From a research perspective, the authors recommend clear research goals with a transparent process that benefits all parties involved. Working principles, ownership, and dissemination policies should be agreed upon at the outset of the project [44]. Once the project has been completed, it is highly recommended that the research findings be translated into policy, interventions, and programs that address the disparities identified. One of the studies examined in this review, Williams et al., used the recommendations from their research meetings to improve diabetes materials and programs for those with visual impairment and diabetes in Cleveland [33]. Their findings enhanced existing programs for community members in real, tangible ways.

Community analysis should be performed early in the partnership, as it was in all of the studies identified in our review. All eighteen studies demonstrated good knowledge of the communities researchers were studying. Communities must be interested in the research and in the priorities suggested[35,41] [45]. Community organizations and leaders who have the support and the respect of the community should be invited to participate [38,40,41]. For example, Anderson and colleagues described the longstanding relationships with community leaders and organizations in Detroit, which allowed them to evaluate over 1,000 community members through a culturally specific diabetic eye disease screening program. Ongoing evaluations of the communication processes throughout the partnership are encouraged [35,38,40,45] [46]. Recognition of the effort of community partners, who often have limited resources, helps to keep morale high [47] [37,38,41]. The goal is to build sustainable partnerships with firm commitments to cost and funding for implementation of designed solutions [40,42,44].

Community members bring important resources to the research process. Community partners and community staff have intimate, invaluable knowledge of community circumstances, culture, comfort levels, fears, and attitudes. They have important contacts that can be utilized in all project phases [47]. In 2009, public involvement in research was reviewed by Staley for the National Health Service. In her systematic literature review, she explores several instances of community engagement in research [48].

In Staley's review of the literature, involved communities identified topics for researchers to address, and proceeded further to shape the research agenda through their specific concerns. The study from our systematic review that comes closest to this is the CBPR work in the

migrant farm worker community. Academic and community partners met and determined that eye irritation was a priority. Then, they worked together to design the study [31]. In Staley's review, sometimes the community initiated the research projects. Others times, communities shifted public discourse to focus on a particular topic, which lead to funding opportunities because of the increased attention. While traditionally, researchers have presented communities with their research questions of interest, community engagement can augment this process. Alternatively, the partnership may decide together what research topics should be addressed.

Lay community members add tremendous value to health education interventions. They are often great recruiters for studies; they know the prospective participants, and with the appropriate social capital, they may add validity to the work[49]. Communal ownership has also been found to increase response rates to questionnaires, which improves the validity of the research [50]. Lay community workers benefit through increasing their skills and capacity by participating in these research projects [47]. Participating in research can help build skills to better advocate for community needs, both by empowering community members and through having a collaborator who has credibility with policy makers [50]. Community partners help to refine research questions and make significant contributions to the interpretation and synthesis of results as they have the most insight into the particular issues in their community[49][51]. There is no description of community partners engaged at that level in the CEnR studies we identified in ophthalmology. Once the data are analyzed, communities may evaluate the conclusions from their perspective and speak to the next steps toward improvement in health outcomes or further interventions[49] [52]. This would be a wonderful next step for vision researchers to utilize to improve the likelihood that their public health interventions are both implemented and maintained, especially in communities who experience a disproportionate share of the burden of visual impairment and vision loss.

CBPR is a specific type of CEnR. It sits at the highest end of collaboration, creating research from shared leadership between communities and academia. Defined as, "A collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change"[53]. The goals of this type of research are to improve health outcomes and eliminate health disparities [3,8]. CBPR addresses health disparities among disempowered communities in at least three ways: through building capacity in underserved populations, through focusing attention on social justice, and through sharing of power and resources[50]. It not only requires community involvement from the development of a research question, it also requires participation throughout the entire process, usually stemming from a longstanding relationship between the two entities[50]. Both CBPR projects detailed in this review, the Photovoice project[29] and the project that improved the eye health of migrant farm workers[30], involved community members from the study design through implementation. CBPR approaches may enhance community capacity to address health inequities [54]. Nonetheless, the number of researchers with specific CBPR experience is limited[50].

There are numerous advantages of CEnR partnerships. In 2004, the Agency for Healthcare Research and Quality assessed the merits of CEnR. The advantages of the research partners included, “greater participation rates, increased external validity, decreased loss of follow-up, and increased individual and community capacity”[53]. In our literature review, Hark and colleagues were able to screen over 1500 Philadelphians with community involvement [26], Quigley et al. were able to screen over 5,300 with the employment of community health workers[21], and Winters et al. also hired a community liaison to facilitate the partnership[25]. When Staley evaluated advantages to communities and researchers, she found that community members, such as those in the Quigley and Winters studies, were often able to attain new skills and knowledge, further their own personal development, acquire support and friendship, find enjoyment and satisfaction, as well as benefit from financial rewards[48]. The new set of skills is often transferable, which may lead to employment elsewhere once the research has ended[47]. Community members are also able to push for better services with newly acquired skills and information [55]. For example, the InCHARGE and EQUALITY programs educate community members about eye disease, which arms community members with the knowledge to be better advocates[20,22]. In parallel, the researchers studied found an improved understanding of community, enjoyment and satisfaction, challenges to beliefs and attitudes, as well as career benefits [48]. Organizations involved found greater access to skilled labor, expertise, and resources than they would have otherwise[35].

There are significant disadvantages to using CEnR approaches. The work done through CEnR is done in a specific community, which raises concerns about applicability to other communities [53]. For example, the Vision Voice project that stemmed from the IMPACT Diabetes Center community-academic coalition is a very specific display of community member experiences[29]. Those experiences may not be generalizable to other groups. Personal disadvantages to community members involved in research were emotional burden, large work load, unsolicited media exploitation, and frustration with level of involvement[35,48] [56]. There are significant opportunity costs to organizations who must choose between furthering their mission through research or other endeavors [35,38,41]. Community partners and researchers endured stretched resources[40,41,44,48] and the need to renegotiate time schedules[48]. Partnerships require increased morale support to continue the work when funding decreases [44]. Researchers also reported loss of control, change in work flow, and a challenge in personal values and assumptions about how to complete the tasks at hand[48]. This may explain why in our literature review, only one of the studies we evaluated detailed the flexibility and release of control to the community[33]. In CEnR, community partners may be tired because of the arduous process of research and seek to implement interventions before they are completely vetted [38,40,41,49]. This may be mitigated by including community members in the intermediate processes, while maintaining open communication [38,49]. Language may become a challenge, whether different languages are being spoken, for example, Spanish and English, or the language of research, which may be new for the community[38,40,41]. These issues must be addressed early to ensure equal footing of both parties.

Community engagement requires a symbiotic relationship. When consents are created with community members at the table, they are often more clear and accessible, which may spur

more research participation. When community partnerships are utilized, the goals of research returning to the community are clear and at the forefront. Ethical concerns are often identified sooner, which allows them to be addressed at an earlier point in the research timeline. These outcomes make it worth the additional resources required for researchers looking to improve community vision health outcomes to utilize community engagement as a central method in their research.

5. Conclusion

Although the studies employing CEnR have been limited in ophthalmology, the field would benefit from more of this type of research. Patients fear blindness and many of the blinding eye diseases are preventable with proper screening and treatment. We need to better address the needs of our patients; CEnR is one tool to bring research closer to program implementation. The National Eye Institute supports education programs for diabetic eye disease, glaucoma, and others and has supported research that has identified serious health disparities in those areas. However, traditional approaches to validate and implement proven interventions to improve community health and close disparities in outcomes have not been successful in ophthalmology[50]. CEnR brings research to the community; this research approach could make significant strides towards bridging the gap between research and implementation for addressing disparities in health outcomes in ophthalmology.

6. Expert commentary

This systematic review demonstrates how principles of community engagement may be used in vision health research. From engaging communities through trust-building, to self-determination, to long-term commitment and the creation of sustainable results, CEnR has augmented the field of ophthalmology. These eighteen studies demonstrate how communities could be engaged to uncover invaluable information, build partnerships, and push organizations forward towards better eye health. Some of the authors of the reviewed manuscripts describe tailored interventions for particular communities, while gathering information that is generalizable to other similar communities in different locations. Others were able to facilitate the expression of the community's voice, which may be more effective than messages from institutions alone. The only lament is that there were so few studies utilizing CEnR. We hope this review provides a glimpse into a very important research modality that would advance the field of public health in ophthalmology in novel ways. As demonstrated in these studies the CEnR spectrum is broad. There are multiple ways to engage communities in research. There are also many communities both locally and globally that are in need of improved eye health; community engagement seeks to find focused ways to assess those needs.

CEnR is designed to bridge the gap between research and those it is intended to help. The National Academies of Science, Engineering, and Medicine have emphasized the importance of involving communities in improving vision health[12]. The NIH and the CDC have taken a particular interest in CEnR. Not only have they funded research opportunities in this arena, they have also created guidelines and frameworks for the creation of the necessary precursor partnerships for this work and for the evaluation of this type of research

in peer-reviewed spaces[7]. Eye health researchers need to increase their utilization of community-engaged approaches.

Ophthalmology is specifically suited for these partnerships because vision loss is ranked alongside memory loss, hearing loss, loss of speech and loss of limbs as one of the public's top health concerns [57]. As a top health concern, communities will prioritize vision and see a working relationship with eye health researchers as beneficial. The field would benefit from community member insight into barriers to the screening and treatment of preventable blindness to combat health disparities and vision loss[13,14,58].

It is no longer enough to treat patients, one must also strive for quality and great outcomes. CEnR is a natural extension for personalization of medicine for communities, as it asks for each community's input in designing ways to combat poor outcomes from disease. Although developing and maintaining community partnerships can be costly both in terms of capital investment and time, there is no better source for information on disparities in health outcomes and possible novel solutions than the people who are experiencing the problem. Community-based research networks already exist in many communities. With honest thoughtful relationship building, ophthalmology may begin to expand old partnerships and create new ones to bring the benefits of CEnR to ophthalmology research and outcomes.

It is not enough to understand disease processes and develop novel treatments and precise management guidelines. These advances must translate to patient care in the real world setting. CEnR may be a bridge that real world.

7. Five-year view

Ophthalmology will begin engaging communities in research. Both quantitative and qualitative methods will be used to improve health outcomes and decrease health disparities in sight-threatening diseases. This will demonstrate the return on investment of this work and spur others to become involved. As the partnerships between communities and researchers are strengthened, both parties will benefit from shared pursuit of the common goal of improving health outcomes in vision.

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Key issues

- Community Engaged Research (CEnR) begins with a balanced partnership between communities and research
- CEnR improves research quality and applicability
- Ophthalmology would benefit from establishing community partnerships in pursuit of CEnR

Figure 1. The Social-Ecological Model: A Framework for Prevention developed by the Centers for Disease Control and Prevention

Figure 2. Community Engagement Continuum developed by the Centers for Disease Control and Prevention

Table 1
Principles of Community Engagement from the Centers for Disease Control and Prevention

Principle 1	Be clear about the population/communities to be engaged and the goals of the effort.
Principle 2	Know the community, including its norms, history and experience with engagement efforts.
Principle 3	Build trust and relationships and get commitments from formal and informal leadership.
Principle 4	Collective self-determination is the responsibility and right of all community members.
Principle 5	Partnering with the community is necessary to create change and improve health.
Principle 6	Recognize and respect community cultures and other factors affecting diversity in designing and implementing approaches.
Principle 7	Sustainability results from mobilizing community assets and developing capacities and resources.
Principle 8	Be prepared to release control to the community and be flexible enough to meet its changing needs.
Principle 9	Community collaboration requires long-term commitment.

Table 2
Application of Principles of Community Engagement from the Centers for Disease Control and Prevention

Study Author	Principle 1	Principle 2	Principle 3	Principle 4	Principle 5	Principle 6	Principle 7	Principle 8	Principle 9
Anjou 2013	x	x	x	x	x				
Anderson 2002	x	x	x	x	x				
Boudville 2013	x	x							
Burnett 2015	x	x							
Dreer 2013	x	x	x	x	x	x			
Earle-Richardson 2014	x	x	x	x	x	x	x		x
Hark 2016	x	x		x					
Ives 2015	x	x	x	x	x				
Lugue 2007	x	x	x	x	x	x			x
Marella 2016		x		x					
Owsley 2008	x	x	x	x	x				
Owsley 2006	x	x							
Quigly 2002	x	x	x	x					x
Rhodes 2016	x	x	x	x					
Ronanki 2014	x	x	x	x	x				
Williams 2009	x	x	x	x	x		x		
Winters 2008	x	x	x						