



Preferred practices for:

**Training and deployment of
Key Informants (KIs) for case finding
for children with severe visual
impairment and blindness**

and

**Improving the follow up of children
after cataract and other surgeries**



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Credit: Ellen Crystal Photography

Foreword

The Kilimanjaro Centre for Community Ophthalmology (KCCO), with support from Seva Canada and other partners, has worked in the area of childhood blindness and low vision since 2002. Over the years we have tested and implemented, in different countries, a range of activities to improve the full continuum of care and to ensure that visually impaired children achieve the best possible visual potential and best possible quality of life. In many low-and-middle income countries the barriers to care and the challenges to achieving the best possible outcome after surgery are complex. Addressing financial and geographical factors alone, although important considerations for almost all families, will not be enough. It is crucial for childhood blindness programmes to ground their interventions on a patient-first perspective as well as on evidence of what works (or does not work) to improve care and quality of life of these children.

This manual has been developed based on the evidence generated through research as well as case studies of childhood blindness programmes in various countries – Malawi, Tanzania, Uganda, Bangladesh, Cambodia, India and Nepal. We are grateful to USAID, through the PGRD grant that supported data collection in 2015/16 in Malawi, Uganda, Cambodia, India and Nepal). We are also grateful to the Champalimaud Foundation for supporting the work in Bangladesh. It should not surprise the reader to realize that the findings confirm the need for an effective and efficient community ophthalmology approach, based on a partnership with local Ministries of Health staff, NGOs, hospitals, and community members and organizations to 1) identify and refer children in need of services, and 2) facilitate the entire continuum of care process.

This manual is intended to provide practical lessons with the goal of influencing the implementation and roll-out of childhood blindness programmes in Africa and Asia. As all of us continue to learn more it is hoped that this manual will be revised. We welcome your input.



Credit: Joe Raffanti

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Training and deployment of Key Informants (KIs) for case finding for children with severe visual impairment and blindness

Background

The WHO estimates that 19 million children aged 15 years or younger are visually impaired. Of these, 1.4 million are irreversibly blind and need visual rehabilitation interventions for full psychological and personal development. The remainder have visual problems that could be prevented or treated. Identifying children with visual problems early in life so that they can benefit from medical and optical interventions remains a key challenge for most child eye health programmes. Reports from various low-and middle-income countries indicate that the age of children undergoing operation for cataract is frequently too high to achieve maximum benefit.

To rigorously assess the prevalence and causes of blindness in children large numbers of children have to be surveyed in order to find a few with blindness or severe visual impairment (CB/SVI). Added to this are technical challenges associated with identifying CB/SVI, especially at an early age. Measuring visual acuity accurately in a field setting can be very difficult, particularly in young children and in those with additional disabilities.

Various methods to try to identify all CB/SVI have been used including surveys of children in schools for the blind, hospital-based registers, or registers for the blind; these are limited, however, since they only provide lists of children who have already been identified at some level.

Recognizing the challenges, in the last decade, a novel approach – using key informants has been proposed and used in several developing countries to identify CB/SVI. The term Key Informant (KI) is used in various ways but it generally refers to community members, who after a very brief training are expected to “network widely to identify children in remote rural areas”.

Available evidence for effective use of KIs for case finding

A literature review conducted by KCCO/Seva Canada on the use of KIs for identifying children with CB/SVI in communities identified 31 publications or other documents describing 22 unique KI programmes. In most publications KIs identified children with blindness or severe visual impairment in one to three weeks prior to a scheduled outreach for screening by an ophthalmologist or other trained eye care professional. In most settings KIs were community volunteers; the remaining settings included formal health sector workers acting as KIs. Most programmes were not prescriptive in how KIs looked for children. The number of children successfully recruited per KI ranged from 0.02 to 1.56 children (mean = 0.48; median=0.25) and the positive predictive value ranged from 12% to 66% (mean=31%). Two studies directly compared community KIs to formal health sector workers: community KIs were 8 and 10 times more productive and the cost per child found was considerably less than using formal health sector workers in case finding. Overall, the available evidence suggests that KIs working in campaign mode in a number of low-and middle-income settings provide an effective and relatively inexpensive approach to identify CB/SVI. There was limited evidence of predictors of effectiveness of KI in the published literature and it is likely to vary in different contexts.

Case studies from six countries, along with findings from the literature review and focus group discussions with programme staff from a number of countries with KI

activities were used to identify preferred practices related to KI case finding. As with all preferred practice manuals or guidelines, the preferred practices reported here need to be considered within the context of specific settings. What works in one setting may not be appropriate in another setting. Furthermore, it should be recognized that, as our collective knowledge and experiences increases we are likely to identify new and better ways to undertake case finding. There is evidence that KI can support surgical follow up; details are found in the preferred practices for follow up section.

Specific preferred practices

The key preferred practices outlined in this document cover the following topics:

1. Key characteristics of successful KIs and their selection
2. KI programmes need to have a coordinator
3. Training of KIs needs to focus on the specific tasks to be undertaken
4. How KIs carry out their work
5. Use a standard register to list children suspected of severe visual impairment/blindness
6. Campaign mode vs long term engagement: it depends upon the context
7. Supervision and regular communication are an essential investment
8. Incentives help keep KIs interested in the programme
9. Can KI be involved in other disability related conditions?

Key characteristics of successful KI and their selection

Selected KIs should be long-standing members of the communities where the KI activities are to take place. KIs should be able to read and write and should be known to have good communication skills. KIs can be effective only if there is a sense of trust towards the activities that they undertake in public spaces and at the household level (questions being asked to parents). The criteria used

“I think most people do not have knowledge about eye health. My training makes use of a lot of pictures and demonstrations. At first it was shocking to them when they see some of the pictures that I was showing. They showed a lot of interest. In the number of the trainings they were able to relate some of the pictures to a number of children they have seen in their community. For me that interest seen during the session showed me really that the issue of awareness is big.”

– Hospital staff, Uganda

to determine who would make an effective KI is often context-specific. In some settings (most notably in sub-Saharan Africa) effective KIs tend to be older, likely due to enhanced credibility and trust within the community. School teachers have the added benefit that they can assist with school-wide engagement. While there is no specific evidence to suggest that men or women make “better KI”, selection by gender is often due to the context of other pre-existing community based programme activities. Thus, in settings where both men and women are involved in community based health related activities, there is equal representation of men and women. In settings, such as in South Asia, where women often carry out community based health activities, they are generally selected to be the KI. In many developing countries women face additional challenges reaching households far from their home, as compared to men; socio-economic or cultural constraints keep their area of influence limited. This suggests that programmes may need to train more women to adequately cover communities, particularly communities with scattered households.

Local context also drives the recruitment of KI; in some South Asian settings KIs are recruited by the local government officials and not directly from the local community leaders. In Africa, local community leaders tend to be more involved in the selection of KIs. Regardless of the setting the recruitment of KIs for case identification included individuals already working as volunteers/ community health workers rather than using individuals with no previous experience in community-based work. As KI work is generally campaign-based over a short period of time most KIs have full-time work (farmers, teachers,

etc.) and have only accepted “volunteer” duties over a short period of time to support eye care programmes. In some settings, the selection of KIs has been made through third-party organizations, an example being women in microfinance groups. Microfinance groups have taken the lead in identifying community-based women leaders to be trained as KIs; microfinance leaders use a cascade approach to help raise awareness about eye conditions in the communities and increase the number of children and adults with eye problems being referred to an eye care professional for further assessment.

KI programmes need to have a coordinator

In all settings with successful KI programmes there is a coordinator, usually identified as the Childhood Blindness & Low Vision Coordinator (CBLVC) who is in charge of the training, monitoring, and supervision of KI activities. In these settings, the CBLVC has other responsibilities at the base hospital which may include patient tracking (for follow up), counseling of parents and children, and recording and reporting of programme activities.

The CBLVC need not be a clinical staff member and in many settings this person has a background in education or counseling. As such the coordinator needs to have good communication skills. Key attitudinal characteristics of the CBLVC include good listening skills, empathy, and good organization. Training of the CBLVC focuses on understanding vision loss in children (definitions, causes, prevention, treatment, optical and low vision intervention,

and rehabilitation). It is essential for the CBLVC to become familiar with the different aspects of care - clinical examination of children, testing vision in children, cataract surgery, optical correction and low vision assessment and provision. The paediatric ophthalmologist must have confidence that the CBLVC is providing accurate information to parents and children. Finally, as the coordinator has many varied tasks in a complex environment flexibility and adaptability are important.

Training of KIs needs to focus on the specific tasks to be undertaken

Training of KIs generally follows standard training guidelines in which the tasks for KIs are the foundation for each training objective and training plan. Common practice is for training to be half a day to one day in length. Longer training programmes may be necessary if additional skills or tasks are desired. An ophthalmologist or training officer and childhood blindness coordinator are typically in charge of the training. It has been noted that having an ophthalmologist present for training gives enhanced credibility to the training and commitment of the KIs. In settings with long-term engagement by the hospital in the community there may be sufficient credibility to enable non-ophthalmologists to be in charge of training.

Even for KIs already working as a community health worker the level of awareness about eye conditions is generally low and successful programmes use a lot of pictures and, where possible, videos for teaching. Didactic teaching without visual aids for the participants will lead to considerable misunderstanding and a lack of skills development. Images of children with various (most common) eye conditions is very useful. Since it can be quite difficult for parents to identify vision loss in infants it will mean that KIs will also find it difficult to identify infants with vision loss. That said, KIs should be provided some messages regarding identification of vision loss in infants (**Box 1**).

Training is typically done at the site or near the site of the planned outreach, although some programmes have brought the KIs to the base hospital when it is more convenient to do so. The number of participants is not more than 25 as there is a need for participants to practice and demonstrate skills prior to completion of the training.

Preferred practices for: Training and deployment of Key Informants (KIs) for case finding for children with severe visual impairment and blindness and Improving the follow up of children after cataract and other surgeries

Box 1: Ways to describe children who likely have good vision

Infants, pre-verbal, and pre-mobile children

- The infant moves his eyes to keep a person in sight (fix and follow)
- The infant's eyes stay fixed on a person while that person is talking.

Verbal, mobile children

- Children do not bump into items in the room
- Children do not squint when trying to detect something far away
- Children do not avoid playing with other children

The training covers only the most common eye conditions affecting children. Medical terms are used minimally and there should be sufficient time for questions and answers. Experience suggests that sufficient time is needed for discussing the topic of "vision loss" and how it might be defined in different settings. While the goal of training is to identify children with severe visual impairment or blindness most KI training programmes do not teach KIs how to assess vision. Instead, the focus is on personal histories and use of terms that can be used to identify children with vision loss.

While there is clear evidence in most developing countries that girls are less likely to be brought for congenital or developmental surgery, there are no specific examples of programmes training KI to address any gender inequity in access to services.

During training KIs are told of the programme expectations in terms of case finding activities that should take place ahead of the outreach visit and that the outreach visit will be scheduled to take place 10 days to 3 weeks after the KI training.

There is limited information, at present, regarding the inclusion of counseling in training activities. That said, in most formal community health programmes there has been some effort to provide counseling training as part of other health-related work.

KIs are generally keen to carry out the work; properly selected, they have a sense of responsibility to find children with severe visual impairment or blindness. Training needs to make it clear that, because vision loss in childhood is rare, some of them will not find any children with severe visual impairment or blindness. It is likely that some children will be listed by KIs even though they may not fit the clinical definition of CB/SVI. Evidence in the literature suggests that these children are likely to have other eye-related problems that require intervention. Thus, programmes need to ensure that outreach following KI training is prepared to manage other conditions.

At the time of training a kit including KI forms, pen, information sheet (with date and venue of outreach) should be provided to all KIs. Assisting KI to complete the top part of the KI forms (their own information) helps to ensure accuracy.

How Key Informants carry out their work

Two to three days after training a call from the coordinator to each of the KIs helps to determine who is active and who is not; back up plans are needed for inactive KIs. KIs are expected and encouraged to use different strategies to find children for referral and programmes often spend time during the training discussing with the KIs, what everyone feels will be the most effective and efficient ways to identify children. In many settings door to door case finding is undertaken. In virtually all programmes this is preceded by announcements at religious gatherings, community meetings, markets or other places where villagers gather. In many settings others can help cascade the work,

helping the KIs to identify children and support parents to attend outreach.

During case finding KIs inform parents and guardians of the date and location of the screening. Other important information that the base hospital would like to highlight can be included but this information should be kept quite limited to avoid misunderstanding and confusion. Probably one of the most important pieces of information may be letting the parent know that, if the child's condition is considered urgent, the doctor may suggest travel (often with the examining team) directly to the hospital. Families need to consider how they could facilitate a child and parent (preferably both) to travel with the team to the hospital.

For KIs with other responsibilities as a community health worker or other community worker, door to door visits are often already part of the weekly or monthly routine. The number of households covered by KIs prior to a community screening can vary widely based on the density of the population in the targeted areas. Many of the KIs that are regular community health workers have a bicycle for transportation. While this facilitates easy access to many households in the community, it is not required and often not within the capacity of an eye care programme to support.

It is common for KIs to report that the identification work can be challenging in the case of babies; there is a need to ensure that KIs are aware that the only way to obtain information on infants is to talk to the parents.

On the day of the outreach visit, KIs often contribute to programme activities by accompanying families to the screening site. KIs can assist in multiple ways; in particular, they can provide some additional counseling and support parents through difficult decisions. It is important that programme staff recognize the work of the KIs in bringing children as this will help improve their credibility and desire to assist with follow up and other activities.

Throughout the time from training to outreach frequent communication between the coordinator and KIs encourages strong engagement.



Credit: KCCO

“Yes, we were given referral forms in the training, and on those forms we write the name of the child, sex, age, name of the parents and how the child was identified. On the form there is a box where the key informants write their phone number.”

– Key Informant, Malawi

Use a standard register to list children suspected of severe visual impairment/blindness

The KIs use a register sheet (see an example in **Annex 1**) provided to them during training to keep track of the households and children identified with potential CB/SVI. Of particular importance is noting the mobile phone number of the parents; if the parents do not have a mobile phone, they will likely have a neighbor who has a mobile phone contact.

The register also serves to provide information for programme staff to assess whether the children identified by KIs are all screened. Programme staff should be collecting information from the registers at the time of the outreach. If there are many missing children the programme may wish to send the outreach vehicle to certain communities to bring children to the outreach.

In some settings the KI registers are collected for compilation while in others the KIs keep the registers, using them to re-visit parents not attending the outreach or to facilitate follow up of children who end up needing surgical or other interventions.

It is helpful to give KIs a hand-out that includes information about common eye conditions in children as well as information about the upcoming outreach visit.

Campaign mode vs long term engagement: it depends upon the context

In virtually all settings KI programmes have been designed and implemented from a “campaign mode” perspective – as a blitz of case finding activities just before a screening visit. Campaign mode also assumes that the KI work is a one-off, that is, that the KI work and outreach visit are for identifying children with vision loss at the present time and ensuring that they receive the necessary services.

In most settings there is limited expectation of KI work after the campaign; ideally however, a KI remains as an ombudsman, linking the community with the hospital for any children needing surgical, medical, optical, or low vision care. It should be remembered that KI willingness to undertake the work is often because they see children from their community receiving specific eye care services. There is evidence that some KIs continue to stay active in their community as case finders, remaining in touch with programme coordinators regarding specific children and their needs. They have been known to refer families directly to the hospital after contacting the programme coordinator by phone. In some settings providing KIs with information sheets to give specific parents helps extend KI engagement after the outreach. Further evidence of the long-term engagement of KIs would help identify the specific characteristics that identify people likely to remain active and to determine the specific activities that they could undertake confidently and effectively.



Credit: Joe Raffanti

“We do not do community screening all the time. In most cases we have walk-ins and others are referrals by key informants. The ones who are referred may not always need surgery. The key informants identify anyone who has eye problems.”

– Hospital staff, Uganda

Programmes need to recognize however, that on-going engagement of KIs can be very time-consuming and challenging. Communication may be difficult and expensive yet, without any contact over a period of time KIs may feel that their work and skills are no longer valued or needed. This may lead to missed opportunities to involve KIs in motivating families to attend follow up visits.

In settings in which more formal health workers have a mandate to undertake community-based health work there is a possibility for long term engagement. That said, there is no literature to suggest that this is practically undertaken. The evidence suggests reasons this may be the case: CB/SVI is a very rare condition and it is difficult to keep health workers undertaking activities that do not yield much in the way of documentable results and there are no routine mechanisms for supervising these activities within most health systems.

Supervision and regular communication are an essential investment

In settings where KIs are part of the formal health system communication channels need to link together the KIs, the medical supervisor of the health workers and the childhood blindness programme coordinator. The most practical approach remains mobile phone communication although this can require significant time of the coordinator if the local health systems are weak. In other settings communication is direct between KIs and the programme coordinator. As the type of work the KIs undertake is not

technically challenging, the programme coordinator is also the supervisor of the KIs. The coordinator needs to maintain and update the KI database on a regular basis. The mobile phone number of each KI needs to be on record and coordinators need to establish a communication schedule with all KIs. Obtaining and confirming mobile phone numbers is best done during the training. Each call should have a specific task: [1] confirming they have started their work, [2] confirming the date and place of outreach (and follow up to confirm status of case finding), [3] the day before the outreach to confirm their participation at outreach (and to bring their registers). Routine communication, although often difficult, is essential for active KI engagement and for managing service delivery. Frequent communication reminds KIs of the importance of their work. Sometimes visits by the coordinator to specific KIs may be necessary.

The outreach visit is the most critical time for childhood blindness coordinators to support and supervise the KIs and coordinators should always attend outreach. Positive reinforcement of the work undertaken by the KIs will enhance the credibility of the KIs in the community and likely lead the parents to view the KIs as trusted members of the team.

When children and parents come to the hospital as “walk ins” it is helpful for the Childhood Blindness Coordinator to determine if the child was identified by a trained KI or not. If so, the coordinator should contact the KI and thank him/her for identifying and referring the child. This means that the programme requires a proper tracking systems/tools, both for tracking KI and for tracking children receiving specific eye care services.



Credit: Ellen Crystal Photography

“Hospital staff recognise me whenever I go or refer children. That makes me feel I am a part of the hospital. I request or not, they (hospital) provide free treatment to these poor children. I take my relatives, too.”

– Anganwadi KI, India

Incentives help keep KIs interested in the programme

Incentives, commonly provided for KIs, can come in many forms and is often dependent on the local context. At one end of the scale, formal incentives may only include a meal on the training day and a certificate of attendance. In these settings, there are often non-tangible incentives such as recognition by the programme and the community of the work or the possibility that undertaking the volunteer work will make it possible for the KIs to obtain paid work.

If KIs are part of the formal health system it is often necessary to provide “per diem” for the work. Given the evidence of low productivity of case finding of formal health workers (particularly in sub-Saharan Africa) programmes need to weigh the cost against the benefits.

Given the large number of KIs that need to be trained to identify children with CB/SVI it is impractical in most settings to offer a financial incentive for this work. While a lack of significant incentives may create barriers for recruiting KIs and keeping them engaged in eye health work, childhood blindness typically attracts those with a strong sense of community engagement and desire for volunteer work.

Can KIs be involved in other disability related conditions?

The initial work on KIs was related to other disabilities, in particular the identification of children in communities with physical disabilities.

In some settings, these individuals are referred to as community based rehabilitation (CBR) workers. There is considerable evidence that KIs can be effective for case identification for a large number of conditions. Some conditions in the eye care field in which KIs have been successful include trachomatous trichiasis (**Figure 1** shows the cover page of the manual already published on this topic). Cataract case finders follow a similar model however, the fact that cataract case finders are generally trying to detect “white cataract” their relevance for general eye care programmes are limited.

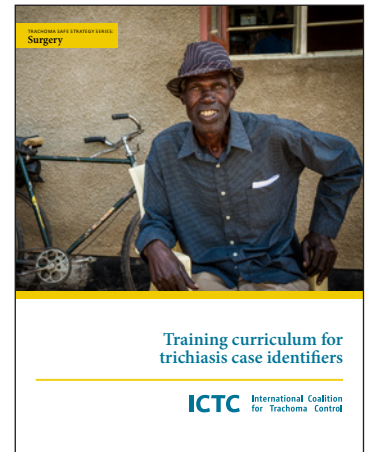


Figure 1: Using Key Informants to identify patients with trichiasis



Credit: KCCO

“Key informants are very good, especially when they are motivated. They do for you real work (...) Key Informants are the best way you can mobilize the community. For example, this region has many languages; it is easier to work with KIs than to do radio promotions.”

– Hospital staff, Uganda

There is a high likelihood that KIs trained in childhood vision loss could undertake other activities such as detection and referral of other disabilities (physical or mental). Similarly, existing KI activities through CBR programmes could be re-tooled to include identification of children with CB/SVI. Regardless of the approach it is critical to retain some form of outreach to rural areas to ensure that children identified are screened and provided services. Simply training KIs or similar personnel to identify children with severe visual impairment or blindness is inappropriate; most of these children will not receive the necessary services and the value of the programme will be limited. In the coming years further work to integrate KI work should provide some of the necessary evidence and approaches to expand this work.

Conclusion and Next Steps

While there is considerable evidence to develop these preferred practices, it should be recognized that there are some gaps in our knowledge and experience. It is anticipated that in the coming years additional experience will provide additional evidence for “what works/what doesn’t work”. While rigorous epidemiologic studies would be ideal, this is both time consuming and costly. Prioritization of key research issues would help. Progress will also be achieved by programmes documenting their progress, using qualitative methods to explore explanations, and sharing their experiences with the broader community. It is anticipated that this preferred practice manual will be improved upon in the coming years, but only if programmes apply some of the principles, learn by doing, and feed back their experiences.



Improving the follow up of children after cataract and other surgeries

Background

Surgery is one component of a comprehensive approach to providing care to children with childhood cataract or other conditions that require surgery. While good quality surgery is essential, it is not sufficient alone to ensure that children achieve their best possible visual recovery. Regular follow-up after surgery is an integral part of the continuum of care and it requires a clear plan, effective and efficient management systems, and people working well together. Good follow up that focuses on a well-informed parent, optical correction, low vision care, and support for appropriate educational placement will ensure that a child achieves both good visual outcome and integration into society.

Available evidence to inform strategies to achieve good follow up

Achieving good follow up after surgery for childhood cataract requires a multidisciplinary approach involving ophthalmologists, nursing staff, low vision and optical personnel and a Childhood Blindness and Low Vision Coordinator (CBLVC). A multidisciplinary approach requires



Figure 2: Result from a systematic review on follow up strategies published in the journal *Eye*

multidisciplinary skills to ensure that the continuum of care (from identification to surgery to follow up to educational placement) is complete. A systematic literature review on follow-up of children with ocular surgical management (primarily childhood cataract) in developing countries and an assessment of current practices regarding follow-up for clinical, optical, low

vision, rehabilitation, and educational placement at Child Eye Health Tertiary Facilities (CEHTF) in sub-Saharan Africa and South Asia as well as a series of case studies and interview with key programme personnel provided the foundation for the preferred practices in this manual.

Having a Childhood Blindness & Low Vision Coordinator (CBLVC) greatly assists effective and efficient follow up

A CBLVC has a very important role in ensuring that appropriate strategies to ensure good follow up and educational placement are implemented. Clinical staff generally do not have the time nor the skills to carry out the roles of a CBLVC. A summary of the range of roles and responsibilities of a CBLVC (including but not limited to ensuring good follow up) is given in **Box 2** while a more detailed description is provided in the **Annex 2**. In order to carry out these responsibilities the CBLVC is part of the paediatric eye care team at the CEHTF and he or she

Box 2:

Summary of Roles of the Children Blindness & Low Vision Coordinator

A “Childhood Blindness and Low Vision Coordinator” is needed to lead the efforts for coordinating all non-clinical care and training. Roles and responsibilities include:

- Organizing activities for early detection
- Counseling of parents & children
- Ensures good follow up after surgery
- Supervision and training of staff
- Linking children

has a well-defined and clear job description. Ideally, the CBLVC becomes the primary link between the hospital and the “community”, the community being those outside of the hospital but in the catchment area of the CEHTF. Given the fact that the CBLVC is involved in training of key informants for case finding of children with severe visual impairment or blindness (thus, away from the hospital from time to time) there always needs to be someone who can provide back-up at the CEHTF.

The list of qualifications that the CBLVC should possess may vary in different settings based on the local context and on institutional factors. In virtually all settings funding for a CBLVC has to come from grant funding; with time and experience it may be possible to include this cadre within routine human manpower systems. In most settings it is common practice to recruit a non-clinician, preferably a candidate with a tertiary level diploma, a degree in social welfare or education. While expertise in counseling is ideal, it is not essential; skills in counseling can be learned. Good communication skills (including good listening skills) and the ability to effectively interact with parents (particularly mothers) and children is essential. Finally, good organizational skills, for tracking children, monitoring their progress, and recording and reporting, are also key for programme sustainability.

“I would say I am handicapped without the coordinator, he does so many other non-clinical work that otherwise would force me to forego some important aspects of the so called ‘Comprehensive pediatric eye care.’ Thinking of a team based approach, I wouldn’t go without a CBLVC.”

– Hospital staff, Malawi

Given the roles and responsibilities of the CBLVC, training generally focuses on gaining a clear understanding of the main eye conditions requiring surgical management, how to counsel parents and children, how to train KI, and how to manage follow up. It is very helpful for a CBLVC to join the paediatric eye care team through the entire surgical process as this helps the CBLVC to communicate with parents in an informed manner.

In most settings the CBLVC also serves as the counselor or provides back up support for the counselor; training needs include counseling.

Using a patient tracking system facilitates accurate follow up

It is impossible to know if follow up has been achieved without a patient tracking system. Clinical charts often do not include sufficient information regarding follow up: did the child return when expected? Did the parent get the necessary counseling? Did the child end up in the most appropriate educational placement? While there are different ways to develop and implement a tracking system (see the **Annex 3** for an example) it should have a number of characteristics (**Box 3**).

A tracking form should be started the moment a child is registered for surgery. Given the fact that the CBLVC is sometimes away conducting KI training or assisting with outreach it is important that one person is always on-site, trained in, and responsible for using the tracking form.

Tracking children for follow up is a dynamic, on-going process and the CBLVC generally needs to review the tracking register twice a week in order to monitor which children have attended or not attended their follow up visits. In settings where some post-operative follow up is done

Box 3: Key characteristics of a tracking sheet

An effective and efficient tracking form should:

- List the mobile phone contact information of the parents. Generally, this requires multiple contacts: neighbors, relatives, etc. in case the parents cannot be reached
- If the child was identified by a KI, list the KI mobile phone contact
- List the expected dates of the next follow up visits
- Be standardized (that is, information is recorded in a standardized way)
- Be designed for easy computerization (note that an app is becoming available for use as well)
- If relevant, space for including directions to the residence of parents (may include a map)

external to the CEHTF it is necessary for the CBLVC to also be in touch with the external facility to confirm attendance.

In all settings, a clearly defined follow up strategy and protocol needs to be adopted and all staff need to be aware in order to avoid confusion. The strategy and protocol should be included as the first few pages of the tracking register to help remind anyone who is using the register.

Mobile phone contact improves parent-hospital interaction and follow up

There is clear evidence that mobile phone contact with parents can greatly improve follow up. Some programmes use a mobile phone reminder prior to the scheduled follow up while other programmes contact parents whose children did not present for follow up; a decision on which approach to take is best done according to the local context. Regardless of the timing of the mobile phone follow up, it is important that the communication is direct

rather than through a SMS text message. An example of a phone conversation about follow up visits is provided in **Box 4**.

Not all parents have a mobile phone and it is likely that parents without a mobile phone will be the poorest of the poor and the most distant from the CEHTF. In these cases, it is important to rely upon local leaders or the KI to maintain the necessary level of communication. In some cases, it may be necessary for a CBLVC to conduct a home visit. Home visits can be expensive and should be limited to instances when additional counseling of both parents is required to influence decision-making.

Box 4: Example of a phone follow up conversation

CBLVC: How are you Mr. Mollel, My name is Abigail, a CBLVC at Hospital X.

Mr. Mollel: Hospital X? They operated on my son's eyes like three months ago, now he is so happy, we are happy too.

CBLVC: Good to know your son Simon is doing fine, you were supposed to bring him back to hospital for follow up last week but we didn't see him, could you please bring him the day after tomorrow, before noon?

Mr. Mollel: My wife told me that, but "Why these multiple visits now? What's going on there? She has been there twice and my son is happy now, he can see everything. What else do you want to do to him?"

CBLVC: The doctor who did surgery would like to examine him to see how your son's eyes are progressing after surgery, you said he can now see everything right; we also would love to test his vision, confirm how much he is able to see and measure for spectacles if needed. So you see there still a lot more to do for your son's vision improvement ... as he grows the eyes are changing ...

Mr. Mollel: That sounds good, you also interested in my son's welfare. Do you know I have 6 girls and 2 sons only?

CBLVC: Oh really? So you are happy now he can see better right? Are you planning to join your wife to bring Simon back day after tomorrow then? Would be nice to meet both of you and discuss more about Simon's vision. You sound like a very understanding man, congrats.

Mr. Mollel: Yeah, thank you very much, I think I will come.

CBLVC: Ok thanks Mr. Mollel. Bye-bye.



In settings in which only one parent (often the mother) brings a child for surgery mobile phone communication with the father may be necessary to influence household level decision making. If the mother does not have the ability to make these decisions, the CBLVC will generally need to talk to the father. This appears to be the case in settings in which girls are less likely to be brought back for follow up compared to boys. Throughout the continuum of care process the CBLVC should aim to reach both parents.

Reimbursing transportation costs is often necessary for good follow up

The indirect costs of seeking care and follow up after care are major barriers parents face in many developing countries (**Box 5**). This is particularly challenging for parents of children who require multiple follow up visits at a facility that is quite distant from their home. While it makes sense for a CEHTF to cover a catchment area of 10 million from a programmatic perspective it can make the distance to travel significant for many parents. Who will take care of the other children? Who will tend to the work? In addition to the cost of transport there are always costs for accommodation and food while away. Programmes are encouraged to estimate the cost (to parents) for attending follow up; this helps hospital staff become aware of the burden on families and helps the programme advocate for support, as needed.

Experience has shown that, even in socioeconomically poor settings, some parents can pay for the cost of transport, accommodation and meals, either fully or in part. Thus, the general approach, after counseling of parents, is to determine whether reimbursement of these costs is needed or not. With time and parental interaction, there is often a greater willingness of parents to contribute to these costs, particularly if they see improvements in their child's abilities in school and elsewhere. Nevertheless, for those too poor to pay, providing transportation reimbursement contributes to improved compliance to follow up. In most settings, the practice has been to reimburse the costs rather than to provide the funds in advance.

Box 5: Costs associated with having a family member away at the hospital

- Transport for child and family member
- Meals during travel to hospital, stay at hospital and return home
- Accommodation while child is in hospital
- Lost wages of person accompanying child
- Inability to support the rest of the family when away at hospital

In some areas, it is not the distance from health centre to the district hospital or CEHTF; rather it is the distance from the village to the nearest health centre that is the greatest challenge. In this situation, the KI may be in the best position to advise and assist. The CBLVC needs to discuss this with the parents (and KI, if relevant) in order to assist them to figure out the best strategy to address transport problems.

Gender issues in improving good follow up

There is some evidence to suggest that girls may not be brought back for follow up as frequently as boys. This may be due to different reasons and programmes are encouraged to use existing data to assess whether there is gender inequity in follow up and to explore the possible reasons for any inequity. The situation for Uganda (2013-2014) is provided in **Figure 3** as an example. A gender gap is particularly apparent in regard to the first follow up visit at the start of the programme.

Figure 3: Uganda: Follow up compliance by sex (2013-2014)

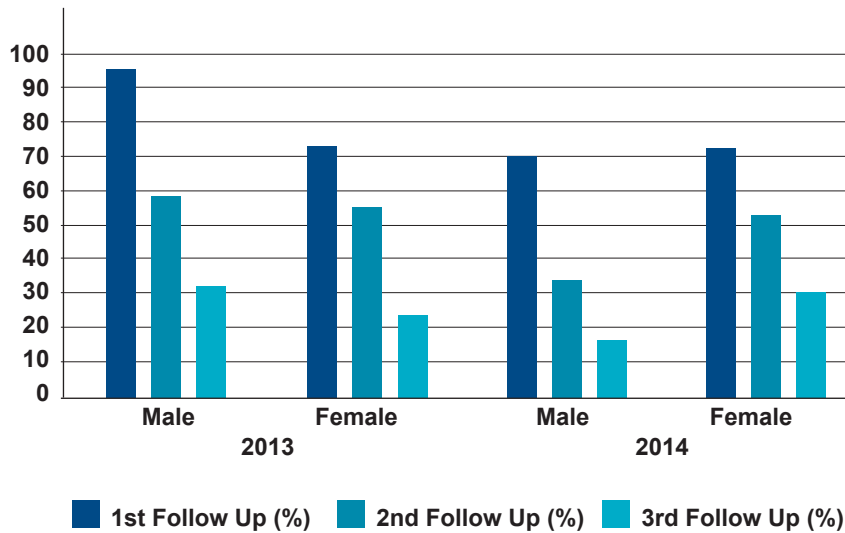
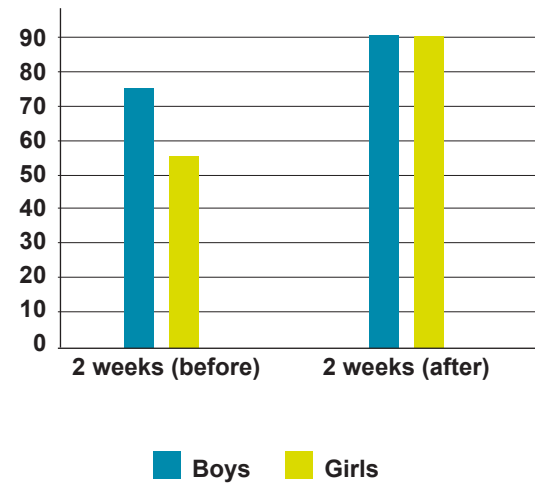


Figure 4: Follow up (at 2 weeks) before and after implementation of a systematic pro-active approach to follow up



In many developing countries women have less experience traveling outside of the village and they may require a male family member to accompany them. As having multiple adult family members not in a capacity to earn income or support family responsibilities, travel has a particular burden on lost income. Women who do not have their own source of income also have limited influence over decision-making at the household level. The more programmes understand the individual situations and needs of families, the better that strategies can be implemented that improve follow up. Since multiple trips are often needed, strong social support within the family needs to be maintained; to this end, the CBLVC will find it more effective to link other key family members into the care of the child.

Research undertaken by KCCO in Tanzania has shown that a systematic pro-active approach to follow up is effective to increase compliance with a follow up schedule, and in closing the gender gap between boys and girls.¹

¹ Eriksen and al. (2006). <https://www.ncbi.nlm.nih.gov/pubmed/16877282>

Quality counseling of parents and children is the foundation of good follow up

The counselor has a major role to play in providing counseling for follow-up services in order to ensure that the most optimal visual outcome for the child is obtained. Thus, quality counseling is a critical component of service delivery for all paediatric eye care programmes (**Box 6**).

If parents are to be part of the visual rehabilitation of the child the information that parents need to acquire is considerable; it is impossible to absorb all of the information at one time. In addition, considerable repetition of key messages is required in order for the information to be retained and acted upon. All parents should receive an instruction/counseling sheet that they can take home. Counseling should be provided at different stages of intervention (**Box 7**). Try not to overload the parents with information. As counseling aims to assist the parent to make decisions regarding current and future management it is important to ask the parent about their understanding and capacity to act upon the information. If some of the suggested key messages are not understood or misunderstood or non-actionable, it is the role of the CBLVC to identify the problem and work with the parents to achieve a solution.

Research suggests that parents become less and less likely to return with their child for follow up if they perceive that their child is coping, even minimally, with daily tasks. Early and frequent counseling of both parents on the long-term interactions needed may help mitigate this problem. Reminder calls, before the follow up date rather than waiting until after a failure to show up, encourages parents to view follow up as an important part of the continuum of care.

It is preferable that counseling be done during outreach screening (linked with the KI programme) to enable more parents to access services for their children in a timely fashion. Good counseling early in the process also ensures that, after surgery, these children are brought back for follow up and receive the recommended interventions and support necessary.

Training in counseling is required by all of those who will be counseling parents and children. A key tenet of the counseling is that the CBLVC and/or counselor serves in the role of “patient advocate.” helping parents navigate an often-complicated set of programmes and systems needed to ensure that their child receives and is able to use surgical, medical, optical, low vision, and educational attainment services.

In some settings, group counseling has been used for peer to peer information sharing and support. At the present time, there is little information on its application and benefits.

KI role in facilitating follow up

There is experience with some KIs continuing their engagement by supporting parents and children to maintain their follow up schedule. As noted previously, this is a particular challenge when the child’s vision and activities of daily living have improved, when the family may view follow up as unnecessary. KIs can communicate with the coordinator if interaction with the family reveals a problem; often the cost of travel is a challenge and it may be possible for the programme to support travel. KIs whose own children are visually impaired have been particularly motivated to help children and parents in the community return for follow up. This may be discussed during training or during the outreach with specific KIs who appear to be especially motivated.

Box 6: Counseling

We do not care for just “eyes” we care for the “whole person”

Counseling should draw on a fact-centered and a person-based approach.

Facts-centered approach:

- What is cataract?
- What happens if cataract is not treated?
- Can cataract reoccur in the same eye?
- What is cataract surgery and how do doctors perform surgery?
- Importance of follow up care

Person-centered approach:

- The actual cost of surgery and the fee for surgery (if any)
- Accommodation while at hospital (and duration of stay)
- Transport to and from hospital
- Care taker?
- Feeding?

Organizing follow up at secondary facilities improves access and builds capacity

Given the distance that parents must travel to a CEHTF it may be desirable to have follow up undertaken at a secondary facility.

Ophthalmologists or Ophthalmic Clinical Officers (OCOs) at the district level can be trained on how to do a clinical assessment after cataract surgery. These facilities are

Box 7:

Counseling periods and key messages

Prior to travel from community to hospital

- The doctor will make the final suggestion regarding intervention at the hospital
- If surgery is recommended, how urgent it is
- The child may need to stay in hospital for one week after surgery to monitor outcomes
- What costs, if there are any, that the parent will need to pay
- Feeding support if any?

At time of diagnosis and scheduling of services at the hospital

- If surgery is recommended, the child may need to stay in hospital for one week after surgery to monitor outcomes
- The need for multiple visits after discharge
- What costs, if there are any, that the parent will need to pay
- The need for other family members to be examined (e.g. Childhood cataract is a rare condition; however, it can run in families)
- Number of caretakers that are allowed at the facility

Prior to surgery

- Surgery is only the first step in a long process of rehabilitation.
- The importance of giving consent.
- Child may require treatment of other associated diseases
- After surgery, the child will need to stay in hospital for several days or up to one week (depending on how far away he lives) to monitor outcome
- Child may need to wear spectacles after surgery

Counseling at discharge

- The need to comply with the given medications (must correctly administer eye drops for a period after leaving the hospital)
- What costs (If any) that they will need pay
- If there is transport support for follow up
- The need for long-term follow up (if cataract -throughout childhood)
- In many cases, the eye had not “learned” how to see, so improvement in vision can be slow, and may take several times.
- When should they come back for follow up
- Child may need to wear spectacles

Counseling at follow up

- Clearly state that you are thankful to the parents for bringing the child back for follow up.
- If child prescribed with spectacles /low vision devices parents need to encourage the child to wear the spectacles and use the given devices.
- The need to change spectacles as the child grows (need for multiple visits)
- If other rehabilitation needs are identified, the location of the centres should be provided
- When follow up is possible external to the surgical facility, parents should be provided with the location of the facility, name and phone number of the contact person.
- All related costs if any should be provided.
- Only after refraction and low vision assessment outlined the appropriate educational placement available.
- When to return to the hospital for follow up

important for continuity of services and connection between the family and the health care facility. After surgery at the CEHTF, the first or second follow up date may be at the district level. If any complications are detected during the district level follow up, the child can be sent to the CEHTF; however, if the child is doing fine, the original schedule by the CEHTF for the third follow up is maintained. The CBLVC Coordinator is the main link here, as he/she coordinates with the district eye staff to confirm who has missed a follow up visit, and then follow through.

Ensuring proper educational placement is key to future educational attainment

Eye care programmes tend to only consider follow up to achieve the surgical, medical, optical, and low vision care and there is often little effort undertaken to link school age children with the appropriate educational environment. This requires working with other non-health care entities, primarily in the field of education. In most developing countries, there are special schools for the blind or annexes but these institutions may not be the most appropriate setting for children to be educated. Ideally, all children should be examined by an ophthalmologist before being placed in a school for the blind or annex. It has often been the role of the CBLVC, in partnership with the ophthalmologist to initiate interaction with schools for the blind or annexes in the area. Establishing a positive relationship may not be easy, particularly if the school feels threatened by the eye care programme; will the ophthalmologist try to have children transferred from the school for the blind to a different educational programme? Establishing a relationship should be viewed as a long-term endeavor and encouraging children already enrolled in a school for the blind to be placed elsewhere, not unless requested by the school authorities, should be avoided. The CBLVC should carry out an assessment of the school to determine what kind of children are most appropriate for placement there. Integrated educational programmes may also be present in the area and efforts to establish a relationship with them, if not present already, should be undertaken.

Ideally, the CEHTF team, as they become aware of all of the educational opportunities open to children, will then be able to develop a plan for how each child can be assisted. This, of course, requires ongoing interaction

with the different educational (and rehabilitation) services. Counseling of the parents is a critical step and should be discussed soon after surgical intervention. When there are different options for educational placement parents may not always choose the same option as an educator. Other factors that parents consider include cost of different educational options and the difficulty in keeping a child with considerable needs living at home. Educational placement should be accompanied by written communication to the identified educational programme. The communication should include the clinical follow up that the child will need in the coming months and years as well as information on the specific low vision devices and/or spectacles to be worn. It may be necessary for the CBLVC to visit the school and teachers to ensure that they understand how to assist the child with spectacles and devices. In some settings KIs have been assisting parents, children, and teachers with placement and post-placement support.

The tracking system should record both the recommended educational placement as well as the final educational placement, as they may be different. There is little evidence to help guide programmes on long-term engagement with educational programmes. There is also no evidence on whether there is any gender inequity in appropriate educational placements. As more children receive the appropriate surgical, optical, and low vision care, there is a growing need to better understand how to help these children also achieve their educational potential.

Conclusion and Next Steps

Previous work has highlighted the importance of combining different strategies to improve follow up rates among children and, ultimately, to achieve the best possible visual outcomes. The CBLVC is a key player with a mandate to ensure that the key strategies are well-implemented. Counseling has been highlighted as one of the most important aspects in service acceptance and adherence. However, evidence shows that counseling is done differently not only across hospital settings, but even within the same institution where different people are assigned to do counseling. There is a need for a more comprehensive and coherent approach to counseling during the pre-intra and post-operative periods, recognizing that different members of the care “team”, from KIs to ophthalmologists, are involved in interacting with parents at different points in time.

Annex 1. KI Referral Form

Childhood Blindness Project, Blantyre

Form 4: KI Referral form

Form for referring child to District Ophthalmic Clinical Officer

Referred to an Ophthalmic Clinical Officer in _____
 (Choose one of the boxes)

1	Blantyre
2	Zomba
3	Thyolo

_____ *District Hospital*

Referred through which Health Centre? _____ (Health Centre)

Date

--	--

--	--

--	--	--	--

Date Month Year

Name of Child _____

Name of Parent/Guardian _____

age

--	--

--	--

Age Months

Sex _____
 (Choose one)

1	Male
2	Female

District child lives _____

Village _____

Nearest Health Centre _____

Child's eye problem

1	Child is Blind
2	Child is blind in one eye only
3	Child is able to see, but has other eye problems

How did you identify this child? _____
(write the method)

Have you advised the parents of this child to go to the Hospital?

1	yes
2	No, reason _____

Name of volunteer _____

Number of volunteer given during training
 (Volunteer Code)

K/I					
-----	--	--	--	--	--

Training session
KI number

Thank you for identifying this child
 If you want to know more call this number: 0111 400 118

Annex 2. Job Description: Childhood Blindness and Low Vision Coordinator.

Essential Job Functions

- Prepare a detailed work plan for the Child Eye Health Project
- Liaise between the manager, pediatric ophthalmologist and the child eye health team and other identified stakeholders in the catchment area for effective and timely implementation of the project activities.
- Support the provision of a high quality and comprehensive service for all children attending the identified clinic
- Provide direct services to children and their caretakers attending the Clinic, including collection of contact data and pre- and post-service counseling
- Establishing ties with other clinics within the catchment area to reduce delays in presentation and follow-up of children.
- Intensive and proactive work on patient follow-up, including developing networks of support for rehabilitation services for children across the identified area.
- Ensure that the patient tracking system for referral and follow-ups is established and is actively utilized
- Implement and refine data management system (data collection, entry and analysis), and monitor and report on childhood cataract and low vision services provided.
- Ensure well organized systems for documentation of resources relating to the project
- Develop comprehensive activity reports of the project in accordance with deadlines
- Assist with training of teachers in schools for the blind and annexes on the importance of early identification as well as the need for providing low vision services for children who can benefit.
- Assist with the training and supervision of key informants and others involved in case detection and referral
- Document best practices and prepare case studies.
- Carry out additional activities assigned by the organization.

Annex 3. Childhood Cataract Tracking Form

Childhood Cataract Tracking Form

Child's Name	Hospital #	
Phone #		
Presented to Eye Department	Date	Comments
Surgery		
Discharge		
Recommended 1st Follow up		
Recommended 2nd Follow up		
Recommended 3rd Follow up		
Recommended 4th Follow up		
Recommended 5th Follow up		
Recommended 6th Follow up		
Recommended 7th Follow up		