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Follow-Up Adherence After Community Health Vision Screening Programs: A Review of the Literature

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Abstract

Objective Although the purpose of community eye screening programs is to reduce health care disparities, the effectiveness of these programs is limited by the follow-up adherence of their participants. The aim of this review is to investigate factors that may promote or hinder participants from attending follow-up ophthalmological exams after community eye screenings and identify interventions to increase follow-up rates. Methods For literature review, PubMed, Web of Science, Embase, Proquest/Global Health Library, and Google Scholar databases were searched to identify studies of community eye screenings published between January 2000 and May 2023. Data from these articles were analyzed to identify barriers and facilitators of follow-up adherence after community eye screenings in the United States and to examine strategies used to increase follow-up rates. Only published manuscripts were included. We excluded studies of school screenings and clinic-based screenings.

Results A total of 28 articles were included. Follow-up rates ranged from 12.5 to 89%. Nineteen articles reviewed facilitators and barriers to follow-up. Seven articles described interventions that were tested to improve follow-up rates after screening. Interventions included prescheduled appointments, transportation assistance, patient education, and patient navigators.

Conclusion Several interventions are promising to increase follow-up adherence in community eye screenings, but more evidence is needed. Future research should focus on randomized trials of isolated interventions to improve follow-up adherence of disadvantaged populations, although this may be limited given ethical considerations and documented lack of follow-up after screening.

Keywords

- ► Health care disparities
- ophthalmology
- ► community health
- screenings
- ► follow-up adherence

Low vision is a significant cause of morbidity and mortality in the United States. Thus, screening programs are a means to prevent harmful sequelae of undetected eye diseases. Diabetic retinopathy and glaucoma are both leading causes of vision loss and are likely to progress undetected,^{2,3} characteristics that make them ideal targets for screening and prevention. However, despite the sensitivity and specificity of screening measures, an important component of screening programs' effectiveness relies on the rate of follow-up after a recommended referral for a comprehensive

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ophthalmological evaluation. Follow-up adherence and engagement with eyecare services are historically low among African American and Hispanic communities, characteristics which make these populations especially vulnerable to progressive eye disease and vision loss. 4–6

It is important to identify factors that impede follow-up visits to ophthalmological services after community screenings. While there has been a handful of investigations into the factors that influence follow-up adherence, there are little data comparing various programs or standardized measures to properly assess the effectiveness of interventions to increase follow-up rates. In this review, we synthesize findings from various community vision screenings. We present data on factors that influence follow-up rates after screening referrals and the efficacy of measures aimed to increase follow-up rates. We also compare in more detail the methodologies of the study which had the highest follow-up rates with the study which had the lowest follow-up rates.

Methods

Search Strategy, Eligibility Criteria, Screening, and Article Selection

This study included articles published between 1 January 2000 and 1 May 2023 in five electronic databases: PubMed, Web of Science, Embase, Proquest/Global Health Library, and Google Scholar. The literature search for PubMed used a combination of controlled keywords: "follow-up," "screening," "ophthalmology," "diabetic retinopathy," "glaucoma," "refractive error," and "cataract."

Eligibility Criteria, Article Selection, and Data Extraction

The articles were manually and independently screened by one researcher (R.Z.), who assessed their titles, abstracts, and if necessary, full-text articles. Articles were included if they focused specifically on follow-up rates after free community eye screenings. Only reports of screening programs in the United States were included to minimize political, cultural, and societal influences. Furthermore, only published manuscripts were included in the analysis. Only reports that focused on community-based screenings were included (i.e., excluded school screenings for children given that we aimed to focus on an adult population). The following data were collected: year published, type of study, region, research focus, number of participants (particularly, the number of patients eligible for follow-up in each screening program), factors impacting follow-up rates, and strategies that were used to increase follow-up rates.

Results

The search identified 717 PubMed, 99 Web of Science, 77 Embase, 18,875 Proquest, and 782 Google Scholar reports. In the end, 28 articles met the inclusion criteria. The selection process is detailed in **Fig. 1**. Of these 28 articles, 19 articles reviewed facilitators and barriers to follow-up. Eighteen articles were non interventional and seven (see **Table 1**

and **2**, respectively) articles described interventions that were tested to improve follow-up rates after screening. Fourteen articles focused on the detection of glaucoma, three focused on the detection of diabetic retinopathy, and eight were general vision screenings. Two articles were based on the same student-run eye clinic, ^{7,8} one of which described the impact of an intervention on follow-up rates. ⁷ Six articles were based on the same multiyear Philadelphia Glaucoma Detection and Treatment project. ^{9–14}

Factors Influencing Adherence with Follow-up

Ten studies were community surveys which were aimed to identify perceived barriers to care. In these surveys, reasons given for not adhering to follow-up included a disbelief in test results, ¹⁵ not feeling that vision was bothersome, ¹² competing priorities, ^{14–21} or illness. ^{14,21} Others attributed the lack of follow-up to a lack of knowledge: not knowing they needed to see an eye care professional ^{15,20} or not knowing how to make an appointment. ^{12,19,20,22} Additional barriers to follow-up included cost ^{18–20} and lack of insurance ^{19,20,22,23} or transportation. ^{13,17–20,22} Lastly, some were simply forgetful ^{12,14,17,21,22} or no longer interested in being a part of a study. ¹⁶

Factors Positively Associated with Compliance

Patient characteristics that were positively associated with compliance included white race, ¹⁰ older age, ^{10,24} higher BMI, ²⁵ higher education level, ^{7,15,26} knowing one's glycated hemoglobin level, ²⁴ uncontrolled glucose levels, ²⁷ poorer presenting visual acuity, ²⁵ increased intraocular pressure, ¹⁰ moderate-to-severe nonproliferative diabetic retinopathy and proliferative diabetic retinopathy, ²³ and a diagnosis of glaucoma, ^{10,13} cataract, ¹² or age-related macular degeneration. ^{10,12} Furthermore, compliance was shown to be more likely if a shorter follow-up time period was recommended, ¹¹ the patient was prescribed eye drops, ¹³ or the patient received laser therapy. ^{10,13}

Factors That Were Negatively Associated with Compliance

Patient characteristics that were negatively associated with compliance included living alone, ¹⁶ smoking, ¹⁶ lacking a car, ¹⁶ Hispanic ethnicity, ²³ or living farther from the hospital. ²⁵

Strategies to Improve Rates of Follow-up

A few studies mentioned specific strategies that they used to increase follow-up, including implementing reminder calls. 13,15–17,28 Other strategies included offering either a free or subsidized follow-up exam, 15,16,22,24,25,29,30 transportation, 7,15,22,25 or patient education, 12,15,28,29 whether verbal or written. Moreover, some provided printed exam results 15,16,24,30 and written instructions on scheduling a follow-up appointment. 15,24,29 Personal encouragement, whether by a community worker or project staff, was also used to increase follow-up rates. Quigley et al also provided Saturday hours in addition to normal hours. 22 Gower et al positioned the screening clinic near the eye care provider and contacted the patient multiple times to reschedule missed appointments. 17

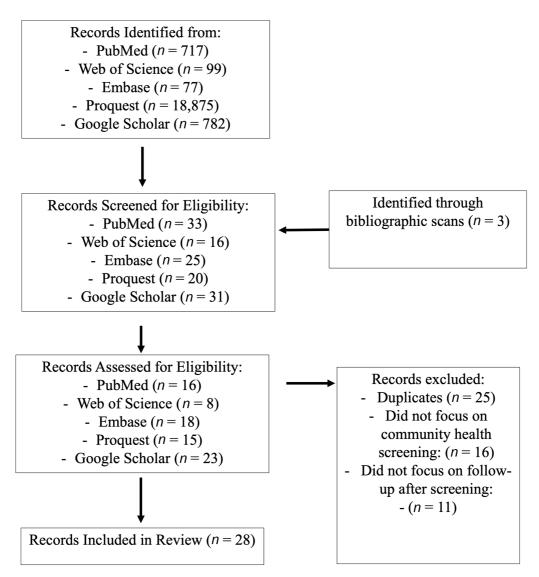


Fig. 1 Flow diagram describing process of articles being reviewed and selected.

Follow-up Rates

Twenty-two studies provided follow-up rates. A total of 21 of these 22 studies emphasized their focus on underserved or low-income populations. Follow-up rates in these studies ranged from 12.5 to 89%. Most follow-up rates ranged between 30 and 50%. 12,17,22,29-32 The lowest follow-up rate was reported by Hennein et al at 12.5% (preintervention),⁷ van Zyl et al²⁹ at 24% (pre-intervention), and Al-Aswad et al³³ at 28.8%. The highest follow-up rates were reported by Tsui et al at 89%,²¹ Gwira et al at 69.2%,¹⁶ Mansberger et al¹⁵ at 69%, and Zhao et al at 63.8% (postintervention).²⁵

Interventions Used to Increase Follow-up

Seven studies which tested the effectiveness of certain interventions to increase follow-up rate were found (Table 2). Interventions included the provision of personalized study staff follow-up reminders, 34 implementing prescheduled appointments, 29 and patient contracts. 30 One study tested a mixed-strategy intervention, including providing referred participants with a voucher stating the value

for free eye exam, scheduling appointments to occur within a max of 4 weeks of screening date, and patient education.²⁵ Another studied the effect of two strategies as one intervention, providing health education and bus tokens for followup appointments at a homeless shelter screening. Two studies examined the effect of incorporating patient navigators into the patient experience after screening.^{9,35}

Comparison of Screening Programs

Of the noninterventional studies reviewed, the highest follow-up rates were recorded by Tsui et al (89%) in White River Junction, Vermont, Gwira et al (69.2%) in New Haven, Connecticut, and Mansberger et al (69%) in Portland, Oregon, and the lowest follow-up rate (28.80%) was recorded by Al-Aswad et al in New York City, New York. 15,25,33 Gwira et al, Mansberger et al, and Al-Aswad et al were focused on glaucoma screenings but used different methodologies and populations. Both Gwira et al and Mansberger et al provided free screening and follow-up examination to those without insurance. Both provided reminder calls to seek follow-up

 Table 1
 Key Characteristics and findings of noninterventional studies of community-based eye screenings

Study	Follow-up Rate	Facilitators of follow-up	Barriers to follow-up
Altangerel et al ²⁶ ;	_	1) Increased level of education ($p < 0.001$)	-
Philadelphia, Pennsylvania; 2009		2) Language spoken ($p < 0.001$)	
Tellisylvalia, 2003		3) Knowledge of accurate definition of glaucoma (which correlates with 1 and 2 $[p < 0.001, p < 0.025]$)	
Ballouz et al ¹⁸ ; Flint and Ypsilanti, Michigan ; 2021	_	_	1) Competing priorities (22/30 of participants)
			2) Knowledge (26/30)
			3) Transportation (26/30)
			4) Cost (23/30)
			5) Convenience/Access (22/30)
Mansberger et al ¹⁵ ;	69%	1) Female gender (<i>p</i> < 0.05)	1) Not believing results of test (41%)
Portland, Oregon; 2007		2) Older age (<i>p</i> < 0.05)	2) No insurance (21%) or eye care provider
		3) Education level of high school or more	3) No time for eye exam (11%)
		(p < 0.05)	4) Did not know they needed to see eye care provider (11%)
Quigley et al ²² ; Baltimore,	41%	_	1) No appointment given (26%)
Maryland; 2002			2) Forgot (20%)
			3) Lack of transportation (9%)
			4) Lack of insurance coverage (6%)
Zheng et al ¹² ; Philadelphia,	48.30%	1) Saw eye doctor within the past year $(p = 0.005)$	1) Forgetfulness (29.7%)
Pennsylvania; 2016		2) Remembered result of their exam $(p=0.04)$	2) Not knowing how to make an appointment (20.3%)
		3) Remembered recommendations given at community-based exam ($p < 0.001$)	3) Vision is not bothersome (18.9%)
Gower et al ¹⁷ ; Columbus,	47.10%	_	1) Forgetting (34%)
Ohio; 2013			2) Lack of transportation (36%)
			3) Scheduling conflicts (26%)
Gwira et al ¹⁶ ; New Haven,	69.20%	_	Survey responses:
Connecticut; 2006			1) Followed by other clinics
			2) Work schedules
			3) Sickness
			4) Being away
			4) No longer interested in study
			Analysis of independent factors:
			1) Living alone
			2) Smoking
			3) Lacking a car
Keenum et al ²⁴ ; Alabama; 2016	29.90%	1) Advanced age (OR = 1.02 [1.01–1.04])	Agreeing to assistance in making follow- up eye care appointment
		2) Knowing one's glycated hemoglobin level (OR = 2.00 [1.34–2.97])	
Adeghate et al ¹³ ; Philadelphia, Pennsylvania; 2019	36.10%	1) Glaucoma-related diagnosis $(p \le 0.001)$	_

 Table 1 (Continued)

Study	Follow-up Rate	Facilitators of follow-up	Barriers to follow-up
		2) Recommendation of a 4- to 6-wk follow-up (p < 0.001)	
		3) Prescribed eye drops or received laser therapy ($p = 0.047$)	
Hennein et al ⁸ ; San Francisco, California, 2021	36.80%	1) High school education	1) No primary care provider
Williams et al ⁴⁰ ; Pittsburgh, Pennsylvania; 2019	72%	_	_
Staropoli et al ³⁹ .; Miami, Florida; 2021	58%	_	Analysis of independent factors: 1) Lack of health insurance coverage (p = 0.014) Survey responses: 1) Lack of health insurance (57%, 17/30) 2) Lack of motivation (33%, 10/30) 3) No time (10%, 3/30)
Rosati et al ²⁷ ; Spartanburg, South Carolina; 2017	21.10%	1) Uncontrolled glucose levels	_
Tsui et al ²¹ ; White River Junction, Vermont; 2015	89%	-	1) Conflicting engagements (38%) 2) Forgetfulness (25%) 3) Illness (25%)
Song et al ²³ ; Durham, North Carolina; 2022	59%	1) Moderate-to-severe NPDR or PDR (p < 0.0001)	1) Lack of health insurance coverage (p = 0.016) 2) Hispanic ethnicity (p = 0.015)
Hark et al ¹⁴ ; Philadelphia, Pennsylvania; 2019	64.90%	_	1) Feeling ill 2) Forgetfulness 3) Transportation 4) Unawareness of diagnosis 5) Conflicting engagements, weather
Hark et al ¹⁰ ; Philadelphia, Pennsylvania; 2017	61.20%	1) Final diagnosis of glaucoma (RR = 1.33 [1.13–1.57]) 2) Male sex (R = 1.19 [1.04–1.36]) 3) White race (RR = 1.26, [1.08–1.48]) 4) Age (RR = 1.17 [1.00–1.37]) 5) Recommendation of glaucoma medication or laser peripheral iridotomy (RR = 1.18 [1.35–1.71]) 6) Diagnosis of age-related macular degeneration (RR = 1.42 [1.13–1.77]) 7) Increased intraocular pressure (>22 mm Hg) (RR = 1.23 [1.06–1.42])	
Atta et al ¹⁹ ; Pittsburgh, Pennsylvania; 2022	-	_	1) Medical costs (50%) 2) Lack of health insurance (41%) 3) Conflicting engagements (12%) 4) Issues with scheduling appointment (10%) 5) Difficulty navigating health care system (10%) 6) Transportation (7%)
Goyal et al ²⁰ ; Detroit, Michigan; 2022	-	1) Older age 2) PCP recommendation 3) Referral	 Lack of health insurance coverage Finances Time Unaware of need Difficulty navigating health care system Transportation

Abbreviations: NPDR, nonproliferative diabetic retinopathy; OR, odds ratio; PCP, primary care physician; RR, relative risk.

 Table 2
 Key characteristics and findings of interventional studies of community-based eye screenings

Study	Study design	Intervention	Follow-up rate	Facilitators of follow-up	Barriers to follow-up
Aleo et al ³⁰ ; Philadelphia, Pennsylvania; 2015	Prospective, nonrandomized	Patient contract	38.1% (Intervention), 43.9% (Control)	_	_
van Zyl et al ²⁹ ; New Haven, Connecticut; 2015	Prospective, quasiexperimental,	Receiving a prescheduled appointment	41% (Intervention), 24% (Control)	_	_
Zhao et al ²⁵ ; Baltimore, Maryland; 2018	Prospective, nonrandomized	1) Standard referral: give appointments onsite, personal reminder calls and text message reminders sent 1 day before appointment, contact participants up to 3 times. Offer free transportation. 2) Implementation of new strategies: Provide referred participants with a voucher stating value for free eye exam, schedule appointments to occur within a max of 4 wk of screening date, patient education	63.8% (Intervention), 55% (Control)	1) Higher BMI: $\ge 30 \text{ vs.}$ <25 kg/m ² <25 kg/m ² 2) Poor presenting visual acuity in better eye <20/40 vs. $\ge 20/40$ 3) Exam findings: Abnormal macula on fundus photography vs. normal macula	1) Distance from hospital: 3 to <5 miles vs. <1 mile from the hospital
Anderson et al ³⁴ ; Detroit, Michigan; 2003	Prospective, randomized	Personalized telephone follow-up by study staff	66% (Intervention), 35% (Control)	_	-
Hennein et a ^{l7} ; San Francisco, California; 2021 ^a	Prospective cohort; nonrandomized	Health coaching Bus tokens	64% (Intervention), 12.5% (Control)	-	1) Shorter duration of stay at homeless shelter 2) Visual acuity better than 20/40 3) Not being born in the United States 3) Lower educational level
Leiby et al ³⁵ ; Philadelphia, Pennsylvania; 2021	Prospective cohort; randomized	Patient navigators and social workers	First visit: 74.4% (Intervention) vs. 39.0% (Control) for first visit 1-yr follow-up: 18.6% (Intervention) vs. 8.1% (Control)	-	1
Hark et al ⁹ ; Philadelphia, Pennsylvania; 2016	Prospective cohort; randomized	Patient navigator	69.8% (Receive follow-up care in community-based setting with patient navigator) 82.5% (Receive follow-up care in office-based setting with patient navigator) 73.3% (Receive follow-up care in office-based setting without patient navigator)	I	1

Abbreviations: BMI, body mass index. ^aTargeted homeless people.

within the next 2 weeks. Al-Aswad et al provided free screening but did not indicate that the follow-up examination was free. Patients who screened positive for nonemergent ocular diseases were referred for follow-up examination, but they were not contacted after the initial screening. In terms of the demographics of each of these studies, Mansberger et al surveyed a predominantly white population in Portland, Oregon; they were able to contact 121 individuals out of 212 participants originally enrolled in the screening. Gwira et al studied 273 participants from an African-American population in New Haven, Connecticut. Al-Aswad et al studied a Manhattan population mostly ≥20 years of age that was 54% Hispanic and 16% African-American and consisted heavily of non-English speakers. However, Spanish-speaking staff were present in this study to address these language barriers. The three studies also defined noncompliance differently. Gwira et al defined noncompliance as failing to follow up after the reminder calls. Mansberger defined noncompliance as having not attended a follow-up exam at the time of the survey. Al-Aswad did not define noncompliance with follow-up, rather stated whether follow-up was available for certain individuals. Meanwhile, Tsui et al, which had the highest follow-up rate, performed general vision screenings on a rural population in the Northeast United States. Tsui et al did not provide information about the racial demographics of the population, but most had above a high school education and ages ranged between 17 and 67 years. Each referred patient received a letter and a phone call reminder 1 week before their appointment. The screening was free but there was no indication as to whether the follow-up exam was free.

Of the interventional studies, the most effective intervention was found to be the provision of health coaching and bus tokens, which increased the follow-up rate by 51.5%. This study focused on the homeless population of San Francisco, California, and examined the intervention's effect on 71 patients (37 preintervention and 34 postintervention).⁷ Additionally, Anderson et al compared the effect of personalized telephone follow-up in 67 patients compared to standard telephone follow-up in 65 patients and found that this intervention raised the follow-up rate by 31% in an African-American population in Detroit, Michigan.³⁴ Next, van Zyl et al provided prescheduled appointments to patients in low-income, predominantly black/Hispanic neighborhoods in New Haven, Connecticut, including 22 patients in the intervention group and 41 patients in the control group.²⁹ As a result, prescheduled appointments increased follow-up rates by 17%.²⁹ In Baltimore, Maryland, Zhao et al focused on an African-American population to increase the follow-up rate by 8.8% by providing a combination of new strategies, including a voucher stating the value for a free eye exam, patient education, and an appointment scheduled within 4 weeks of the screening date. In this study, 199 patients were included in the interventional group while 686 patients were included in the control group. Lastly, the least effective intervention was the provision of a patient contract by Aleo et al in an urban, underserved population in Philadelphia, Pennsylvania. Forty-two patients were included in the control group, while 41 patients were included in the intervention group. Follow-up rates decreased from 43.9% in the control group to 38.1% in the intervention group.

Discussion

To our knowledge, this is the first review that synthesizes the findings of multiple community ophthalmological screenings in the United States, analyzes the facilitators and barriers to attending follow-up appointments, and integrates research on interventions which have been done to improve follow-up to community eye screenings. Studies in this review mostly target vulnerable populations, such as older, low-income, or minority groups.

From our search, seven studies were located which detailed the effect of specific intervention on follow-up rates. One intervention of implementing patient contracts was not shown to be effective, whereas the other interventions were promising in their effectiveness of increasing follow-up rates by a range of 9 to 51.5%. However, the current literature still harbors gaps which should be addressed by future investigations. First, each study was limited by a single-center design, where there is variability in baseline follow-up rates, demographic makeup of populations, and differences in health care systems. Moreover, only three studies utilized a randomized design, ^{9,34,35} while the other four were limited by a nonrandomized study design. ^{7,25,29,30} Notably, as stated by Hennein and de Alba Compomanes, studying some interventions, such as giving health coaching and bus tokens, via a randomized study design can involve ethical problems in vulnerable populations.

The data on the use of patient navigators on follow-up adherence have been mixed. In 2016, Hark et al³⁶ in a subset of the same study showed from a group of 155 patients that the use of patient navigators was not effective in increasing follow-up adherence between community- and office-based settings with and without a patient navigator at the first follow-up visit. However, through a randomized trial of 344 patients published in 2021, Leiby et al, 35 in a subset of the same Philadelphia Telemedicine Glaucoma Detection and Follow-Up Study, showed the incorporation of patient navigators and social workers into the patient experience during community screenings could increase follow-up rates by as much as 34.1%. Patient navigators help provide guidance for patients to arrange transportation, obtain appropriate health care resources, coordinate appointment scheduling, and verify insurance status, rather than placing the onus on the patient.³⁵ A downside to this intervention is that it may be more costly for many ophthalmological screening programs to hire such patient navigators; further cost-benefit analysis here is warranted. In Portland, Oregon, Brinks et al showed that partnering with community organizations could provide resources to manage screenings, scheduling, provision of spectacles and referral to clinical eye care, among other tasks.³⁷ Community organizations could be a source of personnel to maintain the patient navigator role. In student-run clinics or screening programs at academic centers, the patient navigator role could be handled by interested medical or public health students. This intervention was recently implemented at a free clinic at Indiana University School of Medicine and could provide a starting point for other community eye programs. ³⁸ More data will be needed to ascertain the effect of these patient navigators on patient follow-up rates and outcomes.

Another intervention that may improve access to follow-up care is changing the design of screening programs to incorporate an on-site ophthalmologist and provide definitive eye exams and care on the day of the screening, as described in Brinks et al.³⁷ This modification may lessen the burden on the patient to comply with referrals, while avoiding the extra investments that may be necessary for education, reminders, free transportation, and other interventions to increase follow-up rates. It remains to be seen whether the investment in on-site ophthalmologists would be effective and worth the benefits of bypassing the need for initial referrals. Even so, compliance with regular follow-up for those who need it would still be an issue for groups at risk.

This review has some limitations. The heterogeneity in methodology of each study makes it difficult to rigorously compare the effects of each specific facilitator and barrier to follow-up adherence, as well as the effect of interventions on follow-up rates. Moreover, reporting of each study population's demographic makeup varied, with different levels of detail on race and ethnicity, income status, and language spoken. Immigration status may be an important contributor to follow-up rates but was not noted in many of the studies we included. Lastly, this review examines the rate of completion of the first visit after follow-up, rather than adherence to treatment over the years.

Future research on community eye screenings should focus on randomized trials of isolated interventions. Due to the heterogeneity of disadvantaged populations and medical systems, larger, multicenter studies may be helpful. Even without multicenter studies, the reporting of methods and outcomes of eye screening programs should be standardized to adequately assess and compare follow-up adherence at different sites. So far, the implementation of patient navigators, 35 as well as increased health education and transportation assistance, ⁷ shows promise in improving follow-up. It follows that the cost-effectiveness of these interventions should be investigated and optimized for free eye screening programs. Furthermore, as of this writing, there have only been five investigations of student-run eye screening clinics. 8,20,21,38,39 It may be valuable to investigate the follow-up adherence of these clinics further to determine what interventions are helpful to these specific systems.

In conclusion, the true effectiveness of eye screening programs is limited by patient follow-up adherence after the need for a referral has been detected. This review has synthesized the reported facilitators and barriers to follow-up after eye screening clinics. Moreover, the review found that prescheduled appointments, patient education, and transportation assistance are promising interventions to increase follow-up rates. Future research should focus on more randomized trials of isolated interventions to improve follow-up treatment of disadvantaged populations.

Conflict of Interest None declared.

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