TABLE OF CONTENTS

I. INTRODUCTION

A. PURPOSE

The National Eye Institute (NEI) of the National Institutes of Health (NIH) seeks to provide much-needed public education programs to people with low vision. As part of its public health education program efforts, the Office of Communication, Health Education, and Public Liaison awarded ORC Macro a contract to design a pilot program to enhance referrals of individuals with low vision to vision rehabilitation services. This proposed pilot program will be referred to as the Vision Rehabilitation Services Referral Pilot (VRSRP) Program.

The primary purpose of the VRSRP Program is to increase patient referrals from eye care professionals to qualified vision rehabilitation services. ORC Macro has designed the VRSRP Program with this primary purpose as its guiding principle. By identifying the major stakeholders in the referral process, including patients, optometrists, ophthalmologists, office staff, and primary care physicians, ORC Macro developed the VRSRP Program that incorporates the information needs of patients, health care providers, and eye care professionals. This VRSRP Program will enable the NEI to develop and test measurable strategies, identify opportunities and barriers, and provide a cadre of health care and eye care professionals and their patients with access to useful sources of information and services. The program will also assist the eye care and vision rehabilitation professionals in reaching and providing services to those in need.

Through the development and implementation of this VRSRP Program, ORC Macro hopes to identify—

- The most effective audience for a vision rehabilitation referral education program.
- The current barriers to a patient referral education program and how to best overcome those barriers.
- The existing knowledge gaps between the education program and future opportunities, goals, and objectives.
- The strategies and best practices for national expansion of a patient referral education program.
- The most effective materials to place in eye care professionals' office settings that will serve as a quick and easy reference source.

B. BACKGROUND

The National Eye Health Education Program (NEHEP) coordinates education programs on diabetic eye disease, glaucoma, and low vision. Low vision is a visual impairment, not correctable by standard glasses, contact lenses, medicine, or surgery that interferes with a person's ability to perform everyday activities. Low vision can result from a variety of diseases,

disorders, and injuries that affect the eye. Many people with low vision have age-related macular degeneration, cataract, glaucoma, or diabetic retinopathy.

The goal of the low vision program is to improve the quality of life for people age 65 and older who have decreased visual function that interferes with their activities of daily living. The low vision program has developed strategies to reach this goal. They include consumer media campaigns, educational materials, an outreach program for professionals, and a traveling exhibit that is displayed in shopping malls nationwide.

With the initiation and development of this VRSRP Program, the NEI is seeking to expand the dissemination of their education materials and the goals of their outreach program efforts.

The NEI wants to understand issues surrounding referrals to vision rehabilitation services. Studies have shown that referrals to vision rehabilitation services reap positive results both on the part of the patient and the eye care professional. Studies also show that people who could benefit from vision rehabilitation services were not aware of such services and that most were not receiving referrals from their eye care professionals or their primary care physicians to vision rehabilitation specialists and/or service agencies.

In 2001, the NEI conducted 28 national focus groups with eye care professionals and their office staff. This was its first step in identifying opportunities and barriers for a referral education program. The objectives of these focus groups were as follows:

- To determine what ophthalmologists, optometrists, and eye care office staff know about low vision, vision rehabilitation, and related resources.

- To determine what types of resources ophthalmologists, optometrists, and eye care office staff would prefer to use in their offices.

- To determine how the ophthalmologists, optometrists, and eye care office staff can educate persons with low vision and their families and friends.

Through the information obtained from the aforementioned focus groups, and after analyzing data obtained from a literature review regarding the referral system processes, we were able to identify existing barriers, as well as possible opportunities and select methods for enhancing the referral process.

II. METHODOLOGY

In order to design this VRSRP Program, the following processes were undertaken to inform the study:

- Conducted a literature review.

- Reviewed the narrative and transcripts from the Low Vision Focus Groups Final Report: Ophthalmologists, Optometrists, and Office Staff.

- Developed evaluation measures for the VRSRP Program.

The compilation of this information allowed project staff to identify measurable strategies, opportunities and barriers, and useful resources for the development of this VRSRP Program. The literature review yielded information from U.S. and international studies about referral processes. This information will be detailed in the literature review section of this report. A discussion of the findings from the focus groups held in 2001 is also included in that section of the report. The pilot design section introduces the concept underlying the VRSRP Program, identifies opportunities and barriers, and outlines the components of the VRSRP Program. The VRSPP Program section introduces the proposed resources for the program and outlines a multi-method process evaluation design and elements to accomplish measurement.

III. FINDINGS OF THE LITERATURE REVIEW AND FOCUS GROUP REPORT

A. INTRODUCTION

Several authors have undertaken studies involving referrals to vision rehabilitation agencies and referrals from optometrists to ophthalmologists. This section details the findings in the literature regarding such referrals. The initial discussion summarizes the national and international literature and follows with an analysis of the past focus groups. Prominent findings and recommendations are extracted from the literature and listed. Finally, there is a brief discussion on the most effective audience for a referral education program.

B. THE LITERATURE REVIEW

1. U.S. STUDIES

In 1995 the Lighthouse International published statistics indicating that only 1 percent of persons who are 45 years of age and older use low vision clinical services, rehabilitation training, and recreational services. Only 2 percent of survey respondents stated that they used job placement services, only 2 percent stated they received counseling to help in the emotional adjustment to their vision loss, and only 6 percent stated that they used any form of vision rehabilitation service. The overwhelming reason given as to why these services were not used was lack of knowledge of availability.

Greenblatt (1988) surveyed 1,077 ophthalmologists in the U.S. and noted that previous studies of ophthalmologists and low vision patients revealed that a majority of ophthalmologists rarely refer patients to rehabilitation programs, and do not receive information about vision rehabilitation services. The survey revealed that as the severity of visual acuity increases, the number of such patients seen by ophthalmologists decreases. The majority of patients seen had an acuity of less than 20/20 but better than 20/70 in the better eye. More than half of ophthalmologists see six or more patients with moderate low vision (between 20/70 and 20/200) per week, and under a quarter see six or more patients per week with severe low vision (20/200 or worse). Ophthalmologists have little to no contact with patients with no useful vision.

Respondents were asked about the availability of nine different types of rehabilitation services. Almost half (49%) had no knowledge of the availability of peer support groups or special services for patients 60 years or older (45%). About a quarter of respondents had no knowledge of the availability of special educational services for children (26%), professional counseling (24%), or orientation and mobility training (24%).

When asked about what measures they took with patients in various visual acuity categories, for the moderate low vision patient (between 20/70 and 20/200), 6 percent of respondents stated that they do nothing and few said they discuss the diagnosis or provide counseling. Referrals for rehabilitation were made by 46 percent, and 32 percent said they either give low vision aids or refract. Very few scheduled follow-up appointments, referred for a second opinion, or provided information on rehabilitation services. For the severe low vision patient (20/200 and less), nearly all (99%) of the ophthalmologists discuss the diagnosis and prognosis. Slightly less (86%) schedule follow-up appointments, and 67 percent provide information on rehabilitation agencies.

The most common referral was to a low vision service (56%), or a state agency for the blind and visually impaired (49%). The least-made referrals were to peer support groups, special services for patients 60 years and older, and special educational services for children. Just under half made no referrals to professional counseling services or for orientation and mobility training.

Those ophthalmologists who did not receive information on rehabilitation services were less inclined to refer patients and, alternatively, those who did receive information were more inclined. This finding suggests that information exchange between rehabilitation agencies and ophthalmologists will serve to increase referrals. Evidence also suggests that when ophthalmologists view their position in a broader set of circumstances, the more likely they are to interact with other health professionals who may be able to educate them about rehabilitation services. Regarding courses taken on vision rehabilitation, a majority (80%) had taken only one course on low vision aids, and one-third or fewer had taken any other low vision–related courses.

Most (81%) agreed that ophthalmologists should refer to rehabilitation services, and 64 percent thought follow-up appointments should be scheduled. More than half of the ophthalmologists surveyed thought they should provide personal counseling (55%), consult with other health or rehabilitation providers (54%), and provide low vision aids (53%). Slightly less than half thought these roles were inappropriate for ophthalmologists.

Many rehabilitation agencies require that clients be declared legally blind before they are eligible for services, which may drive many ophthalmologists not to refer. Those whose low vision acuity is low or moderate may become bereft of services and left to their own devices in dealing with their vision problems.

Greenblatt made the following recommendations to increase the referral rate:

- Provide additional training for ophthalmologists in vision rehabilitation.
- Increase communications between rehabilitation professionals and ophthalmologists.

- Encourage ophthalmology certifying boards to mandate institutionalized coursework in rehabilitation for all residents, to include psychosocial needs of the patient, services provided by rehabilitation agencies, and assistive devices.

- Encourage professional societies of ophthalmologists and rehabilitation service providers to hold joint meetings.

Fletcher (1994) encouraged ophthalmologists to take steps to refer their low vision patients. He defined low vision as having two major types: central (reduced visual acuity) and peripheral (reduced field). Central low vision causes difficulties with detail discrimination, such as reading and sewing. Peripheral low vision causes difficulties with orientation and mobility, such as seeing curbs or steps and crossing streets.

Fletcher stated that patients with visual acuity in the range of 20/70 to 20/180 can read about normally with magnification and good lighting. Patients with visual acuity of between 20/200 and 20/400 require strong magnification, but reading will be slower. Those with vision in the 20/500 to 20/1,200 range can read accurately with magnification, but will be slow, as well. He recommended that ophthalmologists refer patients to eye specialists with low vision rehabilitation expertise to obtain appropriate prescriptions. Fletcher also recommended educating the patient as to the level of effort needed to become proficient in the use of low vision aids.

Fletcher also advocated tailoring vision rehabilitation to the patient's lifestyle by referring patients to an occupational therapist, an orientation and mobility specialist, or a rehabilitation teacher to ascertain adaptation techniques. The author noted the many aids that are available, such as large-print reading material, enlarged checks, felt-tip pens, and talking watches.

Patients also become depressed and afraid when faced with the prospect of having low vision, and may feel an inability to cope and have a fear of blindness. Fletcher advocated assessing the patient's emotional state and intervening with appropriate treatment to mitigate their fears. For example, patients with macular degeneration should be told that it does not result in total blindness and that their vision can be useful for the rest of their life.

Fletcher lists some resources such as low vision rehabilitation clinics, which can be found through optometrists or ophthalmologists, hospitals, and charitable organizations; and support groups, which can be found through the state department of vocational rehabilitation, or the division of blind rehabilitation.

Greenblatt (1989) surveyed an ophthalmology residency program in the United States. The results showed that although most residency programs offered training in low vision aids, few offered training on other rehabilitation issues.

This study implemented the application of a 1-day curriculum entitled "Rehabilitation for Visually Impaired and Blind Patients." The goal of the program was to inform residents of the potential for independent living that visually impaired people possess, to inform residents of the services offered by rehabilitation agencies, and encourage residents to become involved within the referral framework of rehabilitation services. The topics included low vision aids,

psychosocial needs, low vision simulator exercises, special needs of the elderly and adolescents, and the rehabilitation process. Participants were tested prior to the training and 6 months after.

Most residents saw patients whose vision was not categorized as severely impaired, and few saw patients with no useful vision. Most were aware of six of the nine types of rehabilitation services in the local area, and on the posttest, most were aware of all nine types. There was evidence of significant increase in knowledge about services for the elderly, orientation and mobility training, and professional counseling.

For patients whose low vision acuity was moderate (between 20/70 and 20/200), the majority (53%) said they referred to rehabilitation services, and this increased to 67 percent on the post test. For patients whose low vision acuity was severe (less than 20/200), most residents (93%) stated that they discussed the diagnosis and prognosis and schedule follow-up appointments for half or more of their patients. Half of the residents discussed functional implications and 48 percent discussed information on rehabilitation services with their patients. The categories of providing optical aids, non-optical aids, and training in using optical aids showed hardly any improvement at the posttest.

During the pretest, a majority of residents had referred patients to only one type of rehabilitation service, with most making referrals to low vision services. Almost half had referred to agencies that sold low vision aids, almost one-quarter had referred for special library services, and a smaller amount had referred for vocational rehabilitation, professional counseling, orientation and mobility training, special education, peer support groups, and special services for the elderly.

Greenblatt noted that even when residents' knowledge of available rehabilitation services increased, referrals did not increase proportionally, and concluded that residents need to interact more with rehabilitation specialists and that their schedules should include time for referrals. One chief resident stated that residents' schedules are rigid and allow little time to spend with patients.

As a result, Greenblatt made the following recommendations for improving the referral process:

- Institutionalize training on rehabilitation issues in the residency program.
- Provide lectures on the needs of patients with vision loss.
- Have attending ophthalmologists teach about patient cases where assistive devices and rehabilitation services were used.
- Include rehabilitation professionals in case presentations.
- Encourage certifying boards to include examination questions about patients who cannot be medically cured.
- Have heads of ophthalmology departments invite state agency rehabilitation professionals to regularly attend educational programs.

- Provide adjunct appointments to rehabilitation professionals.

- Offer internships to graduate students in rehabilitation programs.

A study by Kirschen (1992) revealed negative and positive influencers of referrals from optometrists to ophthalmologists. The negative influencers: 1) ophthalmologists had an onsite dispensary, and 2) ophthalmologists used the media to promote their practice. The positive influencers: 1) Ophthalmologists were professionally competent and preferably board certified, 2) they responded to referrals with a written report, 3) they were available for consultation, 4) they had good office staff, 5) they returned the patients to the referring optometrist, and 5) they were known personally by the optometrist.

Kirschen also noted that the fields of optometry and ophthalmology will overlap on a greater basis in the future. The schedule for reimbursement from Medicare for cataract surgery will prompt ophthalmologists to include primary vision care into their practice. However, the increasing number of states that permit optometrists to use drugs for diagnostic and therapeutic purposes will allow optometrists further foray into the area of eye care.

Refowitz (1981), described a study in which ophthalmologists and optometrists were surveyed. The study, conducted from 1974 to 1975, showed that a majority of optometrists send between 1 percent and 14 percent of their patients to ophthalmologists, yet made far fewer referrals to other optometrists. Only 9 percent of ophthalmologists said they make no referrals to other ophthalmologists, while 33 percent of optometrists said they make no referrals to other optometrists. Based on data collected from this survey, it can be concluded that because of the few sub-specialties in optometry, there would be little reason to refer to another optometrist. The study also noted that only 1 percent of optometrists did not refer any patients to ophthalmologists, while 75 percent of ophthalmologists did not refer any patients to optometrists. Refrowitz concluded that ophthalmologists do not return referred patients to optometrists, and this behavior may be fostering animosity.

For both optometrists and ophthalmologists, practice workload increased with referrals, suggesting that the few optometrists who do receive many referrals are either in specialties that receive a lot of referrals (vision training) or have thriving referral relationships with ophthalmologists. The factors that affected referrals were as follows: 1) severity and complexity of the presenting problem, 2) originating doctor's propensity to refer, 3) specialist's respect for referral relationship and etiquette, 4) patient's choices.

Newcomb and Potter (1979) studied the optometry clinic of the Birmingham Veterans Administration Medical Center (BVAMC). They found a 5 percent referral rate from the optometry clinic to other clinics within the BVAMC, the majority of which were to the ophthalmology clinic. The most common causes of referral were cataract, external eye disease, glaucoma, and fundus disorder. Of the 5 percent of referrals, 86 percent of ophthalmologists agreed with the diagnosis of the referring doctor, with a range from 64 percent for 'other fundus disorder' to 100 percent for cataract, diabetic retinopathy, senile macular degeneration, and other diseases and conditions.

Of the referred cases that were confirmed by the consultant, 50 percent were managed by follow-up care, 25 percent were treated with pharmacological agents, 12 percent were treated with surgical techniques, and 12 percent were dismissed. Of the referred cases in which the consultant's diagnosis was different from the referee, 48 percent were managed by follow-up care, 12 percent were treated with pharmacological agents, 2 percent were treated with surgical techniques, and 37 percent were dismissed.

Newcomb and Potter noted their referral rate of 5 percent was higher than Kintner's (1961) 2 percent and Griffin and Luckerman's (1970) rate of 3 percent, and attributed the difference to varying population characteristics. They also noted the higher rate of Kleinstein and Newcomb's (1976) 14 percent, but noted that the VA study compared the number of referred patients to the total number of patients rather than the total number of patient visits.

2. BRITISH STUDIES

A study by Harrison, Wild, and Hobley (1988) outlined the vision services offered under Britain's socialized medicine program. Sight tests have been available free to the public since 1948. The services were originally available through the Ophthalmic Supplementary Service until 1975, when the program was available through the General Ophthalmic Service. Most sight tests were given by ophthalmic opticians, with the remaining by ophthalmic medical practitioners. Ophthalmic opticians are required to refer patients with eye injury, disease, or abnormality to a general practitioner. Study data suggest that the General Ophthalmic Service is a main source of referrals to the hospital eye service, especially cases of glaucoma.

Port (1989) noted that compared with the results of other studies, UK optometrists seem to refer approximately 5 percent of patients, as opposed to U.S. and Australian optometrists, who refer approximately 2 percent of patients. The author posits that relationships between optometrists and ophthalmologists in the U.S. and Australia are less than ideal, and may imply that an optometrist will only refer a patient if the optometrist is fairly certain as to the diagnosis. Also, ophthalmologists in the U.S. and Australia perform a larger percentage of routine eye exams than those in the UK, and patients who are experiencing adverse symptoms may choose to see an ophthalmologist rather than an optometrist, making inherent eye disease less prevalent among U.S. and Australian optometrists' patient population than UK optometrists' patient population.

3. AUSTRALIAN STUDY

Keeffe, Lovie-Kitchin, and Taylor (1994) note that in a survey conducted by the Royal National Institute for the Blind in the UK, only 31 percent of people who were eligible for blindness registration were indeed registered, and that only 12 percent of those with partial sight were registered. Previous estimates of the use of low vision services reveal that only 3 percent of those eligible in Australia use them, 11 percent of those in Canada, and less than 15 percent of those in the U.S.

Several reasons were put forth to account for the underuse of low vision services: lack of public education on common eye diseases, lack of referral by eye care practitioners, and patient failure to attend referral appointments.

Local availability of low vision services was a factor in the rate of referral. More low vision and rehabilitation services, with a coordination of care, would seem to increase efficiency for patients and practitioners. The most common cause of low vision was age-related macular degeneration.

Some suggestions to help improve the referral rate to low vision services: exchange of information between ophthalmologists and low vision service providers, knowledge of peer support groups, and information from low vision centers about services offered.
Since most Australian ophthalmologists do not prescribe low vision devices, patients need to be referred to agencies that do prescribe these devices.

4. SALIENT FINDINGS AND RECOMMENDATIONS FROM THE LITERATURE

FINDINGS—

- A majority of ophthalmologists agreed that they should refer to rehabilitation services and schedule follow-up appointments. However, slightly less than half thought it would be inappropriate for ophthalmologists to provide personal counseling, consult other health or rehabilitation providers, and provide low vision aids.

- Many rehabilitation agencies require that clients be declared legally blind before receiving services, which may deter ophthalmologists from referring patients to vision rehabilitation.

- The referral of patients to vision rehabilitation and the education of patients as to the level of effort needed to proficiently use low vision aids is highly recommended.

- There is a possibility of the onset of depression in low vision patients, and therefore assessing a patient's emotional state and providing treatment is necessary.

- One study noted that when ophthalmology residents' knowledge increased of available vision rehabilitation services, referrals did not increase proportionally.

- Less than 15 percent of those in the U.S. who are eligible for low vision services actually use them.

- One study posited three reasons to account for the underuse of low vision services: 1) lack of public education on common eye diseases, 2) lack of referral by eye care practitioners, 3) patient failure to attend referral appointments.

RECOMMENDATIONS—

- Additional training for eye care professionals in vision rehabilitation should be provided.
- Communications between rehabilitation professionals and eye care professionals should increase.
- Professional societies of eye care providers and rehabilitation service providers should be encouraged to hold joint meetings.
- Training on rehabilitation issues should be institutionalized in residency programs.
- Attending eye care professionals in residency programs should teach about patient cases where assistive devices and rehabilitation services were used.
- Certifying boards should be encouraged to include examination questions about patients who cannot be medically cured.
- Heads of ophthalmology departments should invite state agency rehabilitation professionals to regularly attend educational programs.
- Adjunct appointments should be provided to rehabilitation professionals.
- Internships should be offered to graduate students in rehabilitation programs.

C. ANALYSIS OF PAST FOCUS GROUPS

From February to April of 2001, ORC Macro conducted a series of focus groups (both in-person and online) with optometrists, ophthalmologists, and their office staff. The participants were asked about low vision referral criteria and materials they would like to use to increase education on low vision. Several suggestions were put forth by the participants for materials or services that would enhance their knowledge. Optometrists, ophthalmologists, and office staff agreed that the following would be useful:

- Low vision referral form
- Universally accepted definition of low vision
- Low vision rehabilitation services information
- Low vision devices/product information
- Community-specific information
- Continuing education on low vision for physicians
- Continuing education on low vision for staff
- Patient education video on low vision

- Physician education CD-ROM on low vision
- Patient information on low vision
- Physician resource binder
- Patient information packet
- Development of NEI Web site targeted toward physicians.

D. THE MOST EFFECTIVE AUDIENCE FOR A REFERRAL EDUCATION PROGRAM

Upon review of the literature, the most effective audience for a referral education program would be ophthalmology residents, practicing optometrists, practicing ophthalmologists, eye care providers' office staff, eye care patients, and rehabilitation professionals. Much of the evidence points up the fact that many eye care professionals lack knowledge of the availability and types of services that rehabilitation agencies offer. To increase eye care professionals' knowledge in this area would serve to increase referrals. An education program would also serve to afford rehabilitation professionals insight into the experiences of optometrists and ophthalmologists in dealing with low vision patients. And a well-informed patient is more likely to request that their eye care professional refer them for vision rehabilitation services.

During the focus groups held during 2001, optometrists and ophthalmologists requested information on referrals to low vision services. Studies in the literature demonstrated that increasing the exchange of information among health, vision rehabilitation, and eye care providers would serve to increase the referral rate to vision rehabilitation services. A pilot program that would educate all those involved in the patient-referral process to vision rehabilitation services could be the catalyst to a coordination-of-care network that would serve patients and keep them as its focus.

IV. PILOT DESIGN

A. CONCEPT

The VRSRP Program design has been developed to provide eye care professionals, their office staff, and their patients with valuable information and useful resources while simultaneously providing the National Eye Institute (NEI) with a vehicle to disseminate and test eye health education materials on the importance of referral services. It is the intent of this program to allow for effective evaluation that will encourage program replication and expansion. The design of the VRSRP Program is based on feedback received from the focus groups, and an extensive literature review. Using the proposed components of the VRSRP Program, the following will be achieved:

- Eye care professionals and their office staff will gain an understanding of the importance of referrals.

- Eye care professionals will have the necessary resources and tools to refer patients with

minimal complications.

- Eye care professionals and their office staff will possess comprehensive information regarding low vision and low vision referral.

- Eye care professionals and their office staff will be able to provide patients and their respective friends and family members with useful and convenient information.

- Eye care professionals and their office staff will be equipped to better educate themselves, patients, and the friends and family of patients on the need for referrals and vision rehabilitation services.

B. OPPORTUNITIES AND BARRIERS

The implementation of the VRSRP Program is ideal for the identification of opportunities. Opportunities that may generate from the implementation of this VRSRP Program include, but are not limited to—

- The development of effective and useful referral education tools for eye care professionals and their patients.

- The national expansion of a referral program that facilitates uncomplicated and informed patient referrals.

- The distribution of up-to-date information regarding low vision referral and vision rehabilitation services.

We acknowledge that the VRSRP Program may reveal barriers. For example, during the focus groups conducted in 2001, many eye care professionals identified "chair time" as the most common barrier when working with low vision patients. Focus group participants said that low vision patients often require more time than other patients. Consequently, participants said that financial compensation is not proportionate to the time spent.

C. VRSRP PROGRAM

The three components of the VRSRP Program are resources offered in the following formats: print, audio/visual, and Web-based. ORC Macro proposes the development of a Provider Desk Reference (PDR) as the central component of the VRSRP Program. (Note: Based on feedback received during the 2001 focus groups, various eye care professionals and staff said that low vision patients often ask them for reading material. Therefore, project staff decided that the term "provider" be used instead of "physician.")

The PDR will equip eye care professionals with quick and convenient access to low vision–related information. As such, the PDR will be comprehensive in scope. Information and materials included in the PDR will be developed to facilitate and encourage an informed and uncomplicated referral process for the provider and the patient.

Provider and patient-focused resources will comprise the PDR. The provider-focused print material will include—

- A list of visual rehabilitation resources (both local and national)
- Fact sheets or FAQs pertaining to low vision referral and vision rehabilitation services
- Follow-up referral forms
- Standard referral forms.

Other print material that will be included in the PDR are patient-focused one-page fact sheets that providers may distribute to their respective patients. These fact sheets will allow patients and concerned friends and family members to refer to information at their leisure. The one-page fact sheets and FAQs will allow providers and their staff to reproduce additional copies if needed. Of course, the patient-focused fact sheets will be somewhat different from the provider-focused fact sheets as they will be written in lay terms using large print (16"-18"). However, it should be noted that the patient-focused fact sheets will be as comprehensive as the provider-focused fact sheets.

In addition to patient-focused fact sheets and FAQ's, the PDR will include low vision–related posters and brochures designed to be placed in the waiting rooms of eye care professionals. The purpose of the posters and brochures is to encourage low vision patients to ask their eye care professionals about referrals and available vision rehabilitation services. Diagrams, similar to that on the EYESITE, will illustrate low vision–related eye diseases and conditions.

Based on feedback received from the Spanish-language focus groups, print materials will also be developed for the Spanish-language community. Bi-lingual materials should be culturally appropriate and should avoid transliterations.

The second component of the VRSRP Program is the inclusion of patient- and provider-focused audio and visual materials. Acknowledging that eye care professionals maintain busy schedules, provider-focused audio materials will also be developed so that they can listen while driving or at home. Information provided on the audio materials will be consistent with referral information provided in the print materials, and will be made available in cassette and compact disc (CD) format. In order to ensure the intended comprehensiveness of the PDR, each eye disease or condition will be covered separately, resulting in a low vision audio series. Provider-focused videos will also be developed and will primarily address the need for low vision referrals using vignettes and case studies.

A patient-focused video, available in VCR and DVD format, will be included as part of the PDR. Consistent with the print materials, statements regarding the need for and importance of low vision referrals to vision rehabilitation services will be foremost on the video. The video will also provide patients with information about low vision–related eye diseases and conditions. The intended purpose of the patient-focused video is to encourage low vision patients to ask their eye care professional about referrals to vision rehabilitation services.

As depression is often common in persons living with low vision, the video will address the availability of support groups. ORC Macro proposes the use of "See for Yourself," created by

the Lighthouse International, to play continuously in the waiting offices of eye care providers. However, as an alternative, a video developed from the information contained in the Low Vision booklet entitled "What You Should Know About Low Vision" may also be used.

The third component of the VRSRP Program is the development of Web-based resources. In addition to providing low vision–related information, this component will serve three functions. The first function of the Web-based resources is the facilitation of eye care professionals in accurately and expediently accessing community resources using a ZIP code–driven database (a services locator). The database will be an enhancement to the already existing NEI Web site. Eye care professionals will have the ability to locate local vision rehabilitation services/organizations and other needed low vision services and products. This will also help eye care professionals in the referral process, as they will have a better understanding of available vision rehabilitation resources when determining where to refer patients. By entering the patient's respective ZIP code into the database, all local low vision–related information, resources, and organizations and facilities will be produced within a matter of seconds.

This particular feature of the Web enhancements allows for the second function as well. During the focus groups conducted with optometrists, ophthalmologists, and office staff, it was apparent that many eye care professionals were unaware of the NEI Web site. The proposed Web enhancement will give the NEI Web site greater exposure, while providing valuable information to providers and their respective patients. Eye care professionals will be able to access articles and reports detailing groundbreaking research conducted at the NEI.

The third function of the Web enhancements will be the ability to link other sites on the NEI Web site. ORC Macro staff have already conducted an investigation of available low vision Web sites and discovered a plethora of information to be shared with eye care professionals, office staff, and their patients.

D. OPERATION AND IMPLEMENTATION

The launch of the VRSRP Program sites will be carefully considered. The following will be taken into consideration when selecting VRSRP Program sites:

- Number of persons living with low vision in a particular geographic region
- Number of persons aged 65+ living in a particular geographic region
- Number of available vision rehabilitation centers in a particular geographic region.

During the focus groups conducted in 2001, many eye care professionals said that referring low vision patients is somewhat difficult due to transportation issues. Therefore, selected sites will be nationally oriented and will include rural and non-rural areas in the Northeast, South, Midwest, and West. This will allow the identification of barriers and ultimately possible solutions specific to providers and patients located in rural and non-rural areas. Although a scientific sampling method will not be employed, sites that are representative of national race, ethnicity, and age will be considered, as well.

Once the sites have been selected, the PDR consisting of print and audio/visual materials will be distributed to eye care professionals at the selected sites, and they will also be made aware of the Web-based resources. A downloadable icon that will enable direct access to the NEI Web site will be installed on the computers of participating providers. A toll-free phone number will be made available to participating sites so that they can request technical assistance if needed. The evaluation design is presented in the following section.

V. EVALUATION DESIGN OUTLINE

In the previous section, we presented the proposed Vision Rehabilitation Services Referral Pilot Program. The primary elements of that program are—

1. Print Media such as the proposed Physician's Vision Rehabilitation Services Desk Reference, Vision Rehabilitation Services Fast Facts, other Brief Print Materials.

2. Audio/Visual Media such as Physician's Vision Rehabilitation Services Audio Tape Series and Patient Videos Addressing Low Vision Referral.

3. Web-based Enhancements and Referral Tools, such as Web links and the Low Vision Services Locator.

The evaluation will be framed by the following evaluation questions:

1. Did the vision rehabilitation services referral information reach the intended eye care professionals' audiences? What vision rehabilitation services referral information was sent and to whom?

2. Did the intended eye care professional audiences review the vision rehabilitation service referral information? Did the eye care professionals find the information useful? What did they like most? What did they like least? Did the eye care professionals have any suggestions as to how to improve the materials distributed?

3. As a result of reviewing the vision rehabilitation services referral information, do eye care professionals report having more knowledge about vision rehabilitation services referral? Do eye care professionals and their staff report that a particular program material was more important than the others in their increased referral capacity? Did they report a change in their attitude about referring patients to vision rehabilitation services? Did they report an intention to refer more patients or have they actually referred more patients to vision rehabilitation services?

In selecting an evaluation design, it is important to note a couple of issues. First, evaluation designs emerge not only from the evaluation questions they are designed to answer, but also from constraints such as time, cost, resource availability, program fidelity, and staffing. This issue is particularly salient for the proposed evaluation because it is being designed as a VRSRP Program (suggesting that the scope and depth of the study necessarily be limited at this time). Second, every evaluation design is likely to be a blend of several types (e.g., process, outcome,

and impact) as well as involving several strategies (e.g., case study, focus groups, sample survey, field experiment, and use of available data).

Evaluation is the systematic collection and analysis of data needed to make decisions, a process that most well-run programs engage from the outset. The proposed evaluation comprises two primary types of evaluation: process and outcome. These types of evaluation can also be thought of as a set of assessment options that build upon one another, allowing staff to increase their knowledge about the activities they undertake as they incorporate more options or dimensions of their evaluation.

Every evaluation is designed to utilize data collected in a systematic manner. These data may be quantitative—such as counts of program participants, amounts of program services delivered, or the number of referrals executed. They also may be qualitative—such as descriptions of what transpired during a series of office visits, responses to a series of questions asked in an interview or focus group, or observations of clinical practice. Many successful evaluations have involved process and outcome evaluations that collect and analyze both quantitative and qualitative data.

A. PROCESS EVALUATION

Process evaluation has two main purposes. First, the process evaluation is designed to describe the implemented program. Second, it determines whether the program has been implemented as it was intended. The second purpose is often referred to as program fidelity. A process evaluation should explain any major deviations between the planned and actual program.

The focus of the proposed process evaluation is to determine whether the VRSRP Program (the print, audio/visual, and Web-based materials) reached the intended audiences and what those audiences thought about the program. Information on key characteristics of the program is often collected during the course of a process evaluation. Those key characteristics include—

- Organizational context (type of agency administering the program, size, years in operation, experience providing services to target community and population, community linkages, reputation in the community)
- Program setting (location, facilities, community environment)
- Target population (age range, race/ethnicity, common risk factors, sources of referral or recruitment)
- Program theory (underlying theory, key assumptions about the causal linkage between program services and expected outcomes)
- Program structure (types of services provided, planned frequency and duration of services, methods of service delivery, pattern of client flow through the program, key service referral linkages).

Information on the frequency, length, and duration of each service is usually reported for the typical program participant (i.e., in median or mean numbers). The process evaluation compares this information to the characteristics of the planned program services, and identifies any major deviations between the planned and actual program services. Such a comparison is an important part of assessing the fidelity of the program.

Besides documenting the characteristics of services, consideration should be given to collecting data on participant satisfaction with the services. A good assessment of participant satisfaction requires data on participant perceptions of each program service received and overall satisfaction with the program.

A process evaluation should also document important problems that were encountered while implementing the program. Implementation problems are to be expected. Even the best planning cannot foresee all future conditions or issues that will affect the program. Deviations from a program's design are often caused by implementation difficulties. For example, participants may have greater service needs than the planners anticipated. Information on such problems and the resulting program changes is useful when interpreting outcome evaluation findings. This information is also useful to others who may consider replicating the program.

B. VISION REHABILITATION SERVICES REFERRAL PILOT PROGRAM PROCESS EVALUATION STUDY

The process evaluation is designed to be a multi-method approach combining the results of a number of data collection strategies to address each component of the VRSRP Program. The following is an outline of the proposed evaluation approach.

Approach #1: Telephone interviews with a relatively small, nationally oriented sample of 200 eye care professionals regarding receipt, review, and use of print, audio/visual, and Web-based materials.

The United States will be divided into four regions (e.g., west, northeast, south, and midwest) and one state will be selected from each region. States selected will provide a range of estimated prevalence rates for vision impairment and blindness, include rural as well as non-rural areas, include minority populations served, and generally attempt to mirror the general population of eye care professionals as best as possible. Eye care professionals in those states (found via available lists) will be contacted and screened for interview eligibility. Following routine interview protocol, ORC Macro will make multiple (10) attempts to reach the eye care professionals. In the event that none of the attempts is successful, the next name on the list will be selected and contact will be attempted.

The 20-minute interview will address whether the material was received, what they thought of the organization of the materials, their clarity, completeness, and usefulness. Interview participants will also be asked what materials they particularly like and dislike, and how they think the materials could be changed in order to be improved.

Approach #2: Online focus groups with eye care professionals regarding receipt, review, and use of VRSRP Program materials.

An alternative (or supplement) to the proposed telephone interviews is a series of online focus groups with eye care professionals. The same sort of sampling plan would apply (national orientation, range of state prevalence rates for vision impairment and blindness, rural and non-rural, minority populations, etc.) yet the groups would be composed of 8–10 eye care professionals engaged in a 1-hour focus group that asked the same questions as those in the telephone interviews. For the purposes of this evaluation, 8 or 12 focus groups should be conducted in each selected state to yield useful pilot information.

A disadvantage of the focus group method is the limited number of participants we would be able to contact for the same effort and cost as the telephone interview. An advantage of this method is that eye care professionals (like other medical professionals) are more likely to engage in an online focus group than they would respond to a telephone or mailed survey.

Approach #3: Bounce-back cards for selected written materials.

This is a low-cost evaluation method that yields surprisingly high returns for professional groups such as medical personnel. The bounce-back card will be designed to ask many of the same questions as the telephone interview and online focus group with specific reference to a particular VRSRP Program material distributed (e.g., clarity, usefulness, likes, dislikes, improvements). The bounce-back card is designed to be a pre-addressed, stamped postcard that eye care professionals can remove once they have reviewed the VRSRP Program material and can easily return it.

Approach #4: Web site assessment, including online commenting and site feedback (clarity, ease of navigation, utility).

Once the NEI Web-site enhancements, Web links, and new Web tools (e.g., the referral locator tool) have been developed and implemented, a Web site assessment will be developed to solicit comments and feedback from eye care professionals regarding their use of the NEI Web site. The assessment will provide an opportunity for Web site users to comment on the clarity, utility, and ease of navigation of the NEI Web site as well as suggest improvements. The comments/feedback can be recorded online and in real-time. NEI Web site visitors will also be given the option to complete a short Web site evaluation form that will assist in the continuous quality improvement of the site.

Data from each of the proposed process evaluation approaches will be analyzed using appropriate analytical methods. Narrative and other qualitative data will be content analyzed, as well as relevant patterns, themes, and issues derived, in order to answer the process evaluation questions. Numerical and other quantitative data will be analyzed using descriptive statistical methods and will be reported in such a way that individual respondents cannot be identified.

C. OUTCOME EVALUATION

Outcome evaluations study the immediate or direct effects of a program on participants. For many programs, this often entails examining changes in the knowledge, attitudes, and behaviors of program participants and attempting to attribute those changes to the program delivered to the participants. In order to attribute program outcomes to the delivered program, a common frame of reference is often used in outcome evaluation. That frame of reference is the comparison, conducted with as much rigor as possible, of changes among program participants (operationalized as measurable program outcome indicators) with that of persons not receiving the program. Persons not receiving the program can include those receiving alternative interventions. Alternatively, comparisons can be made between measures of the behavior or conditions being examined and similar information across time, or between measures of outcomes and conjectures about what would have occurred in the absence of the program.

The issue here is one of establishing causality between the program intervention delivered and the outcomes observed immediately following completion of the program. The science of program evaluation states that the ideal way to establish causality is by means of the randomized experiment. The randomized experiment is characterized by subjects being randomly sorted into two or more groups, one group that is designated the control group and receives no intervention or an innocuous one, and the other group or groups designated as the experimental group, which is given the intervention being tested. Outcomes are observed for both groups (in the same time period) with any differences being attributed to the experimental intervention. Sometimes outcome evaluations closely follow the randomized experiment model and for others, practical considerations, time pressures, and cost constraints necessitate major compromises with the ideal.

Prior to designing and implementing an outcome evaluation, two conditions must exist. First, either the project's objectives are sufficiently well articulated to make it possible to specify measures of outcome achievement or the evaluator must be able to establish a reasonable set of objectives and develop outcome measures. Second, the intervention or program should be sufficiently well implemented so that there is no question that key elements of the intervention have been delivered to the experimental (intervention) group. Much time, effort, and resources have been wasted estimating the effects of programs that lack measurable goals or have not been properly implemented.

If the program goals are sufficiently well articulated and measurable and it has been well-implemented, then a carefully designed and implemented outcome evaluation can be conducted with confidence that program effects can be attributed to the program. There are a variety of evaluation designs available for examining the relationship of a program and its outcomes. We will consider two classes of evaluation designs that are useful for the assessment of causation in program evaluation: true experiments and quasi-experiments.

True experimental designs are the strongest in that subjects are randomly assigned to treatment and control conditions and outcomes are measured at the same points in time for each group before and after some program intervention. Quasi-experimental designs are not as strong as true experiments, but they are better than pre-experimental designs. A quasi-experimental design has an intervention group and at least one comparison group, but random assignment is not used.

In many program evaluations, random assignment cannot be used for one reason or another, but other features of the experimental design can be applied. In a quasi-experimental design, outcome measurements are taken on both groups before and after the intervention group receives the program services. The comparison group is composed of individuals who are similar to those in the intervention group, but there are always differences in the characteristics of the two groups. Because random assignment is not used, it is not possible to fully attribute the measured outcomes to the program's interventions. The evaluator's job is to rule out all rival alternative explanations for those outcomes, leaving the program effect as the only plausible explanation.

Weak evaluation designs do not use a comparison or control group, and for that reason, one cannot establish whether there is a relationship between the program interventions and the measured outcomes. Pre-experiments are considered weak designs because they lack a basis for comparison of the outcome measurement. Designs that measure participant outcomes before and after participants receive services or only after the participants receive services—but do not collect similar outcome measures of a comparison group (i.e., persons not receiving services) will be limited in terms of what they can conclude regarding the effect of the services. In both of these cases, the evaluation findings will allow one to conclude that the program participants changed in certain ways (e.g., magnitude and direction), but it is unknown whether the changes would have occurred if participants did not receive the program services.

D. VISION REHABILITATION SERVICES REFERRAL PILOT PROGRAM OUTCOME EVALUATION

In order to answer questions about changes in knowledge, attitude, or referral behavior among eye care professionals that is attributable to the VRSRP Program, it is necessary to utilize a rigorous evaluation design that collects data from eye care professionals who do not have exposure to the VRSRP Program materials.

1. EVALUATION DESIGN

The proposed evaluation design is a national quasi-experimental evaluation of the outcomes associated with the VRSRP Program. The goal would be to compare the knowledge, attitudes, and referral behavior for a random sample of eye care professionals receiving the VRSRP Program with those of a matched sample of eye care professionals who have not been exposed to the VRSRP Program. Eye care professionals participating in the study would be randomly assigned to the treatment group (those receiving the VRSRP Program materials) and comparison group (those not receiving the VRSRP Program materials). Measurements of the eye care professionals receiving the VRSRP Program materials would be prior to receipt, within 30 days after receipt of the materials, and 3 months after receipt. The same measurement intervals would be applied to each member of the comparison group.

2. SAMPLING PLAN

Site and participant selection will be designed to be nationally oriented, not nationally representative. What this means is that a small sample of eye care professionals (n=200) will be selected from four regions of the country (50 per region) to participate. Participants will be randomly assigned to one of two groups (25 per group) in each region: those receiving VRSRP Program materials and those not receiving VRSRP materials. Sampling criteria will include—

- Eye care professionals working in states with a range of estimated prevalence rates of vision impairment and blindness (NEI, 2002).
- Eye care professionals serving rural and non-rural areas.
- Eye care professionals serving ethnic minority populations.
- Eye care professionals serving older and younger Americans.

The outcome evaluation sample will be the same as the process evaluation sample to save time and to make efficient use of VRSRP Program funds.

3. MEASUREMENT

A brief measure of the eye care professionals' knowledge, attitudes, and behavior regarding referrals, referral history (including reasons for referral), and actual numbers of referrals (and reasons) will be administered before the materials are distributed, 30 days after they have been received, and again 3 months after receipt (those not receiving materials will be asked to respond only to the survey measures).

4. OMB APPROVAL

One potential problem with this design is the need for OMB approval. According to federal Paperwork Reduction Act requirements, the Office of Management and Budget is required to review and approve any collection of information that asks more than 9 individuals the same questions. OMB clearance of proposed data collection efforts commonly requires 90 days, added to the time it takes to prepare and submit to OMB a fully specified and complete clearance package from the agency requesting approval.

Because the VRSRP Program materials will require an estimated 6 months to prepare, this problem may not present a difficult hurdle. Assuming work on the OMB clearance package can begin immediately following award of the VRSRP Program contract, it is likely that the OMB package could be prepared, submitted, reviewed, and approved prior to commencement of the evaluation.

5. DATA ANALYSIS

The data collected for the outcome evaluation will be analyzed using appropriate statistical methods. For the design proposed, analysts will examine item responses before conducting any of the comparative analyses to remove out-of-range and ambiguous outcome data. Group equivalence analyses will be conducted with the pre-program data and any differences will be examined for potential biasing effects. Next, data collected before the VRSRP Program materials were distributed will be compared with data collected within 30 days after the VRSRP Program materials had been received. Changes in the data will be noted for both treatment and comparison group members, and then group means and other measures of central tendency will be compared between the two groups. Analyses of variance and covariance (controlling for pretest differences) will be conducted to examine the potential effect of the VRSRP on knowledge, attitude, and referral behavior. Data collected at the 3-month follow-up will be analyzed in a similar fashion to examine latency and recent trends. Tests comparing eye care professionals from different regions, rural and non-rural areas, and populations served (racial and ethnic minorities and non-minorities) will be conducted to determine the importance of those independent variables.

6. WEB-BASED OUTCOMES

In order to assess the outcomes associated with the Web-based enhancements, we propose to utilize Web Trends Log Analyzer. This Web-site data collection and analysis package collects information about Web site hits, page hits, and other simple counters, and generates monthly trend reports. The trend reports include more than 35 pages of detailed information about the hits, views, and usage of the site.

VI. SUMMARY

In 2002, the NEI requested that ORC Macro design a pilot study to enhance referrals to vision rehabilitation services. The goals of the study were threefold—

- To reexamine and reanalyze a report ORC Macro prepared in 2001 entitled *Low Vision Focus Groups Final Report: Ophthalmologists, Optometrists, and Office Staff*
- Design a pilot study
- Determine the evaluation measures for the pilot study.

ORC Macro staff also conducted a review of the relevant literature on referrals and made recommendations based on that literature.

Although we found a great deal of information through the literature review, the most critical and useful information came directly from eye care service providers. This information was, of course, derived from our focus groups with eye care providers. We have taken these groups' suggestions and developed a comprehensive pilot program. We hope the VRSRP Program and its evaluation will provide the NEI with the knowledge and/or guidance on how to enhance

referrals of individuals with low vision to vision rehabilitation services.

BIBLIOGRAPHY

Fletcher, D. 1994. Low vision: The physician's role in rehabilitation and referral. *Geriatrics.* May, 49(5): 50–53.

Greenblatt, S. 1988. Physicians and chronic impairment: a study of ophthalmologists' interactions with visually impaired and blind patients. *Social Science and Medicine.* 26(4):393–399.

Greenblatt, S. 1990. Training ophthalmology residents to treat patients with vision loss. Results of a demonstration program. *Ophthalmology.* January, 97(1):138–43.

Griffin, J. and Luckerman, R. 1971. Referrals from optometrists to ophthalmologists in a prepaid health center. *American Journal of Optometry and Archives of American Academy of Optometry.* July, 48(7):615–618.

Harrison, R.J., Wild, J.M., and Hobley, A.J. 1988. Referral patterns to an ophthalmic outpatient clinic by general practitioners and ophthalmic opticians and the role of these professionals in screening for ocular disease. *BMJ.* November, 297(6657):1162–7.

Keeffe, J.E., Lovie-Kitchin, J.E., Taylor, H.R. 1994. Referral to low vision services by ophthalmologists. *Australian and New Zealand Journal of Ophthalmology.* August, 24(3):207–214.

Kintner, G. 1961. Optometry's role in health maintenance—A study of referrals. *American Journal of Public Health.* November, 51(11):1688–1693.

Kirschen, Morris. 1992. Current referral criteria for optometrists. *California Optometry.* 18(4):14–15.

Kleinstein, R.N. and Newcomb, R.D. 1976. A descriptive epidemiological study of optometry services in the Birmingham Veterans Administration Hospital. *Journal of the American Optometric Association.* December, 47(12):1542–5.

Newcomb, R. and Potter J. 1979. Diagnostic outcomes of optometric referrals in a VA medical center. *Journal of the American Optometric Association.* August, 50(8):881–7.

Port, M.J.A. 1989. Referrals and notifications by optometrists within the UK: 1988 survey. *Ophthalmic and Physiological Optics.* January, 9(1):31–35.

Refowitz, R. 1981. Inter- and intrareferrals within and between ophthalmology and optometry. *American Journal of Optometry and Physiological Optics.* November, 58(11):939–43.