THE LOW VISION PATIENT INTERVIEW PROGRAM FOR THE
LIONS LOW VISION REHABLITATION NETWORK (LOVRNET)

Background

Low vision affects every aspect of a person's life. The average age of people with low vision is 77 years and 80% of people with low vision are over age 65. Because most people with low vision are older, they are more likely than younger vision impaired people to have other diseases and medical disorders that limit their ability to function in everyday life. A recently published nationwide collaborative study showed that 93% of people who seek low vision rehabilitation services have at least one other disease diagnosis. Half of all people who seek low vision rehabilitation have physical disorders that limit their mobility; more than 20% have clinically significant depression; and 10% have memory or other cognitive disorders. Low vision makes limitations on daily functioning from other disorders worse and places them at higher risk for experiencing adverse health events. For example, older people with very mild low vision (20/30 visual acuity) are twice as likely to fall and injure themselves than are people of the same age who have normal eyesight. People with moderate low vision (20/50) are three times more likely to fall and be injured, and people with more severe low vision (20/70 or worse) are four times more likely to fall and be injured. Low vision also increases the risk of medication mismanagement and limits people's ability to care for themselves. Besides amplifying functional limitations and health risks from vision impairments, functional limitations from other health problems also make low vision rehabilitation more difficult. For all these reasons and more, it is necessary for the doctor and the therapist who are providing low vision rehabilitation services to obtain a detailed medical, functional, and psychosocial history from all of their low vision patients in order to develop an optimal plan of care.

Low vision rehabilitation does not correct or restore vision – low vision means that the person's vision impairment is permanent and uncorrectable. Instead, low vision rehabilitation consists of providing patients with vision assistive equipment, modifying their homes to improve lighting and increase safety, and teaching them strategies to enhance their vision and/or perform their daily activities in ways that do not depend on vision.   Similar to teaching a person how to manage his or her diabetes or other chronic health disorder, low vision rehabilitation teaches vision impaired people how to live independently and safely, socialize with family and friends, continue their recreational and community activities, maintain their personal hygiene, manage their health, and in general participate in and enjoy life despite having low vision. Because the needs, preferences, and lifestyle of each patient are unique, low vision rehabilitation begins with a thorough and detailed evaluation of the patient's vision, rehabilitation requirements, and rehabilitation potential. Based on the results of this evaluation, the doctor and therapist, in collaboration with the patient, develop a plan of care based on the patient's rehabilitation goals. Because the goals are specific to the patient, each plan of care is unique. The success or failure of low vision rehabilitation is judged on the basis of the patient's attainment of the agreed-upon rehabilitation goals.

In the case of low vision rehabilitation, the doctor and therapist need to know patients' medical and health history, details of the activities that are important to the patient and are difficult for the patient to perform, and information about patient's physical, psychological, and cognitive capabilities, which

determine rehabilitation potential. The information acquired must reflect the patient's perspective, so it is not appropriate to elicit it from family members or caregivers. Typically, for other types of health problems, this type of information is acquired from patients by giving them a sheaf of papers to fill out at home or in the waiting room before seeing the doctor or reporting for surgery. But, low vision patients typically cannot see well enough to fill out forms and therefore must be interviewed to obtain the necessary information. Consequently, many eye doctors avoid providing low vision rehabilitation services because the patient evaluation is so time consuming and expensive. This time-consuming patient interview is a barrier to meeting the demand for low vision rehabilitation services that LOVRNET aims to remove. Removing this barrier will be accomplished by training Lions Club member volunteers to conduct computer-assisted initial evaluation interviews of low vision patients over the telephone before they meet with the eye doctor and the therapist.

Currently, outcomes of low vision rehabilitation are not routinely measured, so doctors and therapists have no objective feedback about the success or failure of their services. If the outcomes of services are not known, there is no motivation for improving practices and improving treatment, no method of assuring quality of service, and no basis for fairly evaluating and comparing the costs relative to the benefits of the services that are provided. LOVRNET will provide outcome measures to the doctors and therapists by having Lions Club member volunteers repeat some of the interviews of the patients after low vision rehabilitation services have been completed. The results of the two sets of interviews will be used to compute outcome measures for each LOVRNET patient and provide those measures to the doctors and therapists who served the patient.

Low Vision Patient Interviews

Lions Club member volunteers will be trained to administer five different surveys over the telephone to LOVRNET patients. The survey questions are displayed to be read by the Lion volunteer and the patients' responses are entered by the Lion volunteer over the internet. The Lion volunteer can conduct the interview from home if he or she has access to the internet.

The five surveys to be administered to each patient are: 1) Intake History, 2) Activity Inventory (AI), 3) Geriatric Depression Scale (GDS), 4) SF-36 Physical Functioning Scale (SF-36), and 5) Telephone Interview for Cognitive Status (TICS). The interview usually takes about one hour. But, the amount of time varies between patients and sometimes it is necessary to schedule a second session to finish the interview, especially if the patient tires or has trouble paying attention.

The Intake History has a series of questions asking about the patient's vision problems, health issues, physical limitations on mobility and daily functioning, availability of assistance, work issues, and driving/transportation issues. Each question is displayed on the computer screen and the Lion volunteer reads the question to the patient and records the patient's answer by positioning the cursor on a radio button next to the appropriate response and left clicking the mouse button. The depth of the questioning depends on the pattern of patient responses, with follow-up questions chosen by the computer program.

The AI is a questionnaire that asks about the patient's ability to perform daily activities. The AI specifically focuses on those activities most likely to be limited by visual impairments. There are 50 questions that use very general descriptions of activities such a "prepare daily meals" or "manage finances". These 50 general activities are called "Goals" because they describe what the activity is trying to accomplish, there are many different ways these activities can be performed, and they often are listed as low vision rehabilitation goals in patients' plans of care. For each of the 50 Goals, the patient is asked to rate how important it is for them to be able to perform the activity without the assistance of another person. If the patient says it is not important, the computer moves on to the next Goal. If performing the activity independently has some level of importance to the patient, the patient is then asked to rate how difficult it is for them to perform the activity without the assistance of another person. If the patient responds that it is not difficult, the computer moves on to the next Goal, otherwise the patient is asked to rate the difficulty of selected vision-dependent "Tasks" that come under that goal. Tasks are very specific activities that must be performed to say you successfully performed the Goal activity. For example, reading recipes, cut food, measure ingredients, and pour liquids are all Tasks that serve the Goal of preparing a daily meal. If the patient does not normally perform a Task, then he or she can respond that it is not applicable. Tasks are classified according to the type of function that is required to successfully perform the Task: reading function, mobility function, visual motor function (i.e., visually guided hand movements such as sewing or writing), and visual information processing function (i.e., using vision to acquire and understand information in the environment such as recognizing faces, watching TV, searching for an object). The results of the AI are used to set rehabilitation goals and develop the plan of care. The AI, when repeated after services are completed and responses are compared to the patient's AI responses at the initial evaluation, also serves as a low vision rehabilitation outcome measure.

Depression, physical disorders, and cognitive disorders can interact with vision impairments to worsen disabilities and impose limits on how much the patient can improve with low vision rehabilitation. For these reasons it is important to measure these three aspects of the patient's general health, which factor into the doctor's and therapist's assessment of the patient's rehabilitation potential. Depression is measured with the GDS, which consists of 15 questions to the patient about his or her mood and state of mind. Physical disorders are measured with the SF-36, which consists of 10 questions to the patient about his or her strength, stamina, and mobility. Cognitive disorders are measured with the TICS, which consists of a series of questions and mental exercises that test the patient's memory and other aspects of cognitive function. In each case, the question is displayed on the computer screen and the interviewer uses the mouse to record the patient's response.

Training Program for Lions Club Member Volunteers
Lions Club members who volunteer to conduct patient telephone interviews must be trained and certified in two areas. First, interviewers will temporarily be shown the patient's name and telephone number and will be recording sensitive private health information reported by the patient. It is important for interviewers to know and understand federal and state health privacy laws. Therefore, to be certified as a Lions LOVRNET Interviewer, Lion volunteers must take and pass a Health Insurance Portability and Accountability Act (HIPAA) compliance course each year. Second, patient interviews are

very rewarding as a social interaction to both patients and interviewers. But, the interviews are lengthy and it is important that the information gathered be accurate and that the interview time be used efficiently. Also, in the course of answering detailed questions about their health, daily lives, and feelings, patients sometimes become emotional. Therefore, it is necessary for each interviewer to be trained how to conduct the interviews, to understand what the interviews are trying to accomplish, to be empathetic with the patient, and how to handle different situations and reactions they will encounter with patients. The Lions LOVRNET Patient Interview Taskforce will plan the Patient Interview Training Program logistics and develop an approach to informing Lions about the LOVRNET Patient Interview Program and recruiting volunteer interviewers.

Patient Interview Quality Control

Because of the private and sensitive nature of the information that patient interviewers will be privileged to access, it is necessary to assure that all interviewers are mature and responsible citizens who use good judgment, have strong moral character, and are respectful of the rights, feelings, and privacy of others. Thus, the LOVRNET Patient Interview Taskforce will develop policies, standards, and procedures for performing background checks on prospective patient interviewers and evaluating their eligibility to serve in that capacity. The Taskforce also will develop quality control procedures (e.g., recording and evaluating interviews with mock patients, similar to a "secret shopper", and anonymous patient evaluations of interviewers) and methods of analyzing and interpreting interview tracking data to be certain that patient interviews are performed properly. Other quality assurance procedures that will be planned and implemented by the Taskforce include both live and online moderated group discussions, so that interviewers can share experiences with each other and compare notes, and continuing training programs, to update and deepen the interviewer's knowledge about low vision, low vision rehabilitation, and interview techniques

Recognition Program for Lions Club Member Volunteers

Lion volunteers and their Clubs and Districts must be recognized for the patient interview services they provide. The computer system will keep track of the time each Lion spends in training, conducting interviews, and participating in moderated discussions which provide data for defining levels of recognition for the quantity of service provided. Lion volunteers also should be recognized for the quality of the service they provide, which could be based on results of patient evaluations, mock interviews, and other quality assurance procedures. The Lions LOVRNET Patient Interview Taskforce will plan and implement the policies and procedures for recognizing Lion volunteers, Clubs, and Districts who participate in the Patient Interview program.