

# Barriers to Receiving Follow-Up Eye Care and Detection of Non-Glaucomatous Ocular Pathology in the Philadelphia Glaucoma Detection and Treatment Project

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**Abstract** This cross-sectional study aimed to evaluate adherence rates and identify barriers to receiving follow-up eye care in participants diagnosed with significant non-glaucomatous eye pathology in the Philadelphia Glaucoma Detection and Treatment Project. This community-based project aimed to improve detection, management, treatment, and follow-up eye care of individuals at high risk for glaucoma in community-based settings. Participants throughout Philadelphia, Pennsylvania, USA were enrolled. After a comprehensive eye examination, follow-up recommendations were given to each participant. A telephone survey was administered to individuals diagnosed with non-glaucomatous ocular pathology 3 months after initial eye examination to assess rates of follow-up and to evaluate potential barriers to follow-up. Of the 1649 participants enrolled in this project, 249 (15 %) were diagnosed with significant non-glaucomatous ocular pathology requiring follow-up care. There were 143 (57 %) who responded to the telephone survey. Respondents had a median age of 72 years, and were predominately female (69 %) and African-American (64 %). Of the respondents, 36 (25 %) attended a follow-up appointment. Participants who did not remember the results of their examinations, did not remember their recommendations, and had not seen an eye doctor within the past year were less likely to make a follow-up appointment ( $P = 0.04, 0.001$  and  $0.005$ , respectively). The Philadelphia

Glaucoma Detection and Treatment Program was able to detect a significant amount of non-glaucomatous ocular pathology requiring follow-up care. Actual follow-up rates were sub-optimal. Further research is needed to determine interventions to overcome barriers and increase adherence with follow-up recommendations.

**Keywords** Community eye screening · Access to eye care · Barriers · Underserved population · Detection of eye disease

## Introduction

Visual impairment is a known cause of disability and reduced quality of life [1–3] affecting an estimated 285 million people worldwide [4]. In the United States (U.S.), approximately 3.4 million adults aged 40 and older were visually impaired in 2004 and the prevalence is expected to rise to an estimated 5.5 million by the year 2020 [5].

Population-based prevalence surveys have found that undetected eye diseases are common, even in developed countries [6, 7]. Low income [8, 9], older age [6], minority status [6, 8, 10, 11], lack of insurance [12, 13], lack of transportation [14], lower education level [9], and poor understanding [15] are risk factors associated with higher rates of undetected eye disease in the U.S. Undetected eye diseases can have grave consequences, possibly leading to decreased vision and quality of life, fall-related injuries, social isolation, and depression [2, 3, 16, 17].

With the high prevalence of ocular disease and significant morbidity associated with visual impairment, many community-based vision detection programs have targeted high-risk populations with variable success [18–20]. One large community-based program conducted by laypersons

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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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was able to detect a significant amount of ocular pathology, with over a third of screenings requiring referral for a definitive eye examination [18]. Efforts to provide follow-up care were only modestly effective. Another community-based glaucoma detection program also resulted in low rates of follow-up care for further evaluation despite multiple telephone reminders [20].

The Wills Eye Hospital Glaucoma Research Center initiated a 2-year demonstration project, funded by the Centers for Disease Control and Prevention (CDC), known as The Philadelphia Glaucoma Detection and Treatment Project. This demonstration project aimed to improve detection, management, treatment, and follow-up eye care of persons at high risk for glaucoma in Philadelphia through targeted community-based comprehensive glaucoma examinations. The purpose of the present study was to evaluate adherence rates and identify barriers to receiving follow-up eye care in participants diagnosed with significant non-glaucomatous eye pathology at this community-based glaucoma detection program.

## Methods

### Participants

The Philadelphia Glaucoma Detection and Treatment Project was a 2-year demonstration project aimed to increase access to eye care among persons at high risk for glaucoma. Details of the study design are described elsewhere [21]. The Institutional Review Board of Wills Eye Hospital approved the evaluation and review of data from the demonstration project following the principles of the Declaration of Helsinki.

In order to target older adult populations of minority populations at high-risk for eye disease, we partnered with governmental agencies, non-profit organizations, and community-based organizations in Philadelphia that serve senior citizens of minority populations, including African-Americans, Hispanics, and Asians. We selected a total of 43 community sites frequented by high-risk persons, including senior centers, senior housing buildings, and senior community organizations. For each location, site coordinators and Wills Eye health educators jointly developed advertising materials for newsletters, websites, and announcements. For recruitment purposes, Wills Eye health educators provided a glaucoma awareness workshop that was given approximately 1 week prior to the community-based eye examination, which is further described elsewhere [22]. Individuals were scheduled for the eye examination following the workshop and walk-in appointments were accepted.

### Community-Based Glaucoma Detection Examination

Equipment required for a comprehensive eye exam was transported from Wills Eye Hospital to each community site. All participants received a comprehensive eye examination. A trained ophthalmic technician performed the following for both eyes: (1) Snellen visual acuity, (2) undilated fundus color photography with Volk Pictor Digital Retina Camera (Optomed Oy Ltd, Oulu, Finland), (3) central corneal thickness measurement using iPac Handheld Pachymeter (Reichert Inc, Depew, NY, USA), (4) monocular visual field testing using Octopus 300 Static Perimetry (Haag-Streit Inc., Bern, Switzerland), and (5) documentation of ocular, medical, social, and family history. An ophthalmologist performed the following for both eyes: (1) slit lamp examination of anterior segment, (2) gonioscopy assessment, (3) intraocular pressure measurement using Goldmann applanation tonometry, and (4) undilated fundus examination. If needed, participants were able to receive laser treatment on site.

At the end of the examination, participants who were diagnosed with glaucoma or glaucoma-suspect were able to schedule follow-up appointments at the same community site in 4–6 weeks or 4–6 months depending on the recommendation from the ophthalmologist. Participants diagnosed with non-glaucomatous eye pathology were recommended to follow-up with their own eye care provider or a local ophthalmologist located within 2 miles from the community site. They were provided with contact information for Wills Eye Hospital. The examining ophthalmologist determined the criteria for non-glaucomatous ocular conditions that required follow-up ophthalmic care.

### Follow-Up Telephone Survey

Examination results were entered into a FileMaker Pro 11 (FileMaker Inc, Santa Clara, CA, USA) database. Participants who were diagnosed with non-glaucomatous pathology and recommended for follow-up ophthalmic care were surveyed via telephone 3 months after initial examination. A standard phone script was used and trained research staff called participants to explain the purpose of the telephone survey. All participants provided oral consent prior to participating in the survey. The survey consisted of open-ended questions on demographic information, medical history, and follow-up appointment status (“Appendix”). Participants were asked to confirm the diagnosis and recommendations given at the glaucoma detection program examination. If the participant said the incorrect diagnosis or did not remember their diagnosis, they were listed as “did not remember”. The same method applied

for incorrect or unrecalled recommendations. Barriers to follow-up eye care were recorded.

A maximum of 3 call attempts were made for each participant. Calls were made at varying times of day (either morning, afternoon, or evening) to increase the likelihood of contact. If the participant's native language was not English, an interpreter called back to administer the telephone questionnaire. Participants were not offered any compensation for completing the telephone questionnaire.

### Statistical Analysis

Data was analyzed using SAS Analytics Pro software, version 9.4 (SAS Institute Inc, Cary, NC). Survey results were correlated with attendance at a follow-up examination using the Wilcoxon nonparametric test and Fisher's exact test. All tests were two-sided and *P* values less than 0.05 were considered statistically significant.

### Results

A total of 1649 participants attended the Philadelphia Glaucoma Detection and Treatment Project at 43 different community sites between January 3, 2013 and May 30, 2014 (Fig. 1). Demographic characteristics are detailed in Table 1. There were 249 (15.1 %) participants diagnosed with significant non-glaucomatous ocular pathology requiring follow-up. A total of 293 diagnoses were confirmed in 249 participants (Table 2). Of the 249 participants, 156 (62.7 %) were reachable by phone. The mean number of contact attempts was 1.4 for the 156 participants who were reachable by phone. Seventy-four (29.7 %) participants were unreachable after 3 contact attempts were made and another 19 (7.6 %) participants had telephone numbers that were not in service. Of the 156 who were reached, 143 (91.7 %) agreed to participate in the telephone questionnaire.

Among the 143 questionnaire respondents, 69 (48.3 %) made a follow-up appointment with an eye doctor. Participants were significantly more likely to make a follow-up appointment with an eye doctor after their community-based examination if they had seen an eye doctor within the past year prior to the community-based examination ( $P = 0.005$ ), remembered their diagnosis given at the community-based examination ( $P = 0.04$ ), or remembered the recommendations given at the community-based examination ( $P < 0.001$ ) (Table 3).

Thirty-six (25.2 %) of the 143 participants who responded to the questionnaire attended their follow-up appointment at the time of the 3-month telephone interview. Participants diagnosed with visually significant cataract or age-related macular degeneration were more likely

to attend their follow-up appointment at either Wills Eye Hospital or their local ophthalmologist ( $P = 0.046$ ). Factors not significantly associated with making or attending a follow-up appointment included gender, ethnicity, site location, site type (community center, faith-based institution, health center, or senior center), visual acuity of better eye, primary language, education level, living alone or with someone, type of transportation used, having health insurance, or type of health insurance ( $P \geq 0.10$  for all).

The 74 respondents who did not make a follow-up appointment were asked the open-ended question, "Why did you not make a follow-up appointment?" and were allowed to provide multiple answers to the question. The most common responses were forgetfulness ( $n = 22$ ; 29.7 %), not knowing how to make an appointment ( $n = 15$ ; 20.3 %), and vision was not bothersome ( $n = 14$ ; 18.9 %).

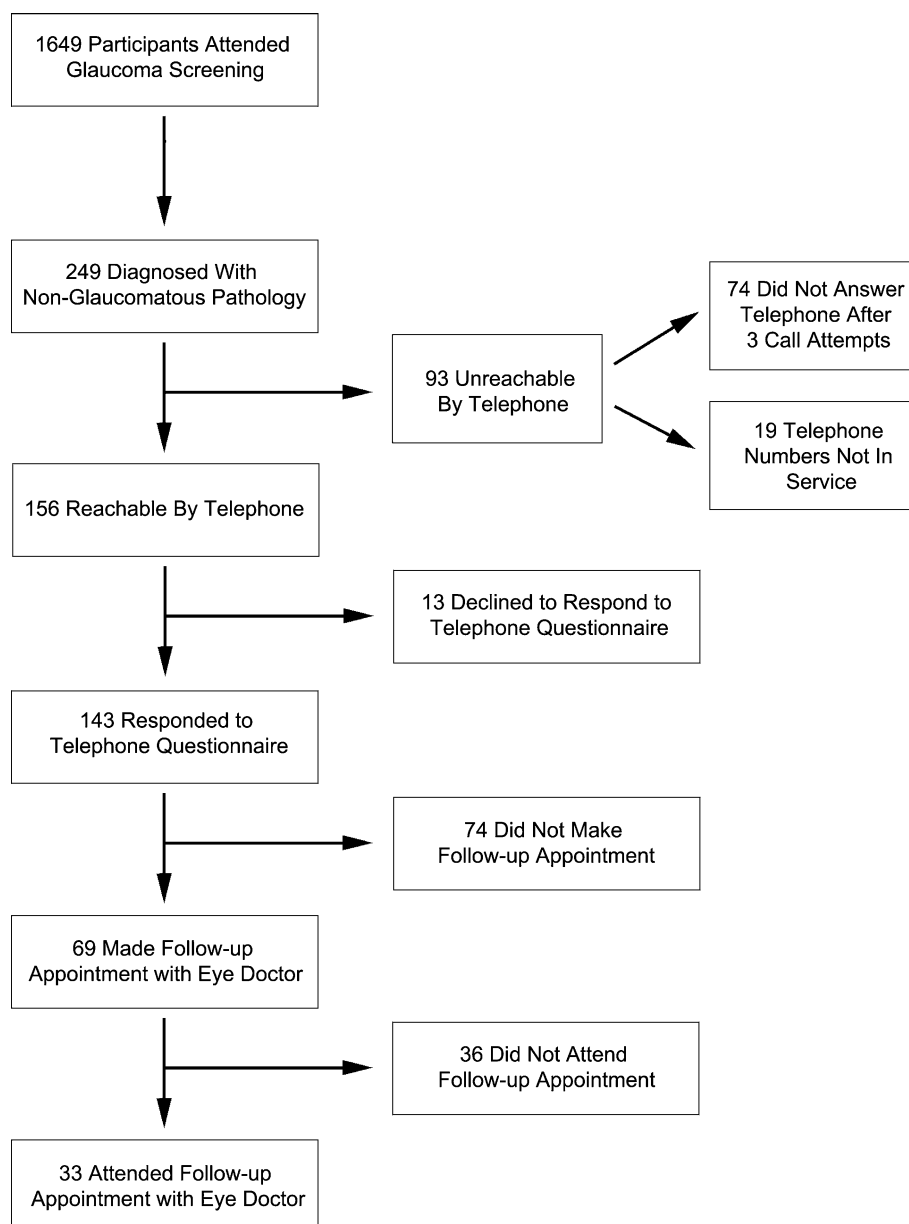
### Discussion

This study is an outcome of a community-based intervention designed to improve detection, management, and treatment of glaucoma for persons at high risk for glaucoma. A significant amount of non-glaucomatous ocular pathology requiring further follow-up was detected after 1649 community-based eye examinations. To our knowledge, this is the first study evaluating the rates of non-glaucomatous ocular pathology detection during a community glaucoma detection program. Undetected eye disease is a significant public health issue due to the impact of visual impairment on disability and decreased quality of life [1–3].

Previous community-based programs, such as the Hoffberger program, have demonstrated that a substantial amount of effort is required to find persons with eye disease who are not already integrated in the health care system [18]. They noted that while health fairs are the easiest sites to offer eye examinations, they are less likely to reach high-risk individuals, such as older adults, homeless, and those with multiple disabilities [18]. Our study targeted high-risk neighborhoods where poverty rates are above the nationwide average of 8 %, as nearly 25 % of Philadelphia families live in poverty [23, 24]. We also reached African-Americans, Hispanics, and Asians in underserved areas of Philadelphia by partnering with governmental agencies, non-profit organizations, and community-based organizations that serve senior citizens of minority populations. With this approach, we examined 1649 high-risk people and diagnosed a significant amount of glaucoma and non-glaucomatous eye pathology.

Despite detection of non-glaucomatous disease, our study found sub-optimal rates of follow-up. Approximately

**Fig. 1** Flow diagram of participants of the Philadelphia Glaucoma Detection and Treatment Project



50 % of questionnaire respondents did not make a follow-up appointment and the most common reason was that they forgot. Our project manager attempted to call each participant to remind them of their results and recommendations within 7 days of the community-based eye examination. However, our study found that 37 % of participants were not reachable by telephone after 3 separate attempts. Other studies have also demonstrated difficulties reaching participants who attended community-based eye examinations through telephone [7]. Even when participants are successfully reached, previous studies have found that telephone, postcard, and text message reminders only moderately improved outpatient attendance [25–28]. Interventions that have been shown to significantly

improved adherence in other settings include multipronged reminders and patient navigators [29–31]. Current studies are underway to determine the effectiveness of patient navigators to improve follow-up care after eye disease is diagnosed from a community-based examination.

Our study found that participants who remembered the diagnosis and recommendations given at the community-based eye examination were significantly more likely to make a follow-up appointment. These results suggest that it is imperative to find ways to help participants retain follow-up health information. However, 36 % of US adults have basic or below basic literacy skills [32]. Populations at “risk” for low literacy are similar to the ones attending our community glaucoma detection program (seniors,

**Table 1** Demographics of participants diagnosed with significant non-glaucomatous ocular pathology

	All persons diagnosed with eye disease (n = 249) n %	Responded to telephone survey (n = 143) n %	<i>P</i> value
Age			
Mean (range)	71 (25–101)	72 (25–101)	0.92
Gender			
Female	175 (70.3)	99 (69.2)	0.78
Male	74 (29.7)	44 (30.8)	
Race			
African American	145 (58.2)	92 (64.3)	0.12
Asian	40 (16.1)	20 (14.0)	
Caucasian	33 (13.3)	17 (11.9)	
Hispanic	13 (5.2)	4 (2.8)	
Other	18 (7.2)	10 (7.0)	
Primary language			
English		122 (85.3)	
Chinese		15 (10.5)	
Spanish		4 (2.8)	
Other		2 (1.4)	
Education			
Did not complete high school		26 (18.2)	
Completed high school		75 (52.4)	
Completed some college or higher		40 (28.0)	
Declined to answer		2 (1.4)	
Living situation			
Living alone		93 (65.0)	
Living with someone else		50 (35.0)	
Primary method of transportation			
Public transportation		84 (58.7)	
Drives car		36 (25.2)	
Received ride from family or friend		22 (15.4)	
Declined to answer		1 (0.7)	
Insurance			
Medicare/medicaid		56 (39.2)	
Other		74 (51.7)	
No insurance		13 (9.1)	
Last visit to an eye doctor prior to community-based eye examination			
Within the past 6 months		25 (17.6)	
Within the past year		25 (17.6)	
Over 1 year ago		88 (62.0)	
Unable to remember		4 (2.8)	
Remembered diagnosis given at community-based eye examination			
No or unsure		81 (56.6)	
Yes		62 (43.3)	
Remembered recommendations given at community-based eye examination			
No or unsure		55 (38.5)	
Yes		88 (61.5)	

**Table 2** Frequencies of significant non-glaucomatous ocular pathology diagnosed

Significant non-glaucomatous ocular diagnosis	N (% of total participants screened)
Visually significant cataract	180 (10.9)
Diabetic retinopathy	39 (2.3)
Age-related macular degeneration	29 (1.8)
Other macular pathology	23 (1.4)
Ptosis	8 (0.5)
Corneal pathology	6 (0.4)
Suspicious nevus	3 (0.2)
Other	5 (0.3)

Participants could have more than 1 non-glaucomatous ocular diagnosis

**Table 3** Variables associated with adherence to scheduling or attending a follow-up appointment

Variable	Scheduled follow-up appointment n (%)	Did not schedule follow-up appointment n (%)	P value																					
Interval of time between last visit to eye doctor and community-based eye examination																								
Within the past 6 months	16 (23.2)	9 (12.2)	0.005																					
Within the past 1 year	15 (21.7)	10 (13.5)																						
Over 1 year	33 (47.8)	55 (74.3)																						
Unsure	5 (7.6)	0 (0)																						
Remembered diagnosis given at community-based eye examination																								
No/unsure	33 (47.8)	48 (64.9)	0.04																					
Yes	36 (52.2)	26 (35.1)																						
Remembered recommendations given at community-based eye examination																								
No/unsure	15 (21.7)	40 (54.1)	<0.001																					
Yes	54 (78.3)	34 (45.9)																						
<table border="1"> <thead> <tr> <th></th> <th>Attended follow-up appointment n (%)</th> <th>Did not attend follow-up appointment n (%)</th> <th>P value</th> </tr> </thead> <tbody> <tr> <td colspan="4">Primary diagnosis</td> </tr> <tr> <td>Visually significant cataract</td> <td>23 (63.9)</td> <td>14 (42.4)</td> <td rowspan="4">0.046</td> </tr> <tr> <td>Diabetic retinopathy</td> <td>5 (13.9)</td> <td>7 (21.2)</td> </tr> <tr> <td>Age-related macular degeneration</td> <td>6 (16.7)</td> <td>3 (9.1)</td> </tr> <tr> <td>Other</td> <td>2 (5.6)</td> <td>9 (27.3)</td> </tr> </tbody> </table>					Attended follow-up appointment n (%)	Did not attend follow-up appointment n (%)	P value	Primary diagnosis				Visually significant cataract	23 (63.9)	14 (42.4)	0.046	Diabetic retinopathy	5 (13.9)	7 (21.2)	Age-related macular degeneration	6 (16.7)	3 (9.1)	Other	2 (5.6)	9 (27.3)
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Only variables with a statistically significant association ( $P < 0.05$ ) are shown

members of ethnic minorities, and underserved), which may reduce the effectiveness of written communication [32–34]. Participants with low literacy rely on oral explanations and visual keys [34], suggesting that implementation of non-written techniques may help participants understand and retain information about their diagnoses.

The second most common reason for not making a follow-up appointment was that participants did not know how to make an appointment. During the community-based glaucoma detection examination, all participants diagnosed with non-glaucomatous ocular pathology were provided with contact information for Wills Eye Hospital and other local ophthalmologists. However, we found that almost 1 in 5

participants did not know how to make a follow-up eye appointment. Approximately 20 % of questionnaire respondents in our study had not seen an eye doctor within the past 3 years prior to the community-based eye examination. These participants are less likely to be integrated in the health care system, and their ability and knowledge of how to make an appointment may be limited. Participants may not have the necessary resources to make an appointment, such as consistent access to a telephone. Furthermore, language barriers may represent an additional challenge for scheduling a follow-up appointment. As previously discussed, patient navigators may help overcome these barriers to schedule an appointment, but further research is needed in this area.

The third most common reason for not making an appointment was that they were asymptomatic. Symptoms are minimal in the early stages of glaucoma, age-related macular degeneration, and diabetic retinopathy. In asymptomatic patients, ocular disease is often perceived to be less serious, thereby reducing adherence. Prior studies have found that lack of awareness or knowledge in patients with diabetes was associated with non-adherence to vision care guidelines [15, 35]. Educating participants about their detected eye disease may help improve follow-up rates. However, previous studies have found that providing eye health education did not increase rates of having a dilated eye examination [36, 37]. Prior to performing community-based eye examinations, our Wills Eye health educators conducted glaucoma awareness workshops. However, participants were not provided with education on non-glaucomatous eye diseases. Further research is needed to determine the effectiveness of education on increasing follow-up adherence for participants at a community-based eye examination.

Our study found that participants of the glaucoma detection program who have seen an eye doctor within the past year prior to their community-based eye examination were significantly more likely to make a follow-up appointment. Those who have seen an eye doctor within the past year may represent individuals who face fewer barriers or have found ways to overcome those barriers. Most participants in our study (62 %) had not seen an eye doctor within the past year, suggesting that many participants of our community-based project still face barriers to obtaining necessary eye care [9, 12–14].

The only variable associated with attending an appointment was the diagnosis given at the community-based eye examination. Participants with visually significant cataracts and age-related macular degeneration were significantly more likely to attend their follow-up appointment. This may be related to the impact on vision, as visual impairment is known to be an important cause of disability and reduced quality of life [2]. As previously discussed, participants reporting that their vision was not bothersome was a common reason for not making a follow-up appointment; similarly, they may also be less likely to attend their follow-up appointment.

A limitation of our study is that a large percentage of participants who were diagnosed with non-glaucomatous disease were not reachable by telephone, due to incorrect or disconnected phone numbers, or the participant did not answer after 3 separate attempts. Therefore, those who were reached may be more motivated to attend follow-up eye examinations.

Another limitation is that the study results cannot be generalized. Our study targeted at-risk neighborhoods with high poverty rates, as nearly 25 % of Philadelphia families

live in poverty compared to the national average of 8 % [23, 24]. Our study population may have been considerably “higher risk” compared to the general U.S. population, which may contribute to lower rates of follow-up.

In conclusion, the Philadelphia Glaucoma Detection and Treatment Project was able to detect high rates of non-glaucomatous ocular pathology requiring further ophthalmic follow-up. Follow-up rates at participants’ own eye care provider were sub-optimal. Increasing participant education, implementing patient navigators to help make appointments, and developing interventions to help participants remember their recommendations may improve follow-up rates after initiating community-based eye examinations. Further research is needed to determine the effectiveness of these methods on increasing follow-up adherence for participants at a community-based eye examination.

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#### Compliance with Ethical Standards

**Conflicts of interest** The authors declare that they have no conflict of interest.

## Appendix

See Table 4.

**Table 4** Telephone survey

- 
1. What language do you primarily speak at home?
    - (a) English
    - (b) Spanish
    - (c) Chinese
    - (d) Russian
    - (e) Other
  2. What is your highest level of education?
    - (a) Did not finish high school
    - (b) High school/GED
    - (c) Some college/Associate degree
    - (d) Finished college/Bachelor’s degree
  3. Do you currently live alone?
    - (a) Yes
    - (b) No
  4. When was your last eye examination before the community-based glaucoma eye examination?
    - (a) Within the past 3 months
    - (b) Within the past 6 months
-

- (c) Within the past year  
 (d) >1 year and  $\leq 2$  years  
 (e) >2 years and  $\leq 3$  years  
 (f) >3 years
5. When was the last time you visited your primary care physician before the community-based glaucoma eye examination?  
 (a) Within the past 3 months  
 (b) Within the past 6 months  
 (c) Within the past year  
 (d) >1 year and  $\leq 2$  years  
 (e) >2 years and  $\leq 3$  years  
 (f) >3 years
- 6a. Do you have health insurance?  
 (a) Yes  
 (b) No
- 6b. If yes to 6a, what type of health insurance do you have?  
 (a) Medicare/Medicaid  
 (b) Other
7. What type of transportation do you normally use?  
 (a) Public transportation  
 (b) Receive a ride from family, caregiver, or friend  
 (c) Car  
 (d) Customized community transport  
 (e) Walk  
 (f) Other
- 8a. Do you remember your results from the community-based glaucoma eye examination?  
 (a) Yes  
 (b) No
- 8b. If yes to 8a, what was your diagnosis?  
 \*Filemaker Pro software inserted the diagnosis given at the initial eye examination here, so the telephone survey administer was able to compare answers. If the participant said the incorrect diagnosis or did not remember their diagnosis, then they were listed as “no” to question 8a and were reminded of their diagnosis given at the community-based glaucoma eye examination
- 8c. If no to 8a, the participant was informed of their diagnosis given at the community-based glaucoma eye examination
- 9a. Do you remember your doctor’s recommendations for [diagnosis inserted here by software]?  
 (a) Yes  
 (b) No
- 9b. If yes, what were your doctor’s recommendations for [diagnosis inserted here by software]?  
 10a. Did you follow-up with your doctor’s recommendation?  
 (a) Yes  
 (b) No  
 10b. If yes to 10a, when did you make your appointment?  
 10c. Did you attend your follow-up appointment?  
 (a) Yes  
 (b) No  
 10d. If no to 10a, why did you not make a follow-up appointment? (Multiple answers permitted)

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