COMPARISON OF EFFECTIVENESS OF USING TRAINED KEY INFORMANTS VERSUS HEALTH SURVEILLANCE ASSISTANTS IN IDENTIFYING BLIND AND VISUALLY IMPAIRED CHILDREN IN MALAWI

Khumbo Kalua

2016

International Centre for Eye Health
Department of Clinic Research
Faculty of Infectious and Tropical Diseases
London School of Hygiene and Tropical Medicine
Funded by BCPB

Thesis submitted for the degree of

Doctor of Philosophy, University of London

Declaration

I, Khumbo Kalua, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature: **Date: 15th November 2016**

Format of the thesis

The thesis for this PhD utilises the traditional “book style” where a full narrative of the work that was done has been presented in form of sections and chapters. The contents section outlines the list of what is presented in the thesis, followed up by the chapter section where detailed subheading on information contained in each chapter are outlined.

Acknowledgements

First and foremost, I would like to give praises and honour to GOD, for making it possible for me to submit this thesis, 10 years after I completed my masters at the London School of Hygiene and Tropical Medicine (LSHTM) in 2006, with a thesis on the use of key informants in identifying blind children in Malawi. As a graduate in community eye health, and a practising clinical Ophthalmologist, I left LSHTM for Malawi, to improve the eye health of children. My first assignment was to identify sources of funding to support my work in Malawi. I applied for my first grant in September 2006, from the British Council for Prevention of Blindness (BCPB).

I was back at LSHTM a year later in 2007, excited after having been awarded the Sir John Wilson Fellowship by BCPB, a PhD scholarship that offered £154,000.00 for follow up studies and field work on the Key informant method in Malawi. Planning to spend most of my time in Malawi, I completed the minimum 3 months' period at the school by December 2007, and relocated to Malawi where I immediately started the pre-pilot, followed by pilot studies and fieldwork, then analysis and write up, with the hope of being able to submit the thesis by 2012.

A series of unplanned events made it impossible for me to submit the thesis until 2016.
After getting feedback comments on the draft thesis submitted to my supervisor, and while working on the revisions in 2011, my laptop was stolen during a workshop in Cameron, and I lost most of my work. It took me more than 6 months to reanalyse the data, and my employers in Malawi requested that I get back to the clinical practice and continue writing the thesis from there.

On 4th January 2013, I tripped, fell down and sustained a complicated fractured radius on my right arm, and had to be admitted at the hospital in Blantyre for an open reduction procedure, followed up by immobilisation of the arm with plaster of Paris for the next 3 months, and physiotherapy. I could not use my right hand at all, and thought this was the end of my career, and that I would not complete the PhD. I recovered towards the end of 2013, and returned to work, with the target of submitting the thesis by July 2014.

Unfortunately, on 13th June 2014, while attending a workshop at Livingstonia beach hotel in Salima district in Malawi, there was a gas explosion and fire accident, my clothing caught fire, and I sustained severe burns affecting 32% of my body weight. I was initially admitted at intensive care unit in Blantyre, where the fear of death doomed upon me, and eventually I was transferred to a specialised burns unit in Johannesburg, South Africa. I had skin grafts and went through a lot of physiotherapy before I could

walk again. I was traumatised, and forgot about the PhD. Miraculously, with a lot of family support, I recovered, and barely 2 years later, I was able to submit the thesis.

I would like to thank my family members and dedicate this thesis to them: my wife, Victoria, who was there throughout the hospital admissions and had to give up her career for a while, for my sake, and my two children, Tapiwa and Yewo, who did not understand why we had to spend so much time at the hospital in South Africa.

I would like to thank Dr Devor Kumiponjera, a respectable Malawian “burns surgeon”, who courageously performed an 11-hour skin graft operation on me, in a hospital were resources were constrained.

I thank my supervisor Clare Gilbert for being there for me and bringing me along as a researcher. I would also like to thank Robin Bailey (LSHTM), Paul Courtright and Susan Lewallen (KCCO) who, through collaborations in Malawi, introduced me to international research opportunities that have contributed to my own growth and career.

I would like to thank the British Council for Prevention of Blindness (BCPB) for awarding me the Sir John Wilson Fellowship, and Blantyre Institute for Community Ophthalmology (BICO), a local NGO that I started in Malawi, in 2008, for providing travel expenses during the submission and viva period.

Finally, I would also like to thank all the community participants and staff, who were involved, in particular staff of BICO, who continue to work with me on many follow up and new research projects, which have risen out of this work.

Contributors to the research presented in this thesis

Person	Position	Contribution
Clare Gilbert	Professor of International Eye Health, LSHTM	PhD Supervisor
Robin Bailey	Professor of Tropical Medicine, LSHTM	PhD Advisory panel
Astrid Fleck	Professor of Epidemiology of ageing, LSHTM	PhD Advisory panel
Paul Courtright	Professor of Epidemiology, University of Cape town	Guidance with referral mechanisms
Susan Lewallen	Professor of Epidemiology, University of Cape town	Training in Stata
Ruby Ng'ong'ola	Childhood blindness coordinator, Lions Eye Hospital, Malawi	Data Collection
Frank Mbewe	Cataract surgeon, Lions Eye Hospital, Malawi	Data Collection
Hendrix Likongwe	Ophthalmic Clinical Officer, Mulanje district hospital, Malawi	Data Collection
Mohammad Muhit	Honorary Lecturer, International Centre for Eye Health, LSHTM	Advice on key informant method
GV Murthy	Reader, International Centre for Eye Health, LSHTM	PhD Advisory panel
Karin van Dijk	Low Vision Consultant, CBM	Advice on management of children with low vision

Abstract

Eye conditions associated with visual impairment and blindness in children, such as congenital cataract, can lead to long lasting visual problems if treatment is delayed. There is need to determine which method can be more effective in identifying blind and visual impaired children.

In this study, two methods of identifying blind and visual impaired children (using key informants versus using health surveillance assistants) were compared in a randomised community study conducted in three districts in Southern Malawi. The ministry of Health was advocating for the training of Health Surveillance Assistants (HSAs) in primary eye care, which included case detection and refer of blind and visually impaired children; and the alternative was the training of key informants (KIs). The study was done to compare the effectiveness of the two methods of case identification and to provide guidelines on optimal approaches of identifying blind and severely visually impaired children in Malawi.

Twelve clusters (group of villages) were selected, and six were randomly assigned to each group. After training in case identification and referral, Key informants and Heath surveillance assistant identified children from the clusters, within a six-week period, and the number of blind and visual impaired children identified in each group was determined and compared.

In total, 159 Key informants and 151 Health Surveillance Assistants were selected and trained, and they identified 550 children with eye problems, among whom, after examination, only 15.1 % were blind or severely visually impaired. Key informants identified one and half times more blind/severally visual impaired children than HSAs (37 vs 22).The prevalence estimates of blindness among children identified by KIs was 3.3 per 10,000 (95% CI 2.7-3.9), while the prevalence estimates of blindness among children identified by HSAs was 1.9 per 10,000 (95% CI 1.3-2.5).The difference was statistically significant (P=0.03), but overall the number of children identified by both groups was lower than was the expected from prevalence estimates of 8.0 per 10,000. False positives between HSAs and KIs were comparable, with 68.8% of children identified by HSAs as blind, confirmed blind on examination, in comparison to 72.5% of children identified by KIs, also confirmed as blind on examination. Cortical blindness seconded by cataract were the commonest causes of blindness.

In conclusion, Keys informants were more effective than Health Surveillance assistants in identifying blind and visually impaired children in Malawi, and this study supports and confirms findings from other areas.

CONTENTS

Chapters

List of Tables

List of figures

List of appendices

List of abbreviations

BL	Blind
BCPB	British Council for Prevention of Blindness
CBR	Community Based Rehabilitation
CES	Comprehensive Eye Service
CO	Clinical officer
CSR	Cataract Surgical Rate
DGH	District General Hospital
DHO	District Health Office
FGD	Focus Group Discussion
GDP	Gross Domestic Product
GNP	Gross National Product
GP	General Practitioner
GVH	Group Village Headman
HC	Health Centre
HSA	Health Surveillance Assistant
IAPB	International Agency for the Prevention of Blindness
ICD-10	International Classification of Diseases (version 10)
ICEH	International Centre for Eye Health
ICT	Information and Communication Technology
IOL	Intraocular Lens
KI	Key informant
LogMAR	Logarithm of Minimal Angle of Resolution
LSFEH	Lions Sight First Eye Hospital
LSHTM	London School of Hygiene and Tropical Medicine
MA	Medical Assistant
MCH	Maternal and Child Health
MMR	Maternal Mortality Ratio
MOH	Ministry of Health
NGO	Non-Government Organizations
NPL	No Perception of Light
OCO	Ophthalmic clinical officer
PEC	Primary Eye Care
PHC	Primary Health Care
PL	Perception of light
PRA	Participatory Rural Appraisal
QECH	Queen Elizabeth Central Hospital

RAAB	Rapid Assessment of Avoidable Blindness
ROP	Retinopathy of Prematurity
SSA	Sub-Saharan Africa
SVI	Severe Visual Impairment
SWAP	Sector Wide Approach
U5MR	Under-five Mortality Rates
VA	Visual Acuity
VAD	Vitamin A deficiency
VADD	Vitamin A deficiency disorders
VI	Visual Impairment
VF	Visual Functioning
WHO	World Health Organization

CHAPTER 1

1 Background and review of blindness and visual impairment

Overview of contents of chapter one:

The first part of this chapter describes the classification of blindness and visual impairment, visual development and visual deprivation, the World Health Organizations “VISION2020” initiative, the challenges of rare disease epidemiology and the magnitude, causes and management of blindness in children. The last part deals with heath systems and primary health care and their relation to primary eye care.

1.1 Classification of blindness and visual impairment

Until very recently the categorization of blindness and visual impairment used worldwide was based on the second revision of 10th ICD edition[1], which was derived from a 1972 World Health Organization (WHO) study of blindness and indicated that the best corrected visual acuity should be used as a standard in determining visual acuity[2]. Blindness is defined as best corrected visual acuity of less than 3/60 in the better eye or visual field loss in each eye to less than 10^{o} from fixation; severe visual impairment as best corrected visual acuity of equal to or greater than 3/60 but less than 6/60 in the better eye and visual impairment defined as best corrected visual acuity of equal to or greater than 6/60 but less than 6/18. Anyone with best corrected visual acuity of 6/18 or better in the better eye is categorized as not impaired. Low vision is defined as anyone with a visual acuity of less than 6/18 down to 3/60 in the better eye.

Since the 1990’s the major causes of blindness and visual impairment in adults in the less developed countries were cataract , trachoma, onchocerciasis and corneal blindness secondary to vitamin A deficiency (xerophthalmia)[3].Cataract was and remains the most common easily treatable cause of reversible blindness in the world[4]. Refractive errors were not considered as a priority and a major cause of visual impairment and were excluded from reports of total number of persons with blindness and visual impairment .However recent data and reports have indicated that uncorrected refractive errors contribute to a large extent to the total number of persons with visual impairment[5]. Calls to include refractive errors in the definition of blindness and visual impairment have attracted attention[6],and WHO, the coordination and directing authority that provides overall leadership on global health matters, published in 2009 a document entitled “change the definition of blindness”[7] in which it indicated that a new definition of blindness needed to be used. This was eventually adopted in the revised ICD-10

Version: 2016. The new definition uses presenting visual acuity and include visual loss from un-corrected refractive errors (table 1 below).

Table 1: Revised World Health Organisation categories of visual impairment

Categories of visual impairment*	**Presenting distance visual acuity**	
	Worse than:	**Equal to or better than*:**
0 Mild or no visual impairment		6/18 3/10 (0.3) 20/70
1 Moderate visual impairment	6/18 3/10 (0.3) 20/70	6/60 1/10 (0.1) 20/200
2 Severe visual impairment	6/60 1/10 (0.1) 20/200	3/60 1/20 (0.05) 20/400
3 Blindness	3/60 1/20 (0.05) 20/400	1/60* 1/50 (0.02) 5/300 (20/1200)
4 Blindness	1/60* 1/50 (0.02) 5/300 (20/1200)	Light perception
5	No light perception	
9	Undetermined or unspecified	
	** or counts fingers (CF) at 1 metre.	

**Refers to visual acuity taken at appropriate distance either in metres or feet.*

***http://apps.who.int/classifications/icd10/browse/2016/en#/H54*

As seen from Table 1, visual acuity is expressed in several ways, usually in metres (English) or feet (American). A visual acuity of 6/6 (English) has an American equivalence of 20/20, and is considered normal vision. This means that at 6 meters or 20 feet, a human eye with normal visual acuity is able to separate contours that are approximately 1.75 mm apart. Any vision less than 6/6 or 20/20 (for example 6/18 or 20/200) corresponds to lower vision.

In the expression 6/X vision, the numerator (6) is the distance in meters between the subject and the chart and the denominator (X) the distance at which a person with 6/6 acuity would discern the same optotype. Thus, 6/18 means that a person with 6/6 vision would discern the same optotype from 18 meters away. More than often, in Europe, visual acuity is stated by solving the fraction to a decimal number; 6/6 then corresponds to an acuity of 1.0, while 6/18 corresponds to 0.33.

1.2 Visual development

Normal visual development in a child is associated with growth and development of normal ocular and central nervous system structures, coupled with normal behaviour development[8]. Development of functions of the sensory and motor visual systems occur in parallel with development of anatomical structures[9].

In comparison to other body systems, the development of the eye and the brain in the uterus occurs earlier and at a faster rate such that by 6 weeks of gestation the basic structures of the eye and the brain are developed[8]. Ocular tissues are therefore more prone to developing defects from any teratogens that the embryo may be exposed to during this period. The rapid growth is evidenced by the large size of the infant eye at birth, with the anteroposterior diameter measuring 17mm which is approximately 70% the size of an adult eye and the volume of an infant's eye occupying half the volume of the adult eye[8].

At birth the ability of the child to see is limited because even though the periorbital tissues and anterior structures of the eye (cornea, lens , iris, anterior chamber) are fairly developed, the retina and visual pathways are not completely developed[10].It is believed that the peripheral temporal retina does not fully get vascularised until after birth (44 weeks after gestation). The optic nerve head reaches almost full size at birth.

Virtual cortical synapses continue to change in number until at least 8 months after birth while complete myelination of the visual pathways is only achieved at 2 years after birth. The template for binocular single vision starts before birth and is completed during the first few years after birth.

Visual stimuli and experiences during the critical period (first weeks and months of life) are essential for the child to achieve full vision[11]. The sole stimulus for vision is exposure to light of different amplitude early in life of the child[8]. In the absence of light stimulation, the entire visual system, including refractive components, the neural components portions of the eyeball, the neuromuscular mechanism, the visual pathways, and the corresponding visual pathways and areas in the occipital cortex, do not develop normally, nor fully function[8]. The "Critical period", also referred by others as the "sensitive period", is the period of visual development in which experience plays a major role. With binocular insult to the visual pathways (bilateral congenital cataracts), the critical time period before which the infant vision may not develop normally may be as early as within the first 3 months of life, and if the media and optical pathways are not cleared, an infant may not attain a normal vision. With severe form of deprivation (such as a child with unilateral congenital cataract), the window of opportunity before vision is affected may be as short as 6 weeks after birth. The explanation is that less cortical cells develop as a result of less stimulus to that eye and more stimulus to the opposite eye.

Figure 1 and 2 shows the visual cortex pathways and its layers respectively (adopted from Day[8]).

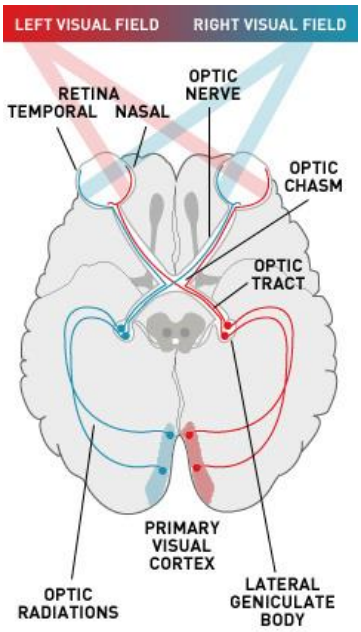


Figure 1: The visual pathways

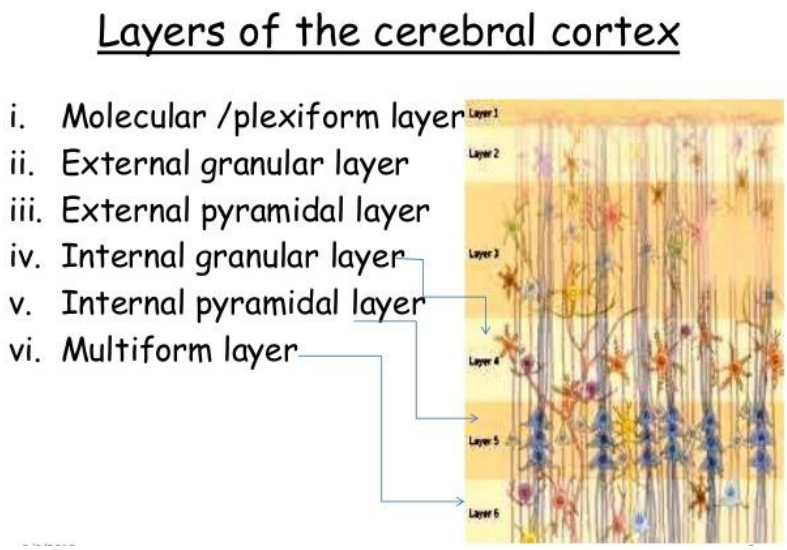


Figure 2: Layers of the visual cortex

As can be seen from Figure 2, the visual cortex has 6 layers and is highly complex to be able to process information from the eyes.

At birth, a new born neonate does not turn his/her head to a diffuse light, or look at mother's face, nor respond to smiles, fix eyes, or follow any interesting object because the visual system is still immature. In the presence of adequate exposure that stimulates the visual pathways ,a child will normally start turning their eyes to a diffuse light by 6 weeks[11].

The period of sensitivity between soon after birth and 6 weeks is very important for the formation of receptive fields and other indices of visual processing and these may be disrupted in a child if maximum visual input is not available. Figure 3 shows visual acuity plotted against age in months.

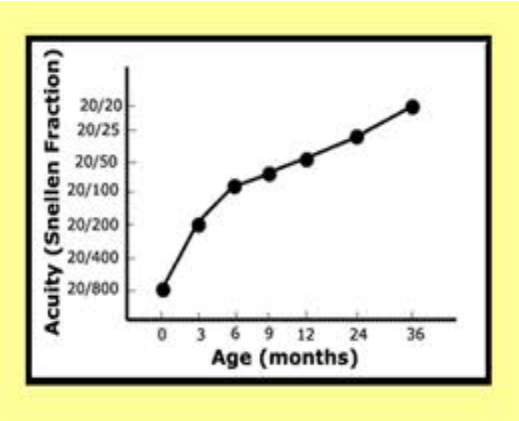


Figure 3: Plot Graph of Visual acuity versus age (first 36 months)

Source[9]

Infant acuity improves rapidly over the first 6 months to approximately 3 years and on average most children's visual acuity reaches adult levels at around 7-8 years. In the developing visual system it is thought that patterned visual stimuli are responsible for guiding the maintenance and final refinement of all the complex neuronal connections that end up within the visual cortex[8].It is therefore obvious that any disruptions to the visual stimuli in a child early in life can prevent normal visual function. All children find it hard to fix /align their eyes immediately after birth, and transient esotropia (eye deviating inwards) and exotropia (eye deviating outwards) occur commonly, being present in up to 50% of all new-borns[12]. This irregular fixation and alignment usually continue for up to 2 months after birth, but after that the eyes should normally be aligned on targets of interest[11], except where there is prolonged pathology that hinders the normal alignment of the eyes.

1.2.1 Visual assessment in children

Visual assessment in children can be complex and needs special expertise and patience. Behavioural clues can give an indication of the child's visual acuity; for example, a child that is not reacting to a bright object shown to them can be a result of the child not being able to see. The state of immaturity of the visual system at birth makes it impossible to do a proper visual assessment in newly born neonates. At two months of age a normal seeing child should be able to follow object and smile at attractive objects; by four months of age a child can see and reach out to objects; by six months a child who is crawling can pick an object at a distance and play with it, and finally by one year a child can point to, walk and lift

an object they desire. In the absence of any motor pathology, a child who fails to do such things needs to have a visual assessment.
Visual assessment involves measuring visual acuity, binocular single vision, colour vision, contrast sensitivity and visual fields. However, distance visual acuity alone is frequently used to measure visual function in clinical practice and epidemiological research[13, 14].

1.2.1.1. Visual acuity

Two types of visual acuity have been reported: recognition acuity-where details in smallest letters, numbers or shapes can be recognised and resolution acuity- where the smallest distance between two objects can be resolved[15]. Visual acuity can be measured by using psychophysical tests and electrophysiological tests[8].

a) Psychophysical tests

Psychophysical tests are often referred as behavioural methods as they require some responses from the child.
Forced choice preferential looking (FPL) is a technique that uses a child's motor response to interpret his/her capability to see. As described by Day [8], a target with gratings (Teller cards, Figure 4 & 5) or a vanishing optotype target (Cardiff acuity cards, Figure 6) of different sizes is exposed to the child and observations are done to determine which grating/optotype the child can see and resolution visual acuity is calculated.

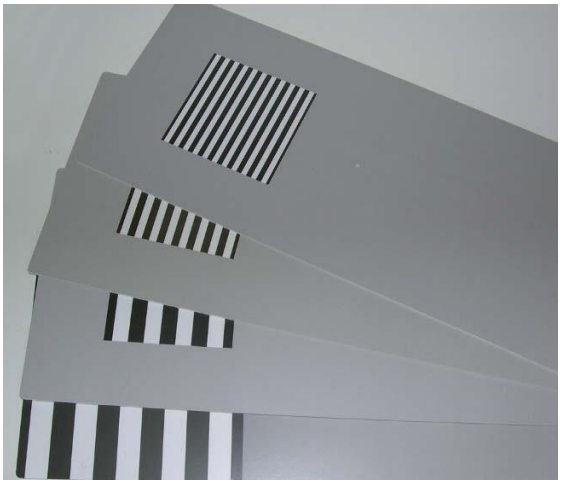


Figure 4: Teller acuity cards

Figure 5: Testing using Teller acuity card

Here the child preferring to look to the left-hand side of the card.

Figure 6: Cardiff cards

The technique is based on the observations of the child's head and eye movements in response to the stimulus. In clinical settings, the threshold is often taken as to when the child makes a definite look at the object. Using this technique it has been shown that by one year of age a child is able resolve 6/30 equivalent gratings while by 3 years a child is able to almost resolve 6/6 equivalent gratings[15]. A weakness of this method is that it relies on the child's movement, and therefore any motor abnormality in the child may affect the final visual acuity. It should be noted that FPL gratings are measured in cycles per degree and equivalence can be obtained with visual acuity obtained with Snellen charts [8]. Forced choice preferential looking (FPL) can be used for children from neonates up to 3 years of age.

Examples of recognition visual acuity include Kay pictures (Figure 7), LEA symbols (Figure 8), and Cambridge crowding cards (Figure 9) [8]. It is thought that grating visual acuity matures earlier than recognition visual acuity.

Figure 7: Kay pictures

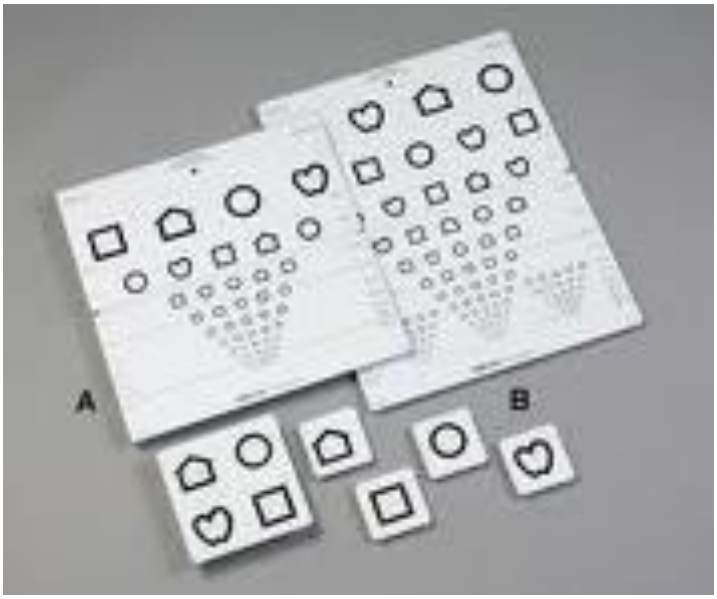


Figure 8: Lea Charts

Figure 9: Cambridge crowding charts

Other psychophysical tests used for older children 3 years and above include traditional Snellen Chart, illiterate E charts, Landolt C, optotypes (Sheridan –Gardner, Lea charts), and Cardiff charts. These are shown in figures 10 and 11[8].

.

Figure 10: Sheridan Gardner test

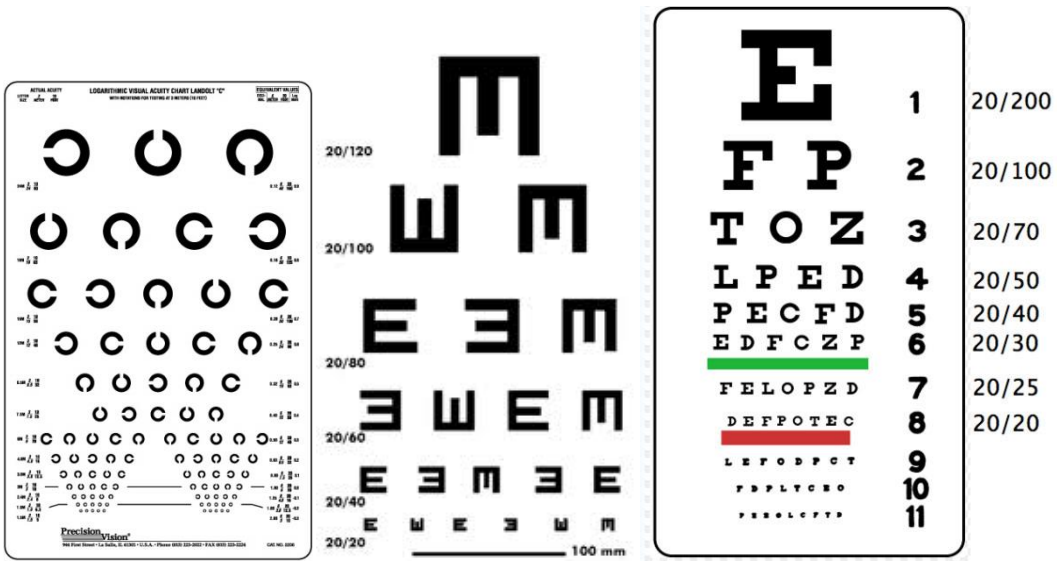


Figure 11: Landolt C, Illiterate E and Snellen charts

In older children, the standardized method involves each eye being tested separately using a LogMAR (logarithm of minimal angle of resolution) visual acuity chart (Figure 12) [16].

.

Figure 12: LogMAR Snellen chart

The LogMAR scale converts the geometric sequence of a traditional Snellen chart to a linear scale and in measuring visual acuity loss positive log values between 0 & 1 indicate vision loss, while negative log values between 0 & 1 denote normal or better visual acuity[16].

b) Electro-physiological tests

These tests are often referred to as objective tests as they are not dependent on the child's motor responses (eye movements). Visual evolved potential (VEP) waveforms are extracted from the electro-encephalogram (EEG), using VEP electrodes placed on the occipital scalp overlying the calcarine fissure, the closest location to primary visual cortex. These are used to measure visual acuity through the VEP response amplitude obtained at each frequency, for a wide range of spatial frequencies. Each individual amplitude is in turn plotted against its spatial frequency, and then a regression line of best fit is drawn and extrapolated to a point to where the response would be zero, which corresponds to the visual acuity. In this case, the visual evoked responses (VER) resulting from rapid changes in grating sizes produce VEP.

Using this technique, it has been shown that visual acuity development in a child is rapid from birth and that by 12 months a child is able to resolve 6/6 gratings (much earlier than estimates obtained from behavioural techniques). In older children with pathology, VEP findings do not correlate as closely with Snellen or other psychological methods.

1.2.1.2. Binocular single vision

Development of binocular single vision involves development of both stereopsis and fusion. While as stereopsis refers to the ability to perceive depth resulting from two slightly disparate images simultaneously presented to the two eyes, fusion refers to the ability of the visual system to combine non-identical but similar images from the two eyes into one image. Binocular single vision is only possible in the presence of binocular foveal fixation occurring as a result of ocular alignment. There have been debates as to when stereoscopic vision develops in a child [17], but preferential looking studies suggest that in the presence of normal visual stimulating mechanisms the earliest evidence of stereoscopic vision which involves depth discrimination occurs at approximately 3 months which quickly becomes refined, such that by 5 months of age the infant should be able to correctly discriminate objects which have at least 1 arc minute of disparity[17]. Thereafter stereoscopic visual acuity should continue to improve gradually during the first few years of life and possibly reach nearly adult levels by age of 6 years[8].There is evidence that there can be complete recovery of binocular single vision in strasbimic eyes if they are aligned by as early as 2 years of age[8].The continuous absence of proper alignment of the eyes in the first years of life leads to amblyopia (see section on amblyopia) with the possibility of permanent loss of vision.

1.2.1.3. Colour vision

In a normal developing child, the ability to match colours is usually reached by two years of age. Pathologies leading to defective colour vision can be congenital or acquired[8]

.

1.2.1.4. Visual fields

Assessing a child's visual field depends on several factors ;the distance at which a target is presented, how interesting the target might be and whether the target is fixed or not[18].It appears that the ability to switch attention in a controlled manner between objects occurs between two and four months, and binocular visual field develops slowly up to the age of 12 months. A simple way of assessing visual fields in children involves confrontation techniques-when an examiner directly faces the child and then introduces an object from far peripheral to assess the child's visual field. This test alone is adequate to assess significant visual field defects such as hemianopia. However other conventional visual fields tests need to be done for minor defects but these are rarely done in children as the process is often complex and requires sophisticated equipment not often comprehensible by children.

1.2.2 Visual deprivation and amblyopia

According to Von Noorden [19, 20] , amblyopia is defined as "a loss of spatial resolution (visual acuity) without overt retinal pathology". This definition implies that poor vision is present in an otherwise physically normal looking eye- commonly referred to as "lazy eyes." Long standing amblyopia may be associated with changes in the visual cortex and neuronal losses disturbing the normal neuronal connections and visual processing mechanisms in a child; these may not be fully reversible in later life even with maximum occlusion or penalization therapy, the two common forms of treatment for amblyopia. There are three major forms of amblyopia: i) strasbimic amblyopia, ii) anisometropic and iii) deprivation amblyopia [8, 19, 20], which are described in detail below:

i. Strasbimic amblyopia

Strasbimic amblyopia results when the child's eyes are misaligned. Differences between the eyes in focusing the image (anisometropia) or in magnifying the image (aniseikonia), and/or partial occlusion of the image in one eye may lead to a preference for the better eye, such that the other eye develops a strasbimic misalignment that eventually leads to amblyopia[8]. Even though the retinal images may be independently clear in each eye, one eye may be used for fixation more than the other with a resulting amblyopia in the less dominant eye. However, if each eye is used equally for a given portion of the time

(child uses each eye alternatively), the resulting condition is usually an alternating esotropia, which is unlikely to lead to amblyopia. Ocular misalignment at or immediately after birth can give rise to strasbimic amblyopia early in infants as young as 4 or 5 months of age[21].

ii. Anisometropic amblyopia

This occurs when differences in refractive error between the two eyes results in the weaker eye developing poor vision. In cases of hypemetropia even a small difference of 1 dioptres between the eyes is adequate to cause amblyopia while for myopia the difference between the eyes has to be much larger (at least -3.0Ds). Astigmatism also predisposes the eye more to amblyopia, with as little as 0.5DC difference between the two eyes causing amblyopia [8].

iii. Deprivation amblyopia

For deprivation amblyopia to occur the image in one eye or both eyes has to be unclear during the early critical period of life[8], which falls between 6 weeks and 3 months of life after birth, depending on whether the pathology is in visual and cortical axes of one or both eyes . Such amblyopia may be caused by uncorrected refractive error (astigmatism, aphakia), interference with the optical pathways (due to corneal scar, congenital cataract), or from glare that results in degradation of the retinal images (such as in cases of aniridia). The resulting visual consequences depend not only on the severity of deprivation, but also on the degree of difference of deprivation between the two eyes, age at onset of the deprivation, and duration before treatment is initiated. Accelerated pathologies causing defects in retinal imagery immediately from birth (e.g. dense cataract) may affect the development of the visual system so strongly such that removal of the cataract later in life, followed by optical correction and occlusion amblyopia therapy, may not be sufficient to achieve acceptable levels of visual acuity for the child to function normally. The difference in the two eyes in image clarity is an important factor in determining the extent of amblyopia. However, if blur is not too severe or there is no major difference in blur between the two eyes, the visual acuity may markedly improve once the obstacle has been removed and proper optical correction has been initiated, followed by intensive amblyopia therapy. The danger and challenge comes when only one eye is involved and a long period has elapsed before therapy as the resulting visual deprivation in the affected eye leads to profound and often not completely reversible amblyopia. It is now known that the success of treatment for severe unilateral amblyopia decreases with the late age of onset of pathology (usually after 5-6 years), even though it is still not uncommon to see unilateral traumatic cataract sustained after the age of 8 years still developing dense amblyopia, if not properly corrected within the first few weeks on diagnosis [22].The serious consequence that may occur in an

untreated child and the importance of early diagnosis and treatment of visual problems in children is discussed in section 1.4.4 (control of blindness in children).
It should be noted that because delayed treatment can have long standing consequences, proactive case finding is needed. In order for this to be done, programmes that ensure that adequate staff are trained at all levels of the health system need to be put in place so that children with amblyogenic factors (e.g. strabismus, cataract, uncorrected refractive errors, ptosis, corneal ulcers) are detected early and promptly referred for management. It therefore does not come as a surprise that the VISION2020 initiative has prioritized blindness in children[23].

1.3 Global blindness and VISION 2020

VISION2020

The World Health Organization (WHO) reported in 1995 that globally there were 45 million blind people and if no concentrated efforts were done to reverse the trends in blindness, the figure would rise to 76 million by the year 2020[3]. An additional three times the number of blind persons were estimated to have visual impairment. This realization led to the launch of the “Global Initiative for the Elimination of avoidable Blindness” in 1999 popularly known as the “VISION2020: Right to Sight”. VISION 2020: The Right to Sight is the global initiative of the International Agency for the Prevention of Blindness (IAPB) with its partner (WHO). Members of IAPB include international non-governmental organizations (NGOs), professional bodies, national non-governmental associations, academic institutions and the corporate sector [3, 24].

VISION2020 components include three pillars: major blinding eye disease control, human resource development at all levels (clinical and managerial), and infrastructure development; all these backed up by advocacy and community participation[3]. Global estimates from 2004 indicating that there were 37 million blind persons and 124 million with low vision[4, 5], suggested that there had been a decline in blindness probably resulting from an increase in VISION2020 activities[25, 26]. Both the 1995 and 2004 estimates of blindness did not include refractive errors as a cause of blindness[27], but it is now recognized that refractive errors globally contribute another 8 million blind persons and 145 person with visual impairment[5]. Therefore the new figures indicate that globally there are a total of 314 persons with visual impairment (45 million blind, 269 million with visual impairment) [5]. A total of 1.26 million children are blind, with almost a third living in sub-Saharan Africa[28].

Priority diseases for VISION 2020 as set in the first phase (1999) included cataract, trachoma, onchocerciasis, refractive errors and blindness in children, either because these diseases contribute a

larger burden, or these were either preventable or treatable, and they had demonstrable cost effective interventions.

1.4 Blindness in children

1.4.1 Definition

The World Health Organisation (WHO) defines a child as someone who has not yet attained their 16th birthday, and blindness in children refers to all conditions/diseases that cause the child to have a presenting visual acuity of <3/60, or a constricted visual field of <10^{o} from the central of fixation, in the better eye. The other categories of visual impairment in children are as indicated in table 1.

Why is blindness in children a priority for Vision 2020?

The prioritizing of blindness in children in the VISION2020 initiative is the result of a number of factors. “Blind years” is one factor that is important in determining the burden of eye disease. “Blind years” refers to the average number of years that someone who has become blind will remain alive with that eye disease. Based on life expectancy, it is said that on average, a person who is blind from age related cataract will live for approximately 5 years before dying, while a child who becomes blind at 5 years may live for 50 years [29]. In terms of disease burden, the burden of one blind child who lives blind for 50 years (50 blind years) is equivalent to 10 blind adults who live for 5 years each (50 blind years). Blindness in children has more than half the number of ‘blind years’ attributable to cataract in adults[29].

The causes of blindness in children are different from adults, implying that different strategies are needed for control. Moreover, children’s eyes are not a replica of small adult eyes and they respond differently to treatment, and need specific expertise, training and equipment. As already discussed, delays in management can lead to long lasting, irreversible amblyopia.

Consequences of blindness on the family and community

As most of a child’s early learning comes through vision, early onset of blindness and visual impairment can have negative impacts on the overall development of a child. If there is no intensive help for visually handicapped children from the earliest months of life, they are prone to delays in different areas of developmental which include social adaptation, sensory-motor understanding, environmental understanding, verbal comprehension and expression of language [30-33] . The impact of blindness and visual impairment among the family and community has not been well studied especially in developing countries. However, some of the negative social impacts of child disability on the family have been documented [34, 35], and those reported include increased stress and depression among affected family

members, which can lead to increased possibility of parents divorcing or living apart, and also of not going out to work. Some positive impacts of child disability on the family have also been suggested and these include bringing of different extended family members together resulting in increased family interactions, and a greater awareness of their inner strengths[34].

A high proportion of visually impaired children in industrialized countries have chronic untreatable conditions which causes severe visual impairment and blindness with associated motor, sensory or cognitive impairments that are not amenable to simple ophthalmic treatment and procedures but require long term visual rehabilitation, educational support and/or developmental interventions[36]. Interventions for such children are usually very expensive, time consuming and need family support and multiple referral networks. In contrast, a high proportion of children in developing countries suffer from avoidable conditions (preventable or treatable) resulting usually from short-term illnesses (cornea ulcer, vitamin A deficiency), which have well known available treatment modalities, are usually non-complicated, non-expensive and often need public health community interventions. It is therefore important to have a clear understanding of the magnitude and causes of blindness and visual impairment in children from different regions and different social economic status to guide policy in planning resources for appropriate, area specific interventions.

1.4.2 The challenges of rare diseases epidemiology

Since blindness in children is a rare condition, obtaining reliable epidemiological data on prevalence, incidence and causes can be very difficult. The challenges faced also apply to all other rare diseases.

There are a number of reasons why it may be difficult to obtain reliable data about blindness in children [13], viz:

1. Measuring visual function in children, particularly those under the age of 5 and those with additional disabilities, can be very difficult and time consuming. The late maturation of vision may mask disorders that may be present from birth posing further challenges.
2. Very large sample sizes are required to determine the prevalence of rare diseases through population based cross sectional surveys. Such studies are rarely done as they are difficult and expensive to undertake.
3. The different definitions and research tools used by researchers to classify causes of blindness and visual impairment in children from different areas makes it hard to find comparable studies. In studies that address causes of blindness in children, it is noted that researchers frequently use different cut off categories of visual acuity (some use <6/60 and below as blindness in children, while other use <3/60 and below). Regarding how visual acuity is measured, different researchers use different acuity charts (Snellen charts, LogMAR, Lea charts), and some researchers may use two different charts

based on the age of the children in the study. Some researchers prefer to use the best corrected visual acuity while others use the presenting visual acuity. Such differences make it hard to identify comparable studies.

4. Studies on outcomes e.g. following cataract surgery in adults are usually conducted over a relatively short period. However, important outcomes in children can only be reliably determined through long-term follow up, which is difficult to achieve in studies of children.
5. Lack of agreement among researchers and ethical research governing bodies as to who should or should not give consent (children, their parents or both) when children participate in research may discourage some researchers from undertaking studies involving children.

The available data on the magnitude and causes are, therefore, limited and this should be taken into account when interpreting any research findings on prevalence, incidence and causes of blindness in children.

1.4.3 Magnitude, prevalence, distribution and causes of blindness in children

Prevalence and sources of data

Population based surveys (either specifically designed to assess visual loss in children or designed for other purposes)

Population based cross sectional surveys are the gold standard method for estimating prevalence because of the statistical processes involved in calculating sample sizes and systemic sampling that is involved in selecting the sample for examination. They can be used to estimate the prevalence of blindness, visual impairment and low vision and also can give a good measure of the causes if the sample size is large enough[13]. However, because blindness in children is rare (see section on rare disease epidemiology), very large sample sizes (30,000 plus) are needed to give precise estimates and an even larger sample size (60,000) is needed for determining rare causes. Population based surveys are technically difficult to undertake: they are very time consuming and expensive; they require meticulous enumeration and are likely to have low response rates in children (children may be away at a school or play; are unlikely to cooperate; and parents of disabled children may not acknowledge that they have a disabled child). If the characteristics and causes of blindness in the children examined are different from those absent, this will lead to bias in prevalence and causes.

The clinical teams involved must not only be highly skilled to be able to measure visual acuity in children in field settings, but also require the right equipment. These complexities mean that only a few population based surveys have been undertaken over the last 20 years [37-46].

Some of the earlier population based studies, which were not designed to estimate prevalence but for assessing the status of vitamin A deficiency in children, have provided some data on prevalence and causes of blindness in children[47]. However, these studies are prone to selection bias and are likely to miss children whose causes are not obvious and they may also give an imprecise estimate as the sample size was not determined for visual impairment. Sub-Saharan Africa has only reported 3 population based surveys over the last 30 years [39, 47, 48]. The earliest study was undertaken in the Lower Shire Valley in Malawi in 1986[47] with the aim of estimating the prevalence of vitamin A deficiency (xerophthalmia) and deliberately targeted very remote, poor areas. The prevalence of blindness was 1.1/1,000 children, but this is likely to have been an overestimate as xerophthalmia and blindness are associated with extreme poverty[49]. The second study, conducted in Ethiopia[39], was a national household survey of adults and children undertaken to estimate the prevalence of trachoma in children aged 1-9 years, and determine the prevalence of blindness at regional and national levels. The primary focus in children was the prevalence of trachoma and vitamin A deficiency. The sample size for the study was 25,777, with children aged between 1-9 years contributing approximately 30% of the sample. Since this was a national survey, the sample size for children (approximately 8,000) may not have been adequate to confidently generalize results to the entire population[13]. However, the study produced important results as regards to blindness in children in Ethiopia. A brief description of the study is as follows: Households were selected through probability proportional to size (PPS) i.e. larger communities contribute more households than smaller ones. Basic eye examination by a nurse included a torch examination of the anterior segment of the eye to assess vitamin A deficiency and presence of trachoma, and visual acuity for children aged 5 and above. Parents were asked about night blindness in their children. In cases with suspected pathology an ophthalmologist did the funduscopy and ascertained the causes of visual acuity loss. However, the standardized WHO form for recording causes (anatomical and aetiological) in children was not used. The prevalence of blindness in children aged less than 16 years was reported to be 1/1000, but the 95% confidence interval and the causes of blindness in children were not reported.

A recent study was conducted in Sudan [48] in a refugee camp comprising of 29,048 children in 5 camps of internally displaced people in Khartoum, and thoroughly examined 916 children aged less than 16 years.

The prevalence of blindness in the camp was 1.4 per 1,000 children and the leading cause of blindness was cornea blindness, secondary to vitamin A deficiency (40%), followed by amblyopia (32.5%). Data on prevalence and causes in camps are likely to vary from children from the rest of the country, depending on the level of NGO support in regard to nutrition supplements in children. Data collected from community based rehabilitation (CBR) programmes that deal with children with disability can be used to estimate the prevalence and causes of blindness and visual impairment. Many shortfalls are associated with using such data as the community workers are not usually equipped with the right skills to identify blind and visual impaired children and are likely to miss children.

Other sources of data such as “piggy backing” into other surveys (RAAB, census data, questionnaires, health management information systems) can provide useful information but are prone to selection bias and, information and observer bias. Studies using data from health facilities need well organized health systems to capture reliable data. Setting up such systems is still generally a challenge and rarely properly done in many parts of Africa, mainly due to lack of human resource and technology to implement an effective Health Management Information System(HMIS) and analyse such data.

The key informant method

The key informant method[50] has recently been used to determine the prevalence and causes of blindness and visual impairment initially in Bangladesh and subsequently in other countries in Asia (i.e. Iran) and Africa (i.e. Ghana, Malawi) [51-54]. Key informants have been used after successful training as an alternative to population based surveys to identify conditions such as mental health[55], AIDS[56] and epilepsy in children[57]. According to Muhit [58], Key informants (KIs) are “local volunteers who live and/or work in their communities and through their vocation have a social role and are likely to know the local context, the people and the conditions in their community”. The KI method has been shown to be a relatively quick and effective method of identifying blind children in the community[58]. The method involves several stages; firstly, identifying the clusters and contacting the community, with mapping of social networks; followed up by selection of local volunteers (Key Informants) who are trained for a day in how to find blind children. They are given two weeks after training to find children who have visual problems in their community using community networks (going door to door, church announcements, village announcements and other means of communication). An eye clinic is set up in the community on agreed dates when all the children identified have their visual acuity measured, are examined by ophthalmic personnel and referred, if necessary. The whole process takes about 6 weeks. Using this

method over 10,000 blind children have been identified in Bangladesh [50, 54]. Traditional healers, who could become key informants, have been trained in primary eye care with limited success[59]. The challenge of using key informants in estimating prevalence is that the population denominator is usually an estimate and assumes that KIs have covered the entire area, but it is very likely that not all cases in the catchment area are ascertained; the result is a minimal estimate of the prevalence.

Mixed methods approaches

This method uses already available in-country sources of data (such as routine hospital records) and collects data using new methods which may include population based studies and data from blind schools (where blind children are sent for education). The method is recommended because it eliminates bias obtained from using individual sources such as blind schools' surveys or population based surveys alone. It is known that with inclusion education being promoted; only children with severe visual problems are likely to remain in the blind school/annexes while children with moderate visual impairment join the mainstream schools. Studying children in the blind schools/annexes alone may not therefore give an accurate picture of the entire country. On the other hand, trying to conduct population based surveys everywhere maybe very expensive and impractical. Where there is some locally available data (from blind schools, eye hospitals, screening programs), this can be collected and compared with data from a population based survey in another area of the country. Limburg et al [60] used a mixed method approach in Vietnam by comparing a population based survey to results from examining children from blind schools. They found out that in the population based study, children were blind from all causes, with uncorrected refractive errors dominating, while in the blind schools, they found that cornea and retinal were the main causes. Cama et.al [61] in a study of childhood visual impairment in Fiji also used a mixed method approach (blind schools, key informants, CBR and eye clinic registers), and found out that only using one source could have underestimated or overestimated their findings on causes.

Prevalence and under-five mortality rate

A linear relationship is likely to exist between prevalence of blindness in children and under-five mortality rates[13, 28](i.e. the higher the under-five mortality rate, the higher the prevalence of blindness), hence under-five mortality rates have been used as a proxy indicator (Figure 13) and table 2.

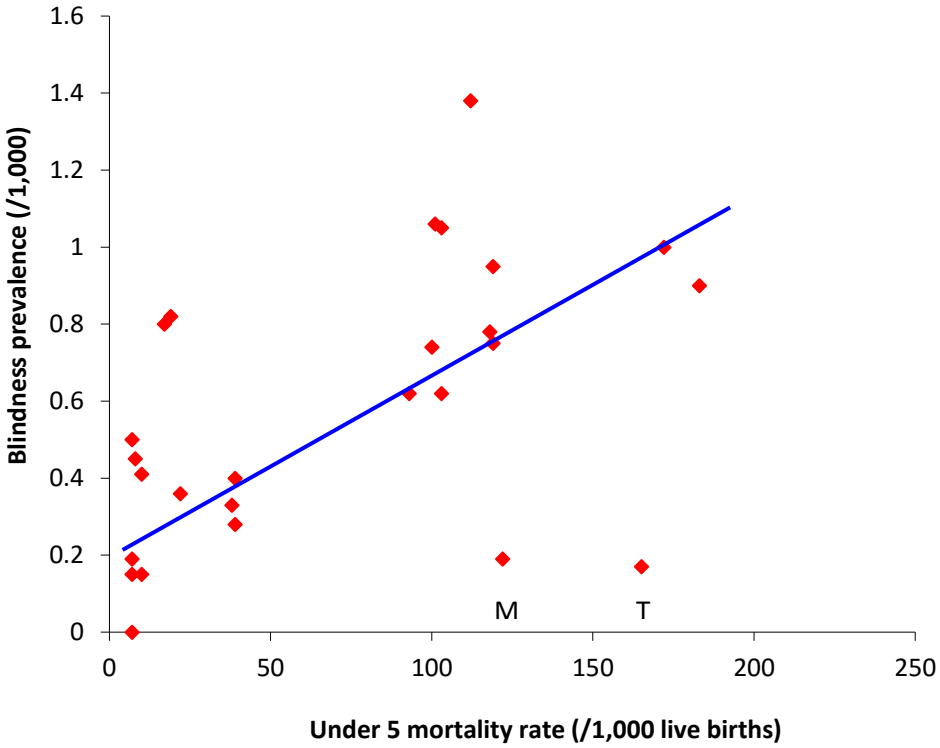


Figure 13: Relationship between blindness prevalence (/1,000) and under 5 mortality rate (U5MR)

*From Gilbert & Rahi, with permission [13].

Note: Linear regression line excludes data points from the two studies with unexpectedly low prevalence estimates: in Mongolia (M) and Tanzania (T).

Table 2 summarizes shows how U5MR can be used as a proxy indicator for prevalence of blindness.

Table 2: **Under-five mortality rates as a proxy indicator of and prevalence of blindness.**

Under-five mortality rates	Estimated prevalence of blindness per 1,000 children*
0-19	0.3
20-39	0.4
40-59	0.5
60-79	0.6
80-99	0.7
100-119	0.8
120-139	0.9
140-159	1.0
160-179	1.1
180-199	1.2
200-219	1.3
220-239	1.4
240+	1.5

*copyright from Chandna & Gilbert[28], with permission

As can be seen from table 2, the prevalence of blindness increases with higher under-five mortality rates. Prevalence of blindness is therefore likely to be highest in sub-Saharan Africa where under-five mortality rates are still high. Even though under-five mortality rates have only recently been used as a proxy to indicate which communities of children are at risk of vitamin A deficiency diseases as a public health problem[62], the relationship between the prevalence of blindness and U5MR was suggested several years ago[13]. The prevalence of blindness in children ranges from around 0.3/1,000 children in the developed world to 1.5/1,000 in the poorest countries [23, 28] (as shown in table 2). A 2010 report by UNICEF [63], and another study at the same time by Rajaratnam et al; [64], in which a systematic analysis of progress towards Millennium Development Goal 4 was conducted for *Neonatal, postnatal, childhood, and under-5 mortality for 187 countries (1970-2010),* suggested that U5MRs (neonatal, post-neonatal, and childhood mortality) were on the decline, but that Sub Saharan African countries (SSA) remained to have the highest rates, with 49.6% of all deaths in children younger than 5 years occurring in sub-Saharan Africa. It is likely that the higher prevalence of blindness in poorer countries and the correlation with high U5MRs reflects not only an environmental exposure to diseases which not only cause blindness in children, but which are also causes of child mortality, such as Vitamin A deficiency disorders (VADD), measles, and meningitis.

Vitamin A deficiency disorders as a cause of morbidity and mortality in children

Information from observational studies in the early and mid-1980s suggested that xerophthalmia (the eye signs of vitamin A deficiency) was a major cause of blindness in children [23, 65-67] and that children with xerophthalmia had higher mortality rates than those from the same community without the eye signs [67, 68]. The link between vitamin A deficiency and morbidity/mortality in children[69] has been documented through 14 clinical trials(10 larger trials, 4 smaller) conducted between 1986 and 2008 [68, 70-81] and these are shown in Table 3. Initially the trials only included children aged 6-72 months, but later trials have included neonates and women of child bearing age.

The first clinical trial of Vitamin A was conducted in 1986 in Sumatra, Indonesia by Sommer and the Aceh group [70] and investigated the impact of vitamin A supplementation on childhood mortality in a rural area. Participants (preschool children) were randomized to receive a high dose vitamin A supplement or placebo for 1 year. Mortality in the control group was higher than among those who were supplemented. The study was the first clinical trial to demonstrate vitamin A supplementation was associated with decreased mortality (by as much as 34%). A further placebo controlled randomized clinical trial of weekly high dose vitamin A to preschool age children in Southern India by Rahmathullah et.al (1990) found that the risk of death in the supplemented group was reduced by 54%. A summary of the findings of clinical trials on vitamin A supplementation and the effects on childhood morbidity and /or mortality is shown in Table 3.

Table 3: Summary of clinical trials of vitamin A supplementation and child mortality/morbidity studies

	Study author, year and place	Study group	Total Number	Impact of vitamin A supplementation
1	Sommer 1986; Indonesia	Preschool children	25,939	Decreased mortality by 34%
2	Rahmathullah 1990; India	Preschool children	15,419	Decreased mortality by 54%
3	Vijayaraghavan 1990; India	Preschool children	15,775	Contradictory: Respiratory infection rates high in children with VAD. No effect on mortality
4	West 1991; Nepal	Preschool children	28,630	Decreased mortality by 30%
5	Daulaire 1992; Nepal	Preschool children	30,000	Decreased mortality by 26%
6	Herrera 1992; Sudan	Preschool children	28,753	No effect on mortality
7	Ross 1993; Ghana (2 studies)	Preschool and school children	21,906	Decreased mortality by 20%
8	Stansfield 1993; Haiti	Preschool and school children	11,124	Increased morbidity (through diarrhea and respiratory infections)
9	Agarwal 1995; India	Preschool	17,861	Decreased mortality by 16.9%
10	Pant1996.Nepal	Preschool	40,000	Decreased mortality by 2 years (RR 0.57)
	Other small clinical trials on morbidity			
11	Barreto 1994; Brazil	Preschool	1,240	Fewer diarrhoea episodes
12	Venkatarao1996; India	Infants	471	No effect on child morbidity
13	Donnen 1998; DR Congo	Infants	900	Low doses associated with reduced morbidity High doses –no effect
14	Chowdhury 2002; India	infants	1,520	Reduced incidence of diarrhoea and measles

Impact on vitamin A supplementation in different age groups

The majority of the clinical trials demonstrated that high dose vitamin A supplementation given to preschool age children has a positive impact on mortality with only two trials above (3 and 6) not finding any effect. Studies 8 and 11 to 14 also investigated morbidity. Study 8 found an increase in morbidity as a result of vitamin A supplementation, while the rest found a reduction in morbidity.

Several systematic reviews of the effect of vitamin A supplementation on childhood mortality and morbidity have been conducted between 1993 and 2011 (Fawzi 1993; Glasziou 1993; Gogia 2009 and Imdad 2011). The reviews by Fawzi et.al[82] and by Glasziou et.al [83] concluded that vitamin A supplementation was associated with a significant reduction in childhood mortality when given at periodic levels in the community. However, recently Gogia et.al [84] in a systematic review and meta-analysis of neonatal vitamin A supplementation on infant mortality and morbidity concluded that there was no evidence of reduced risk of morbidity and mortality to justify the supplementation of vitamin A to neonates. A systematic review by Imdad et.al[85] on vitamin A supplementation in children aged 6 months to 5 years concluded that it reduces child mortality from all causes by approximately 24%.

Incidence

Sources of incidence data

Obtaining incidence data for a rare disease such as blindness in children is even more challenging because individual eye diseases are uncommon[13]. Hence only a few sources of data (blindness registers, active surveillance and disease specific anomaly registers) are available, mostly from countries with well-organized health systems. The data obtained through these collection methods can be a reliable tool for comparing changes in incidence and causes of visual impairment over time. Incidence data on severe visual impairment and blindness has been obtained through the British Ophthalmology Surveillance Unit (BOSU) in UK[36] and from registers in Israel[86], Kuwait[87], Greenland[88] and one region of the UK[89]. Studies in the UK reported an incidence of blindness of 4 per 10,000 children per year and a cumulative incidence by 16 years of 5.9 blind children per 10,000 children per year while studies from other countries reported incidences between 0.5-0.8 per 10,000 children per year. The studies differed in the age range of children studied and also the data collection methods so it is not possible to compare their findings.

How many children are blind?

Previously reported data in 1990 and 1999 indicated that there were 1.5 and 1.4 million blind children respectively[4, 90]. The latest data[28] estimates that there are 1.26 million blind children; this represents a 10% reduction over the 11 years since the 1999 estimate. Table 4 shows how the number of estimated blind children has changed from 1990 to 2010 and table 5 shows the changes that have taken place between 1999 and 2010[25].

Table 4: Estimated number of blind children

Number of blind children (millions)*	Year	Source	Total child population (millions)
1.26	2010	Chandna & Gilbert[28]	1880
1.4	1999	Vision 2020	1773.6
1.5	1990	WHO	1455

Table 5: Changes in number of blind children between 1999 & 2010

	1999		2010 estimate		% change between 1999 & 2010	
	Child pop (millions)	Blind children	Child pop (millions)	Blind children	In child population	In estimates of blind children
Lower in 2010 than 1999:						
China	340	210,000	340	116,000	0.0%	-44.8%
Other Asia and Islands	260	220,000	266	136,000	-2.3%	-38.2%
EME + FSE	248	90,000	244	70,000	-1.6%	-22.2%
Latin America & Caribbean	170	100,000	170	71,000	0.0%	-29.0%
Not much change:						
Middle East Crescent	240	190,000	241	168,000	0.4%	-11.6%
India	350	270,000	345	280,000	-1.4%	3.7%
Higher in 2010 than 1999:						
Sub-Saharan Africa	260	320,000	274	419,000	5.4%	30.9%
TOTAL:			1,880	1,260,000	0.6%	-10.0%

* From Gilbert, with permission [13]

Estimates in 1999 and 2010 were based on the association between U5MR and the prevalence of blindness in children

As can be seen from table 5, Sub-Saharan Africa is the only region where the estimated number of blind children has increased between 1999 and 2010.This can partly be attributed to: 1) better research methods of estimating the number of blind children in SSA, especially adding epidemiological data from various sources, which were not there before and, 2) a significant child population increase in the region.

The number of blind children has been calculated excluding children blind from refractive errors. This is because even though there have been several surveys of refractive errors in children in specific areas of

the world [91-98] there are inconsistencies in definitions and categorisation of visual impairment and blindness that make it difficult to estimate the number of children who are blind from uncorrected refractive errors. The World Health Organisation reported in 2014 that there was a total of 19 million children who are visually impaired, and among which 12 million were visually impaired due to uncorrected refractive error (http://www.who.int/mediacentre/factsheets/fs282/en/).

Causes of blindness

Sources of data

In contrast to limited prevalence and incidence sources of data, the sources of data for causes of blindness and visual impairment in children are many and include: population based cross sectional surveys, multiple methods, community based rehabilitation (CBR) programmes, key informant method, registers, low vision clinics, hospital records and studies of children in annexes and schools for the blind, and other special education institutions [13]. Population based surveys, the key informant method and CBR can be used to reliably establish causes where a large population sample (>60,000) has been chosen [13]. The other methods are however prone to many forms of bias (information, observer and selection bias). For registers and hospital records, the use of different personnel to examine and record causes is likely to lead to observer bias. Many children may not be registered or not seen at the hospital leading to selection bias.

Though blind school studies and other special education institutions are relatively easy to do (large number of children gathered at one place) and less expensive compared to other methods, they also are likely to have selection bias on the causes due to the non-random sampling methodology (children in school not representing blind children in the population) and other reasons stated below:

- Most of the developing countries have few schools which are located in urban areas hence only a few children from such areas may attend as parents who are rural are often reluctant to send a blind child far away.
- Even though parents may notice that they have a blind child and wish to send the child to school, as long as the child is less than 5 years, they are unlikely to be admitted as most special schools in developing countries only take children who are aged 5 and over. If the cause of blindness in children less than 5 years is likely also to cause mortality (such as meningitis) and children die before starting school, then the blind schools will underreport such causes.
- Blind schools are also unlikely to take children who have multiple disabilities such as cerebral palsy hence causes of blindness, which are also causes of other disabilities are likely to be underreported.

Even though the key informant method has been used in Bangladesh[50, 54] Ghana[53], Malawi[99] and Iran[52] to establish causes of blindness in children; the proportion of children identified that do not report for eye examinations are likely to lead to bias in causes if the causes among those who attend are different from the causes among those who do not attend.

Classification and causes of blindness in children

Causes of blindness in children can be classified using the WHO classification system [100] which classifies causes according to 2 categories:

1. Anatomical classification –determines the structures involved.
2. Etiological classification -determines the time of onset of the condition leading to blindness.

The anatomical diagnosis can be established after performing a visual acuity test and clinical examination; while in most cases it is difficulty from history to establish the time of onset especially in situations where antenatal, birth and postnatal records are not kept. However, establishing etiological underlying causes can be useful for planning possible intervention preventive strategies.

Causes by aetiological classification

The factors that may cause blindness or visual impairment according to the time of onset in a child are shown in table 6.

Table 6: Predisposing factors at each time of onset

Time of onset	Possible predisposing factors
Hereditary	Autosomal, X linked, mitochondrial genetic diseases chromosomal abnormalities.
Intrauterine	Congenital infections, drugs taken in pregnancy
Perinatal	Birth trauma, infections
Childhood	Infections, trauma
Unknown	

Causes by anatomical classification

The common structures that are involved anatomically in blinding conditions are summarized in table 7. The four main causes of reversible (preventable or treatable) blindness in children (corneal scarring, cataract, retinopathy of prematurity, and refractive errors) are discussed in detail below.

Table 7: Anatomical structure and possible pathologies causing blindness in children

Anatomical structure	Examples of structure pathologies
Whole globe anomalies	Phthisis, microphthalmos, anophthalmos, or may be disorganized or removed because of trauma or other causes.
Cornea	Corneal scarring (from infective, non-infective and nutritional causes), keratoconus and corneal dystrophies.
Lens	Cataract surgical complications (aphakia, pseudophakia or dislocated lens, amblyopia) and congenital ectopic lens anomalies (Marfans syndrome).
Uvea (iris, choroid and ciliary body)	Congenital colobomas, absence of tissue (aniridia), uveitis
Retina	Retinopathy of prematurity albinism, , retinoblastoma, retinal dystrophies, ,
Optic nerve	Optic nerve atrophy, optic nerve hypoplasia, glaucoma
Refractive errors	Myopia (short sightedness), hypermetropia (long sightedness), and/or astigmatism
Brain	Cortical blindness, cerebral damage

A summary of the regional variation in the causes of blindness in children is shown in table 8.

Table 8: Regional variation on causes of blindness in children

Region	Main anatomical causes	Explanation
Established market economies such as UK, Sweden, US	CNS Retina	Able to manage ROP as facilities well developed
Middle economies such as Brazil, India	ROP Retina	Neonatal services not well developed to screen and manage ROP
Poor economies such as sub-Saharan Africa	Cornea	Measles and vitamin A reduced but still a challenge

Note that the most important treatable cause of childhood blindness is untreated or poorly treated cataract, which is responsible for 5–20% of all cases, and occurs in all regions [102]. As corneal blindness is declining in many countries in Africa and Asia, cataract is becoming a relatively more important cause of avoidable blindness[102].The WHO form for childhood blindness, the database and coding instructions can be downloaded from ICEH website[103].

Common causes of blindness and visual impairment

Cataract

A cataract is defined as any opacity in the lens. Congenital and acquired (developmental) cataracts are a significant cause of vision loss in children[104] both in the developing and developed nations and currently the commonest cause of treatable blindness in children[13, 54, 101, 105-107]. Some of the characteristics used for classifying cataracts in children include age of onset (congenital vs. developmental), location (unilateral versus bilateral), pattern/ presumed cause (autosomal versus inherited) and the morphology (lamellar, cortical). Defined by age at onset, a congenital cataract is visible in the first year of life, while developmental cataract occurs after the first year (12 months) of life. It may be difficult in some circumstances to determine whether the cataract in a child was congenital or developmental if the child presents at an older age of more than 1 year and there is an unreliable history from the child's parents. The age of onset of a cataract may give a clue but does not necessarily indicate its cause. Congenital cataracts may be hereditary or secondary to a noxious intrauterine event such as rubella infection. In terms of causes at presentation, roughly one third of congenital cataracts are associated with other disease syndromes and one third are inherited, with the remaining third having unclear causes [104, 108]. Genetically-determined systemic diseases that are associated with cataract include galactosaemia, Lowe's syndrome, lactose intolerance, Down's syndrome, Marfans syndrome, trisomy 13 and 18, and Turner's syndrome [108].

Hereditary cataracts

Hereditary cataracts are seen in all populations and are estimated to account for approximately 25% of all cases of congenital cataracts. Hereditary mendelian cataracts may be inherited as autosomal dominant (most frequent), autosomal recessive, or X-linked traits. According to recent articles by Shiels et al [109] on genetics of hereditary cataract, the novel genes for Mendelian cataract include about eleven loci for autosomal dominant cataract (1p, 1q, 2p, 2q, 3q, 14q, 15q, 17p, 17q, 19q, and 20p)], four loci for autosomal recessive cataract (3p, 7q, 9q, and 19q), and one for X-linked cataract (Xq)[109-111].The involvement of the lens maybe in isolation, or lens opacities may be associated with other single or multiple ocular anomalies, such as microphthalmos, aniridia, other anterior chamber developmental and angle anomalies, or retinal degenerations. It is well known that there is a regional variation of hereditary diseases as a cause of blindness in children[112], and that genetic diseases are responsible for a higher proportion of visual impairment and blindness in children in countries with higher levels of socio-economic development [112]. Many of the well-known genetically determined disorders that cause cataract and other visually impairing/blinding conditions in children may be increased in families and societies which have consanguineous marriages. This is particularly true and common among Asian families who have the highest noticeable rates of consanguineous marriages. Dorairaj et.al

in a population based study of prevalence and causes of childhood blindness in a rural population in India found that among the parents of blind children, 83.3% of all children with cataract had parents with consanguineous marriages and that 71.4% of all blind children (from all causes) had parents with consanguineous marriages [37].

Bilateral congenital cataract may occur in a child from family which has a positive history of cataracts or other blinding conditions, or may occur in a child without positive family history. Parents or other relations may notice early that their baby does not seem to look at them and they may also notice bilateral white pupils. By age 3 months, a baby with severe bilateral cataracts will start to develop nystagmus on attempted fixation and/ or an associated squint as a result of visual deprivation. Bilateral congenital cataract is now the most common cause of potentially treatable blindness in infancy. Early surgery leads to better visual results provided that optical correction is started early and amblyopia therapy has been initiated [113]. Chak et.al [113] traced 122 children in the United Kingdom(UK) who had been diagnosed with congenital/infantile cataract, and had surgery over a 12 month period between 1995 &1996, and reported on their long term (at least 6 years) postoperative visual acuity. The authors found that the median post-operative visual acuity for bilateral cataract was 6/18 while for unilateral cataract it was 6/60. Poor compliance with amblyopia occlusion therapy was the single most important factor that predicted poor visual outcome. Early screening of children for congenital cataract was linked to improved post-operative visual acuity. Unfortunately delays in diagnosis and referral result in most children with bilateral severe congenital cataracts being seen very late.in developing countries[114]. A study in Tanzania that explored reasons for delays in presentation to hospital for congenital and developmental cataract [115] found that the mean delay between recognition and presentation to hospital was 34 months and that the main predictors for late presentation were long distance from the hospital and the educational status of the mother.

Rubella

Congenital rubella syndrome is still responsible for some of cataract cases seen in some developing countries. In one study in India [116], IgM antibodies to Rubella virus were demonstrated in 8.4% of all children who had congenital cataract and were operated within 12 months. Viral infections in a non-immunized pregnant mother occurring in the 3rd week of the first trimester when the eye is forming are likely to involve the lens and lead to congenital cataract[117]. Rubella infection in the mother during first trimester causes congenital cataract, deafness and cardiovascular malformations [118], a triad commonly referred to as congenital rubella syndrome. Congenital rubella syndrome may also include microphthalmos, cornea dystrophy, coloboma and iris abnormalities [118] although cataract can be an isolated finding and maybe unilateral.

Management for congenital cataract

Regardless of the age of child, cause and location of the cataract, most ophthalmologists agree that the management of cataract that causes significant visual loss includes surgery followed by long term post-operative period which includes correction of refractive error and low vision. Surgery for paediatric cataracts should be performed by an ophthalmologist who has been trained /oriented in paediatric cases as the approach is different from conventional adult cataract surgeries. There have, however been debates as to whether very early surgery for congenital cataract should be avoided for risk of congenital glaucoma [119-123], and how long one should wait in a child who presents with cataract in the early days of life [124]. There have also been debates on what surgery should be done in a child with cataract (lens aspiration with Intraocular Lens (IOL) implantation versus lens aspiration with aphakic correction) [125-130]; aspiration versus lensectomy plus primary posterior capsulotomy [125, 127, 131-134], and safety of IOL's[135-137] and at what age IOL can be safely implanted in children [138, 139] [140]. Questions have been raised as to what procedure brings the best in terms of visual outcome, short and long term outcomes and cost effectiveness [129, 134, 141-145]. Few properly randomized clinical trials have been conducted comparing different methods and different outcomes [146-148]. One study in India compared the effectiveness of surgical intervention for bilateral congenital cataract between pars plana lensectomy to lens aspiration and primary posterior capsulotomy [149] and found no statistically significant difference in terms of visual acuity between the two groups. However, the authors noted that the findings from the aspiration group were significantly associated with more complications, agreeing with observations from other studies [148, 149]. Another study on management of unilateral cataracts compared the effect of using primary intraocular lenses versus using contact lenses for aphakia eyes and found that visual acuity was better in eyes with IOL than those with contact lenses [150].

Other studies have compared the effect of treating stimulus deprivation amblyopia resulting from cataract and other causes that were long standing and have eventually been operated on [151-153]. The opening of several paediatric oriented centres equipped with paediatric teams (ophthalmologist, anaesthetists, nurse, low vision therapists, and orthoptists) in low and middle income countries to offer better surgical services for children with cataract in the last few years is an encouraging development; however good quality surgery in the absence of a good postoperative care and an effective programme of follow up is likely to lead to suboptimal long-term visual recovery outcomes.

Postoperative care and long term follow up

It is important to monitor and diagnose immediate postoperative complications that may affect the final outcome of vision in a child (inflammation in anterior chamber, corneal oedema, bleeding, iris capture,

IOL prolapse, vitreous prolapse, infection, etc.) and manage them accordingly. Correction of aphakia (where no IOL has been inserted) should be done in the immediate post-operative period and children who have been inserted an IOL in their operated eye should be refracted [154] before discharge from hospital. Most children with congenital cataract who present late for surgery will have some form of amblyopia [155-158] and amblyopic therapy should be instituted as soon as possible. Once the child has been discharged they will need to frequently come for reviews and change of glasses. Proper referral linkages and communication channels between the operating centre and the community where the child will go need to be established[159], and parents need to be properly counselled and be motivated to come for follow up visits (through provision of transport refunds) [160].

Corneal blindness:

Until recently corneal opacity secondary to vitamin A deficiency (xerophthalmia), measles and traditional eye medicine was generally agreed to be the most important cause of preventive/treatable blindness in low income countries [102]. There is evidence that greater measles immunization coverage and vitamin A supplementation programs over the last twenty years have resulted in reduction of corneal blindness in children [54, 102, 106, 161-165], and have contributed to the reduction of under-five morality rates in lowest income countries [63, 166] which are linked to vitamin A deficiency and supplementation. Due to regional differences in immunization coverage and vitamin A supplementation, corneal opacity remains an important preventable cause of blindness in children in some parts of the world. Corneal blindness in children can be caused by the following: measles, nutritional (vitamin A deficiency), infectious agents (ophthalmic neonatorum, bacterial, viral and fungal), use of harmful traditional medicines, inflammatory conditions, inherited corneal dystrophies, and trauma [167].

Refractive errors

Refractive errors are the commonest and most easily correctable cause of visual loss in adults and children [168]. Until recently, there was little information about how much refractive errors contributes as a cause of blindness in children [13]. Information on refractive errors as a cause of visual impairment in children is available through standardized data from 8 population based surveys of refractive errors and these have highlighted the importance of refractive errors [91-98, 169]. The findings of these studies indicate that prevalence of blindness (corrected VA<6/60) resulting from refractive errors in children aged 5-15 years' ranges from 0.2% to 1.5% (2per 1,000 to 15 per 1000 (Table 9).

Table 9: Prevalence of refractive errors in children aged 5-15 years

Country	Year	Sample size	Blindness definition (corrected)	Age group	Prev. %	Relevant U5MR	
						Year	U5MR
S Africa [93]	2002	4,890	≤6/60	5-15	0.20	1995	65
China rural [98]	1998	5,884	≤6/60	5-15	0.20	1991	38
China urban [92]	2003	4,364	≤6/60	5-15	0.00	1996	38
India rural [94]	2001	4,082	≤6/60	7-15	1.30	1994	119
India urban [95]	2001	6,527	≤6/60	5-15	0.46	1994	119
Malaysia [91]	2003	4,634	≤6/60	7-15	0.00	1996	15
Nepal [96]	1998	5,067	≤6/60	5-15	1.50	1991	117
Chile [97]	1998	5,303	≤6/60	5-15	0.6	1991	17

*From Gilbert & Rahi[13] ,with permission

Refractive errors in children are much more common in Asian populations than other races, with prevalence of severe refractive errors in Asian races ranging from 1.3-1.5 per 1000, while in black Africa population prevalence is often less than 0.2 per 1000 [13]. One recent study among urban dwelling Chinese preschool children aged 3-6 years found that refractive errors (presenting vision < 6/18 correctable to ≥ 6/18) contributed to 75% of the visual impairment in that age group [38]. Overall myopia is the commonest cause of refractive error in older children, with the very young ones having hypermetropia, which reduces with age. Myopia can be classified into two groups, low to moderate degree of myopia (referred to as simple myopia >=-0.5 to -6.0 dioptres) and high or pathological myopia (greater than 6.0 dioptres). Blindness and visual impairment caused by refractive errors can be corrected through prescription of glasses.

1.4.4 Control of blindness in children

General principles

Management of blindness in children is a priority for the following reasons: special expertise is required, several causes of blindness (vitamin A deficiency) are also related to child mortality [65]; and children who survive while blind have a large number of blind years to live hence contributing to more disability[170] in the society.

Data available from many low and middle income countries suggest that a high proportion of causes of blindness in children can be prevented (cornea scaring, measles infection, ophthalmic neonatorum); and that another proportion have conditions that can be treatable (cataract ,glaucoma, and retinopathy of prematurity); and that depending on location; between 30-73% of all children have avoidable causes (preventable or treatable) [13].

It is therefore important that all programmes dealing with blindness in children implement strategies that address not only prevention and treatment but also have rehabilitation and special education components for children that have unavoidable causes of blindness. Because most young children do not complain of their condition and may only be noticed by parents, guardians or teachers at school, it is important that information, education and communication (IEC) messages regarding blindness and visual impairment in children is available to all stakeholders that may be involved in identifying blind children and that management plans should include early identification and referral of children from communities and health facilities. If parents suspect and report that their child may not be seeing well, they should be believed and their child should be thoroughly investigated to establish if indeed there is a condition that may need specialist referral [10]. Assessing vision in a child can be challenging; and in some circumstances, other clues such as noticeable behaviour changes can lead to establishing whether the child is seeing or not [28].

A good history obtained from the mother or guardian that spends most time with the child can give clues to the extent of the visual problem and possible causes of blindness in a child.[10]. A clear history from the parents that the child has been noted to have a white spot in one or both eyes may suggest that the child has cataract; retinoblastoma or cornea scarring. A detailed examination by the ophthalmic personnel should establish the final diagnosis. In all causes of blindness; treatment will depend upon the cause and on how long the problems have been going on [10].

Cornea Scarring

Cornea blindness can be prevented at the primary level (before the onset of the disease), secondary level (taking action to prevent complication of corneal scarring occurring as a result of disease) and tertiary prevention (taking further actions to restore vision). Primary prevention can be done at the community level, secondary prevention at the level of district hospital and tertiary prevention at a tertiary hospital. An essential key to preventing corneal blindness in children involves understanding the existing health systems in the community that have programmes not specially targeting corneal disease but may benefit and avoid duplication of effort to fight corneal disease (measles immunization programmes, nutrition, water and sanitation). At the primary level, such programmes may give vitamin A supplements, advocate on foods rich in Vitamin A and treat eye infections and injuries. In addition, programmes may

engage in eye health promotion aimed at discouraging use of harmful traditional eye practices which are still common. Secondary prevention involves providing intensive treatment to diseases that have already set it (such as corneal ulcer, trachoma, etc.) such that the healing takes place without corneal scarring. In most cases, topical antibiotics, antiviral and antifungal will need to be supplied to the affected eye for a considerable amount of time. Tertiary prevention which involves corneal transplant to restore vision is rarely done in developing countries for two reasons: 1) there are usually no eye banks to store eyes for transplants as setting up an eye bank in a developing country is complex; 2) most of the eyes with corneal scars are also vascularised and not suitable for transplants. Once children have developed corneal scarring with vascularisation they will be poor outcome even if corneal transplant is done [171] and most likely remain as blind and low vision children and rehabilitation/special education services should be planned for them. Primary and secondary prevention should therefore remain the main strategies for preventing corneal blindness[172].

Management of amblyopia

Delayed treatment in children with eye conditions that are associated with visual impairment and blindness especially in one eye can lead to long lasting amblyopia (see section 1.2 above). If there is evidence of amblyopia, the child should be managed as soon as possible to avoid further complications (such as strabismus). Several studies have recently provided insights into how amblyopia may be most effectively managed and all agree that a coordinated multidisciplinary approach (involving ophthalmologists, opticians and orthoptists) is needed [173-178]. Management of amblyopia firstly involves determining and correcting the cause (refractive error, cataract, etc.) and this is usually done in the form of medical/optical and /or surgical intervention. Providing the full refractive error correction in a child with amblyopia is a crucial step that can determine the success of the amblyopia therapy. [179, 180]. Moseley et.al [179] report that correcting refractive errors alone improves the amblyopic vision even in cases where there has been strabismus. Refractive error correction is followed by occlusion therapy, penalization and other medical therapy[181]. Several variables affect the outcome of therapy and these include age on onset of the visual deprivation, type of amblyopia, duration of treatment, long term follow up, compliance, previous treatment, refractive correction and visual acuity at start of therapy. Debates about which methods are more effective in treating amblyopia (penalization versus occlusion therapy) and when to start and stop treatment [174, 179, 182, 183] have continued for many years without definite conclusions. Evidence from systematic reviews suggest that in moderate amblyopia, atropine penalization [184] is as effective as patching, in terms of visual acuity improvement and stereo acuity outcomes[178, 185, 186]. One study by Repka et.al [187], which compared results of intensive amblyopia treatment in children aged 7-12 years using either 2 hours of daily patching or weekend atropine penalization found that visual acuity markedly improved in both groups after 17 weeks of

treatment even though the patched group had slightly better visual acuities than the atropine group. A recent Cochrane systematic review by Li and Shotton [178] on the use of conventional occlusion therapy versus pharmacological penalization for amblyopia treatment concluded that atropine penalization was as effective as occlusion therapy, and that since atropine is cheaper than occlusion therapy, atropine can be used as first line treatment in the management of amblyopia. Though patching or penalization alone may be sufficient for improvement of visual acuity, it is not uncommon for binocular single vision (which includes depth perception) not to be fully achieved even with maximum therapy [188].
Intensive early screening and compliance with treatment for amblyopia is associated with improved outcomes but there continues to be debates on the length of the time that one can intensively treat amblyopia in order to achieve the maximum therapy. In many circumstances amblyopia treatment regimens are not standardized and differences exist among orthoptists from different centres, even in same countries [175, 189]. Evidence from systematic reviews [178] show that even though visual acuity in the amblyopic eye continued to improve for the first 6 months of starting therapy, there was hardly any additional improvement in the visual acuity after 24 months of therapy. Children with cataract, glaucoma and other blinding pathologies who have surgery should therefore be thoroughly assessed for amblyopia; and therapy should be initiated as soon as possible.

Long term follow up of all children who had cataract surgery is essential because amblyopia can develop later in life even if the initial surgical outcome was good. Long term is a particular challenge in Africa where children do not have residential addresses that can easily be traced up.

Controversy still exist regarding the importance of early detection and correction of refractive errors in preschool children because refractive errors are common in this age group and there is a lack of evidenced-based guidelines to warrant their correction [190].
In regard to correcting refractive errors in school-age children and adolescents, a recent systematic review of studies of justification of screening for correctable visual acuity deficits was inconclusive, and highlighted the need for well-planned randomized controlled trials, in various settings, to be undertaken so that all the potential benefits and harms of school based vision screening programmes can be assessed [191].Another recent randomized trial comparing strategies for correcting refractive errors in school students in Tanzania [192] found that there was poor uptake of spectacles, with only 1/3 of children using spectacles after 3 months of being provided with them, even when spectacles were provided free of charge. The study raised doubts about the value of school based vision-screening programs in Africa. Reasons obtained from the study for non-compliance to wearing spectacles included peer pressure and parental concerns about safety of spectacle use in children, cost of purchasing spectacles and difficulties in accessing good quality local optical services [193]. A possible solution would be to distribute readymade spectacles during the screening sessions, but there has been debates

on their usefulness in children. One reason given against the idea is that the child's pupillary distance is not taken into consideration when prescribing the already made glasses, and this may result in the child using the glasses which are decentred and most likely not comfortable for a child such that the child may stop wearing them after a short time. The other reason for not using already made glasses for children is that the frame chosen may not be attractive or gender sensitive and a child may end up being bullied by peers at home or school because of wearing such glasses. Such a child may be forced to abandon the good visual acuity that glasses offer. A randomized, clinical trial evaluating ready-made and custom spectacles delivered via a school-based screening program in China found that although visual acuity was slightly better with custom spectacles, no difference was found in acceptability in this population of students with predominantly simple myopic refractive error and supported the use of readymade spectacles in a school-based refractive services program, saving costs and improving the logistics of service delivery [194].This may be very true for Africa were most of the population is rural and difficulty to reach and maybe better served by already made spectacles.

In summarizing this section on blindness in children, it is important to emphasize that control of blindness involves setting up strategies at all level of prevention (primary, secondary and tertiary level) and that adequate service delivery requires not only setting up paediatric ophthalmology centres that offer comprehensive eye services (eye care, low vision, rehabilitation and special education) [160, 195], but also establishing new and strengthening already existing community networks that address maternal and child health, as these can be used as channels for identifying and following up of blind and visual impaired children. The scope of work for control of blindness in children for a country or region can therefore only succeed in the presence of efficient health systems that have strong engagement with communities.

1.5 Health systems

1.5.1 Framework of a health system

The WHO defines a health system as "comprising all the organizations, institutions and resources that are devoted to producing actions whose primary intent is to improve health" [196]. According to this definition, for a health system to be categorized as well functioning it must respond to the health population needs and expectations in the following four ways:

1. Improving the health status of all individuals, families and communities in a country.
2. Taking up the challenge to defend the inhabitants of the country against conditions that may threaten the health of its citizens.

3. Ensuring that sick people are protected from incurring large expenses as a result of their ill health.
4. Ensuring that all citizens have equitable access to health care at all levels.

Health systems that fully address the issues of quality, equity and efficiency are therefore much more likely to demonstrate improved performance in their control of existing and new diseases in developing countries [197]. Such successful health systems usually involve multiple organizations and institutions that give resources that are devoted to producing health actions that will lead to improved health outcomes [198]. According to a document by WHO that outlines various ways of strengthening health systems in developing countries [198], the four vital important functions of health systems have been outlined as follows:

1. Service provision: This involves all partners that provide either formal and informal services and/or public and/or private services and also organizations that are involved not only at the level of service delivery but also those that are involved at a much higher level along the lines of management and administration.
2. Resource generation: This is a very broad category that encompasses key inputs that are necessary for the success of a health system and these include; adequate human resources, physical assets (equipment), drugs and recurrent medical supplies.
3. Financing: Without finances, any health system cannot run effectively and efficiently. The health system should therefore be able to generate accurate information regarding the resources needed and the potential sources available for financing the system, how the resources can be efficiently mobilized and deployed to areas where they can be used for service provision that will lead to improved health service delivery.
4. Stewardship: this refers to the overall governments and not non-governmental organizations responsibility of taking care of the country's health system, and provision of the mission statement and vision of government in regard to improving the health system, provision of what health policies and regulations have been put in place to ensure that data generated through health systems is used to improve practice and translates into policy regulation that further improves health.

Stronger health systems are essential for delivery of health care interventions that can lead to improvement in health of residents from any particular area. However, most African countries have particular challenges in improving health care interventions as progress towards any defined targets is often hindered by weak, poorly functioning or in some cases non-existent health systems that cannot deliver even the minimum required health care interventions. Unless such countries work out how best to approach health system strengthening and what appropriate specific actions need to be implemented in

different settings, they are unlikely to achieve any long-term goals such as Millennium Development Goals. This is especially more important when dealing with diseases such as blindness in children, which are rare and expensive to tackle, and need to have proper systems in place. As expressed by the WHO, “without significant health systems strengthening, many countries would make little headway towards the Millennium Development Goals (MDGs), the “3 by 5 “ target, and other health objectives” [199]. The key questions that WHO, health allied partners and many countries would like to have answers concern how best to approach health strengthening, when and what specific types of action are appropriate to specific settings. The World Health Organisation in a document entitled *“improving health outcomes for the poor”* [200], further warns that “without a health system that can use money well, spending will not merely be inefficient: it may be useless or even counterproductive”. This view may be contrary to what most ministries of health from poor developing countries view as a major obstacle to scaling up and improving health services, usually listed as lack of finances rather than non-existing or weak health systems. It is therefore imperative that before such countries are given large sums of finances for expenditure for health, well-functioning health systems that will lead to efficient use of existing resources should be put in place.

World Health organisation has described the six interrelated elements (building blocks) that make up a well-functioning health system[201], namely 1) Good leadership and governance that is essential for the overlooking and success of the other five elements, 2) Heath management information systems, 3) Health financing, 4) Essential products and technology, 5) Human resource for health and 6) Service delivery. The building blocks, what they aim to achieve and the overall outcomes are illustrated in Figure 14.

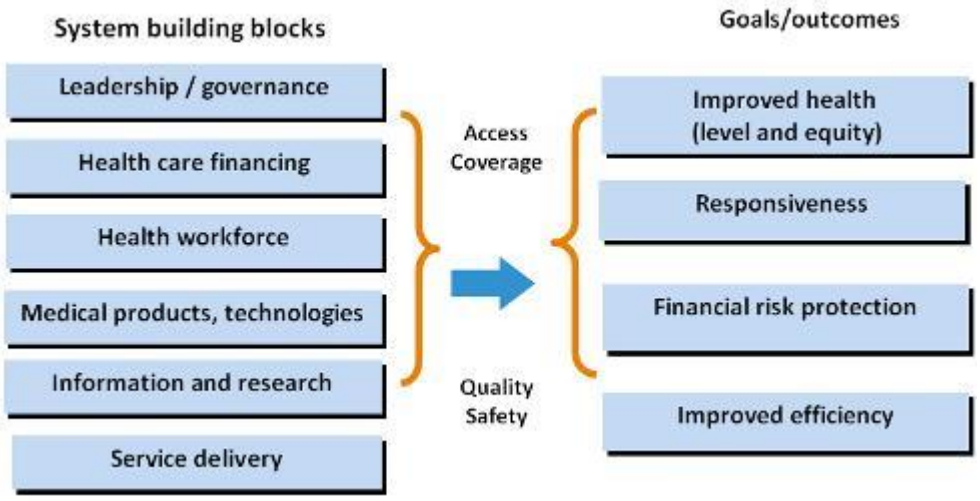


Figure 14: Framework of a health system.

**Adapted World Health Organization http://www.wpro.who.int/health_services/health_systems_framework/en/*[196]

Although this generic framework applies to general health, applying it to eye care would also lead to improved outcomes in the eye health of communities. To improve eye health, eye health systems require good governance/leadership to ensure that adequate human resources for eye care are available at all levels, finances (government or private) are allocated to support all aspects of the health system, and that there is a good eye service delivery (with readily available consumables and using appropriate technology), and information gathered is processed and fed back into the system to improve eye service delivery. This is however rarely the case and the poor state of eye health systems in many parts of the developing world is one of the greatest barriers to increasing access to essential eye care[201]. For example, in sub-Saharan Africa (SSA), there is a critical shortage of human resource at all levels and the result in a serious lack of persons with skills in data management (information and communication technology) making it impossible to collect appropriate useful data that can improve service delivery and other programmes using national health management information systems (HMIS). Kirigia and Barry [202], in an article entitled “Health challenges in Africa and the way forward” , note several reasons for weak health systems in Africa and these include: serious challenges involving leadership and governance, lack of registrations and their enforcement in health, communities not actively participating in planning and monitoring of health services, weak inter-sectoral collaborations, inequities in health and inefficiencies in resource mobilizations. The authors conclude that it may not be possible to adequately implement efficient health systems in sub Saharan Africa unless there is a concentrated fight against corruption, adequate and sustained investments in social sectors, coupled with favourable macroeconomic and political environment.

According to WHO, among the 57 countries with extreme shortage of health workers in the world , 36 (63%) of them are in Africa [203]. The severe lack of health human resource at all levels especially in sub-Saharan Africa has led WHO to recommending “Task shifting” as a solution to the crisis. “Task shifting” is defined as “rational redistribution of tasks among health workforce teams to maximize the efficient use i.e. delegation of tasks to less specialized health providers”[203]. The World Health Organisation recommends that task shifting must be aligned with overall strategies aimed at “broader strengthening of health systems” if it is to prove sustainable and optimize health service delivery. This can only be achieved in a set up where health service delivery has an integrated component of health systems research.

1.5.2 Health system research

According to Sadana and Pang [204], Health systems research (HSR) , also known as operational research, involves improving health of the people and communities targeted. Useful HSR should lead towards strengthening health systems of a country or targeted area. Baris in a document produced for

WHO [205], defines HSR as research that produces knowledge that can be applied to communities, to organize themselves and achieve desired health goals. Improvement of health of individuals/societies should be a key priority of HSR and targeted societies should be given an opportunity to understand the implications. Health systems research include research on health policies, practice and health interventions that have a potential to influence policy and improve health service delivery[206]. An article on operational research in Sub Saharan Africa by Theobald et.al[206] , states that though HSR is meant to bridge gaps between research, policy and practice , there are very few examples of studies in sub-Saharan Africa that have demonstrated how this can be done. Such studies involved engaging multiple stakeholders and tried to link the researchers with the beneficiaries (communities, policy makers and service providers). English et.al [207] argues that in an attempt to improve hospital care through HSR in Africa, most hospitals claim they know what needs to be done, but do not know how. Unfortunately, they disregard local partners who may give solutions. A major weakness in implementing useful HSR in developing countries is that HSR is often poorly coordinated, fragmented, and not well understood, resulting in researchers in different disciplines often working in isolation, while addressing same problems. The setting up of research priorities by academic institutions or funding bodies not located in countries where the research is conducted leaves local frontline workers and researchers with no choice but to follow the set agenda, which may not be very relevant to their needs. The highly competitive process of obtaining research grants often results in most of the available funding being accessed by researchers from the developed countries (because of their strong research track records), further depriving research capacity development for researchers from low and middle income countries. The WHO Global Forum for Health Research, in an effort to influence research funding partners to fund more research in middle and low income countries where most of the worst health problems are, highlighted in 2004 that sadly, “only 10% of the world’s health research funding addresses 90% of the world’s major health problems” [208]. The forum suggested that before HSR is conducted; there is need for discussion of the agenda with local stakeholders to ensure that research topics meet the local needs and that the knowledge generated will be effectively used. A good health systems research should generate knowledge relevant for decision making that is applicable not only at the level where the research was targeting but also at other levels (global, regional, national or district level) of health service delivery.

Health service delivery in a country can be in the form of public services (belonging to the state or state supported), private profit/non-profit services (belonging to individuals/companies, charities and non-Governmental organizations-NGOs) or a mixture of both (public private partnership). The distinction between what is considered as a public versus a private health provider has mostly been to do with ownership of the services (public belonging to the government while private belonging to individuals or organizations). This definition is limited as it does not determine the nature and level of services provided by either group, which in other circumstances maybe the same. Giusti et.al [209]

propose that for a health service delivery to be categorized as public it must be guided by a government policy, must have a mission statement that targets the entire population, must be non-discriminatory, and must contribute to a goal that promotes health of an entire country. Even though not funded by governments, most non-profit and non-governmental organizations providing health services can be categorized as public health providers if this definition is used. Non-profit organizations and NGOs contributions are sometimes regarded as private, even though they are guided by a government policy and follow government goals.

Regardless of the categorization of service provision, the focus of most health service providers can either be on providing all or one of either preventive, curative, rehabilitative or diagnostic services. Such services are usually offered at three different levels of service delivery: tertiary level (where highly specialized medical personnel are based), secondary level (where general practioneers and midlevel health practioneers are based), and primary level (where community health worker and volunteers are based). At each level of service delivery, healthy seeking behaviours determine who accesses and how often the offered health services are utilized by various members in the community.

1.5.3 Health seeking behaviour

It is not uncommon to find that in areas where health services are within reach there are still long delays from the onset of illness among individuals and the time of presentation to a health facility [114, 115].The delays can often be explained by understanding the health seeking behaviours. According to Conner and Norman[210], “healthy seeking behaviour refers to behaviours that keep a healthy physical and social state, and those that lead to any departure from that state”. Illness behaviour relate to processes that are associated with seeking attention to alleviate pain. Kroeger [211] discusses two models that may explain health seeking behaviours: the pathway model and the determinants model. The pathway model describes all the processes taken by an individual from the time symptoms are recognised until at a point when one accesses a health facility, explores social cultural factors that affects that decision. The determinants model, on the other hand, uses a result oriented approach with quantitative methods of investigation that focus on the biomedical determinants leading one to choose a service [211]. Health services research that focuses on health seeking behaviours can lead to better understanding of what factors are involved in decision making, and information generated can be useful for improving policy, planning and implementation of many health programmes [212]. In one study on determining social cultural factors of leprosy that were associated with health seeking behaviour in two different religious communities in Sudan, the lack of knowledge that leprosy was treatable by modern medicine in both communities greatly influenced the communities health seeking

behaviour, to preferring spiritual and traditional medicine rather than modern medicine[213]. The findings of the study led to a health promotion and awareness intervention on the causes and treatment of leprosy, which eventually led to the entire community changing their health seeking behaviour and using modern medical treatment.

It is obvious that decision making about accessing health care is complex and often determined by other socio-economic and cultural factors that affect the family or community concerned[214].On a household level, in regard to a family seeking help for a sick child, studies of health seeking behaviours usually focus on health seeking behaviour of the child's mother, who traditionally has the responsibility to take care of the child. However, in some societies, it is not uncommon that when a child is sick, the father decides on the child's treatment. This is usually because fathers have more economic power in those societies. In other cultural settings, despite the father having the economic power, the decision to seek treatment for the child rests on much broader extended family members (which include uncles and grandparents). This may be true in poor households where an extended family member need to be involved to provide financial assistance.

Health seeking behaviour is one of the important factors that can contribute to an individual's wellbeing. In a study from Tanzania [215], it was noted that patients' health behaviour in seeking treatment and willingness to pay for cataract surgery depended on the perceived cultural need for sight. Cultural reasons may determine why some children with cataract present late at the hospital [114, 115] and some of these have included perceptions about importance of gender (girls are more likely to be brought late to the hospital as they are considered less of a priority than boys who are usually considered future family carers). It is becoming common practice to explore health seeking behaviours not only using qualitative methods, but also in combination with quantitative methods[216]. An advantage is that findings from quantitative studies can be validated using qualitative methods and conversely, information obtained during qualitative research can be used to develop questionnaires for quantitative studies. With such an approach, a better understanding of the personal, cultural, and socioeconomic factors that determine health seeking behaviours can be obtained. In cases of blindness and visual impairment in children, one can use a qualitative method known as Participatory Rural Appraisal (PRA) to explore health seeking behaviours, perceptions and causes of blindness on a community, and complement it with formal quantitative studies to determine prevalence and validate causes.

Participatory Rural Appraisal (PRA) utilizes a range of techniques (such as focus groups discussions and social mapping techniques) which have unique features of being iterative, innovative, interactive, informal and acceptable to the community [217]. In one study in a rural remote setting in Kenya, PRA was used as an alternative to population based study to identify children with disabilities that included marked visual impairment [218]. Communities were mobilized and identified 237 children with

disabilities, among whom 6.3% had obvious visual problems. It should be pointed out that even though PRA method can be used to identify visual impairment in children, the tools used are only good at giving clues to communities to identify obvious eye pathologies in children, but are less sensitive for determining causes of visual loss where the eyes look normal. Also, as PRA is only an exploratory method, it is not intended to determine prevalence. However, PRA maybe used to explore ideas and community interventions that may be used to strengthen primary health care and primary eye care programmes in an effort to control blindness.

1.5.4 Primary Health care (PHC) and Primary eye care (PEC)

According to World Health Organisation(WHO), Primary Health Care (PHC) is “essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every state of their development in the spirit of self-reliance and self-determination” [219-221]. The WHO has been advocating for the inclusion of PHC as part of the global health care package for more than 30 years.

In 1977, all the member states of the 30th World Health Assembly globally affirmed that the main social target of governments and the WHO in the next two decades (1980-2000) would be: “the attainment by all citizens of the world by the year 2000 of a level of health that would permit them to lead a socially and economically productive life” [222]. This was followed up by the International Conference on Primary Health Care in Alma-Ata, USSR in 1978, attended by member states from all over the world, who identified primary health care as “the fundamental and practicable approach for attaining this ambitious well acceptable social target”[220]. Primary health care should be able to improve a country’s health system and the social economic status of a country[219]. The WHO states that existing gross inequalities in the health status of the people between the rich and poor is partly due to the absence of an efficient PHC. According to WHO, and echoed by Twaha e.t.al [223, 224] “efficient PHC is the first level of contact of individuals, the family and community with the national health system and must bring health care as close as possible to where people live and work”. The five principles of PHC are community participation, equity, inter-sectoral collaboration, sustainability and appropriate affordable technology. Inequity in health services delivery remains a major problem in sub Saharan Africa, with the poorest areas hardly having access to any services. Anyangwe et.al [225] report that sub-Saharan Africa which bears 24% of all the global disease burden only has a total of 3% of the global health work force. Realizing that the gap in accessing health services between the rich and poor is getting wider 30 years after the initial Alma Ata declaration for primary health care was

made, the WHO called for renewed interest in PHC as a national, regional and global health strategy[226, 227]. To succeed with PHC, according to WHO, inequities in health can be addressed by addressing social determinants of health through: improving daily living conditions, tackling maldistribution of power and resources; and assessing impacts of actions taken [228, 229].

The PHC model has had many challenges in the least developed countries, and considerable progress has not been made due to a rise of new problems such as HIV/AIDS that were not originally planned for. There are 8 key components of primary health care[220] that were originally outlined in the Alma Ata conference; viz:

- Water and sanitation
- Food and nutrition
- Immunisation against 6 major childhood diseases
- Mother and Child Health (MCH)/Family Planning (FP)
- Prevention and control of locally endemic diseases
- Treatment for common diseases and injuries
- Health education about prevention / control of important diseases
- Provision of essential drugs

It is important to note that in the least developed countries, most of PHC activities at community level are implemented by PHC workers who are usually based in the community and in regular contact with the community members.

Comprehensive versus selective Primary health care (PHC)

Much as there is a universal agreement as to the importance of PHC in strengthening health systems and improving the overall health of a community there has been debate as to whether PHC should follow a broad comprehensive (multi-sector developmental approach) or a narrow focused selective approach (disease focus)[230]. Those who advocate for comprehensive PHC do not necessarily believe that health is merely the absence of disease, but an integrated improvement of several factors (socio economic, water, food, nutrition and housing). The principals of equity and community participation are encouraged when setting up priorities.

On the contrary, those who advocate for selective PHC believe that health is achieved when disease is absent. The priority is on managing diseases or causes of disease that contribute a large proportion of the total burden of disease (morbidity or mortality) and those that have highly cost-effective

interventions (e.g. cataract and cataract surgery). Originally, the term “selective PHC” was used by Walsh & Warren[231] who suggested that “selective PHC was an interim strategy for control of priority diseases in the developing countries based on prevalence, morbidity and mortality and that diseases with a higher burden should be given higher preference”. Examples include prioritising immunization (measles & DPT), malaria treatment and control of diarrhoea in children. It was felt that due to inadequate funding of the health sectors by most governments, only cost effective public interventions with high impact needed to be prioritised. This approach is still very popular, especially for supporting partners who are pressurised to demonstrate quick results, for the funding obtained.

A summary of the differences between comprehensive and selective PHC are outlined in Table 10. It should be noted that the distinction between selective and comprehensive PHC may not very clear when it comes to implementation, such that most programs adopt aspects of both approaches. Programmes with selective approaches, but which train general community health workers, still have some comprehensive aspects to the programme. The opposite is true for comprehensive PHC programmes that often address only certain aspects of PHC in their implementation.

Table 10: Comprehensive versus selective Primary Health Care

	Comprehensive*	Selective
Values	Values equity, community participation and inter-sectoral approach	Values effectiveness, efficiency and cost-effectiveness
Concepts	General well-being implies health	Absence of disease implies health
Orientation and accountability	Usually horizontal, empowers and is accountable to community	Usually vertical and managed vertically
Timeframe	Extended(long-term)	Limited (Short-term)
Examples of actors	WHO, World Bank Sector Wide Approaches (SWAPs)	UNICEF International Trachoma control IMCI, Global fight for TB, HIV and Malaria

Adopted from Walsh & Warren[231]

Each approach on its own has weaknesses that opponents capitalise on. Comprehensive PHC is thought to be too expensive, ambitious and unrealistic for developing nation, too long-term and too expensive and not to give solutions to problems that need urgent attention [231]. The lack of using clinical and epidemiological indicators at baseline and at final point within a defined period of time gives a challenge on how to empower communities and further adds doubts to the benefits of using this approach [230]. On the contrary, selective PHC has its own weaknesses. It often involves top-bottom planning and communities are rarely involved in planning and decision making. More than

often the agenda being pursued may be more of a global than a local one, and issues of equity for the minority or disadvantage populations may not be taken on board. The focus on medical health problems also ignore other important sectors which may contribute to the overall well-being of the targeted audience [232].

The WHO recent endorsement of PHC [227], as a way of offering health service delivery especially within the poor developing nations, still does not advocate for comprehensive over selective PHC, and the debate as to which approach is best will continue in the near future. In-view of this challenge, some eye care programs, are being designed to have both components, so that it may be possible to integrate all components of primary eye care into primary health care.

Integration of primary eye care into primary health care

The recent calls by VISION 2020 and other allied eye partners and enthusiasm to integrate primary eye care into PHC has affected the way PHC workers work and there is need to think of which skills they need to acquire for them to be effective in delivering primary eye care (PEC) and especially in regard to program control of eye diseases in children. Benefits of integration have included increased geographic coverage of mass drug administration and increase in coverage target rates; overall improved primary health care delivery [233, 234], improved information systems and strengthened relationships between the health services and the community. [235-239]. The challenges of integration have included severe shortage of human resource capacity to implement the programmes and scale up[236], lack of personnel with skills in specialized areas; difficulty to supervise and monitor activities, large financial costs for professional development of disease-specific programs due to continuous change of staff roles and staff being resistance to integration [240]. The task of integration is more challenging in countries like Malawi where PHC workers are expected to deliver eye services as part of their routine services in addition to many other tasks. The justification to use PHC workers comes from evidence that integrated health system, rather than fragmented health service is a much more cost effective method [241] of delivering health services . A review of the Malawi national eye health plan document[242] showed that apart from endorsing the need to integrate PEC into PHC by 2011, the document did not mention how this was meant to be done, either through comprehensive or through selective PHC.

There have been several propositions as to how PEC can be integrated into PHC [243, 244] as some of these include:

a) comprehensive /inclusive primary eye care where PEC workers are involved in health promotion within the community, case screening, recognizing eye problems, providing initial treatment and referring where appropriate

b) Selective PEC where specific high impact PHC interventions such as Integrated management of childhood illnesses (IMCI) and Vitamin A supplementation is utilized by PEC.
c) Priority eye conditions identification where PEC workers are only trained in a specific task (e.g. teachers screening for refractive errors in schools).

Different regions have followed different approaches to delivery of primary eye care with limited successes. For example in most countries in Africa, it is reported that only 30% of people have access to comprehensive eye care and the spread of available services is unevenly distributed, with the most rural areas having less access to eye care services [243]. Whatever approach of PEC is followed it is clear that some aspects of PEC can, in the long term, be integrated into PHC using health promotion and can contribute to the prevention of blindness as shown in Table 11.

Table 11: Relationship between components of PHC and prevention of blindness in children

Water & Sanitation	Messages regarding face washing for prevention of trachoma infections in children
Food & Nutrition	Health promotion messages regarding food reach in Vitamin A for prevention of cornea diseases.
Immunisations	Health education messages regarding detection of cataract in children, immunisation against rubella, and treatment of infections in early pregnancy, which can cause cataract
Maternal and Child Health	Health promotion to mothers on early case detection of diseases in children such as cataract, glaucoma. heath promotion messages regarding harmful eye medicine
Control of local endemic diseases	Health promotion messages for Trachoma
Treatment of diseases	Treatment of Ophthalmic neonatorum.
Essential drugs	Health promotion regarding use of essential eye drugs

Successful integration of PEC into PHC within the community may result in PHC workers being engaged in eye health promotion that can lead to identification of a variety of eye conditions in children. However in the presence of only very few studies that have documented the process of integration, there is need to critically look at the available evidence of successes of existing primary eye care programs that have been integrated into PHC [243, 244] before further investments into PEC are made. It is important to define the minimum correct knowledge and skills requirements for a primary eye care workers and ways how to transfer such skills within the policy framework of primary health care. Some of the challenges to the successful implementation of PEC have included correctly determining how long a successful integration can take, the type of personnel to be involved, managing

their training needs, and finding ways to embed primary eye care in existing PHC without losing focus on eye care[244].

For some of the poor African countries to achieve successful integration, there must be a long term political will to promote eye care as part of the overall country's health care, a need to have policies that allow training of primary health workers in primary eye care in place, and mechanisms to mobilize adequate resources for capacity building and eye service delivery. The competing diseases, such as malaria and HIV/AIDS, that are associated with increased mortality, are usually of high priority by most Ministries of Health, but this should not deter efforts to put eye care on the national health agenda, and identify alternative resources, especially in countries like Malawi, which has scarce dedicated human resource for eye care.

1.6 Malawi

1.6.1 Overview

This section describes Malawi in regard to location, climate, historical background, administrative and political structures, culture issues, socio- economic indicators, education, population and health indicators, general health and eye health services delivery and the role of primary health care workers known as Health Surveillance assistants (HSA's) in health service delivery in Malawi.

Location

Malawi is a small landlocked country in Southern Africa that shares boarders to the north and northeast with Tanzania, to the Southeast, South and southwest with Mozambique and to the west with Zambia (Figure 15) [245].

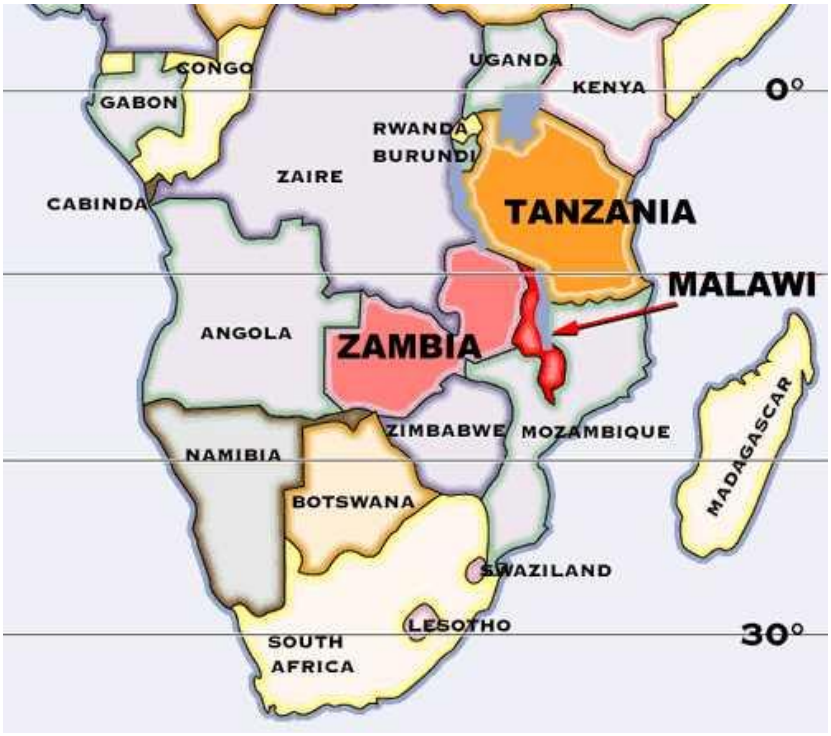


Figure 15: Map of Africa showing Malawi borders

The country is approximately 900 kilometres long, and has a surface area of 118,480 km^2, 1/3 of which is fresh water (Lake Malawi). Lake Malawi is third largest in Africa and the eighth largest freshwater body in the world and harbours several species of fish, which are a source of protein for many Malawians [245].

Climate

The country can be roughly divided into four major physiographic zones: the high-altitude plateaus consist of a number of isolated mountains such as Mulanje, Dedza, Zomba, Nyika and Vipya, the medium-altitude plain occupying more than 75 per cent of the land surface, the lakeshore plain lying along Lake Malawi and the lower Shire valley in the south- a wide rift valley which is hot, dry and dusty and famously known as the “blindness belt of Malawi” because of trachoma.

The country has two distinct seasons: the rainy season from November to April and the dry season from May to October. The rainy season is hot and humid while the rest of the year is mainly dry, dusty and partly cool. Mobility during the rainy season can be very challenging in many rural parts of the country as the roads are not usually very accessible. This poses a major health challenge as most emergency services requiring transfer of patients from rural health facilities to district hospitals are not fully operational.

Political & administrative structures

Malawi was formerly a British protectorate known as “Nyasaland” but gained independence in 1964. Since then Malawi has retained political stability, and there have been no internal tribal wars. There are many tribes and languages in Malawi, with the main tribe being “Chewa” and the language being “Chichewa” and other prominent languages and tribes being “Tumbuka” and “Yao”. English is the official working language. Approximately 12% of the country residents are Muslims; while the rest are Christians [245].

Administratively, Malawi is divided into 5 zones which are located with the 3 regions (North, central, and south) (Figure 16). There are twenty-eight districts, in total. The capital city of Malawi Lilongwe is located in the central region of Malawi, while the main commercial city is “Blantyre” in the southern region which is located at a distance of 300 km from Lilongwe. There are two other cities: Mzuzu in the northern region of Malawi which is at a distance of 400 km from Lilongwe and Zomba in the Southern Region which is located only 60 Km from city of Blantyre.

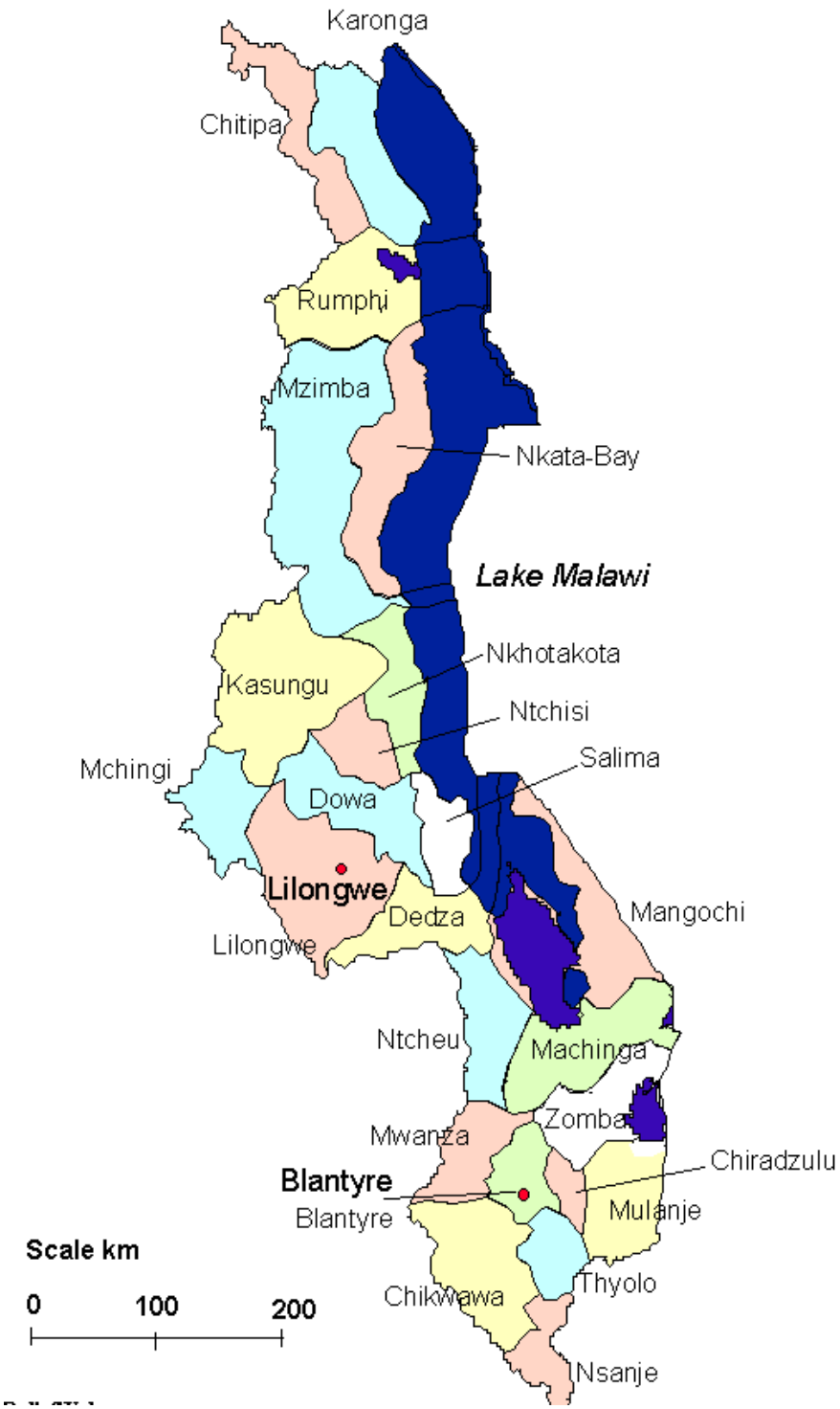


Figure 16: Map of Malawi showing administrative districts

The local community is village based with a common clan ancestry and /or a similar cultural grouping. The village is headed by a traditional chief who has several assistants comprised of elders of his/her clan. In some areas, several households belonging to one village could be scattered over several kilometres. Several villages can be grouped together under one group village headman (GVH). The highest ranked ruler is the traditional authority who covers a large geographic zone in a district and is a powerful and respected traditional ruler.

Socioeconomic characteristics

The backbone of the Malawi's economy is agriculture with over ¾ of all residents being farmers. The main occupation is subsistence farming, fishing and cattle rearing and agriculture produce is the main contributor to the gross National product –GNP (defined as the value of all the goods and services produced in an economy, plus the value of the goods and services imported, less the goods and services exported). The main cash crops for Malawi are tobacco, tea, coffee, groundnuts and cotton. Food crops include maize, cassava and rice. Fishing and small-scale irrigation farming for rice and sugarcane occurs in all parts of the country. Malawi remains one of the poorest countries in the world, ranked 165th poorest nation in the world with a gross domestic product (GDP) per capita of USD 1100 [245, 246]. Approximately 52.4% Malawians live below the World Bank poverty line(1.25 USD/day) [247].

Transportation & communication

There are tarmac roads from the capital Lilongwe to all the cities and most districts in Malawi and also going all the way to the Tanzanian border, Mozambique and Zambia border. Apart from these major tarmac roads, there is a good network of dusty roads in all districts in the country. Public transport in form of buses, vehicles and bicycle taxes are available and reaches within 5-8 kilometres of most residential areas. Almost all the dusty roads are passable by vehicles during the dry season but some roads are impassable during the rainy season and this makes access to services including health facilities difficult during the rainy season.

The availability of mobile cellular network even in the remotest areas has revolutionised communication in Malawi with most residents in rural areas being able to be reached through a mobile phone. Almost every village resident has an access to a mobile phone either through private ownership or through a shared telephone located within reach and where information can be passed on.

Education

The majority of children attend formal education in Malawi through public schools offered mainly by government and faith based organizations. Private educational institutions are mainly limited to urban and semi urban areas.

The Malawian school system starts from nursery (pre-primary) school (usually available only in urban areas) at about age 5 years through primary school (from age 6 years) that lasts for 8 years followed by four years of secondary schooling, and finally up by university/colleges. At the time of leaving primary school most children will be aged about 14 -16 years old, and because 16 years is the legal marriage age in Malawi, a number of girls in rural areas get married after primary school. The average enrolment at primary schools was low in 2004 (54%), with fewer girls than boys, but the number is reported to have improved to around 60-70% in 2008, and to approximately 80% in 2012. Adult illiteracy rate is reported to be high in Malawi, with approximately 60% of the residents not able to read and write. According to the Ministry of education records in Malawi (from 2007), approximately 18, 000 of pupils in primary schools in the country have low vision and require special needs education [248].In the absence of routine school screenings and eye examination, it is difficult to verify the current school data .

1.6.2 Population and health indicators

The population and health indicators as captured in 2016 at the WHO website (http://www.who.int/gho/countries/mwi.pdf?ua=1) are shown in table 12.

Table 12: Malawi population distribution and health indicators

Health & other Indicators*	% or Number
Population % under 15 years	48.2
Population distribution % rural	84
Population density	105 per km^2
Life expectancy at birth	59
Number of live births per year	651,700
Total fertility rate (children per woman)	5.4
Under-5 mortality rate per 1000	68
Maternal mortality ratio per 100 000 live births	510
General government expenditure on health as % of general government expenditure	8.9
Human Development Index Rank (all countries)	165 out of 177
Gross Domestic per capita US$	750
Population living below national poverty line ($1.25 per day) %	53

Source: http://www.who.int/gho/countries/mwi.pdf?ua=1[245]

Between 1990 and 2015, the under-five mortality rate markedly reduced from 245 to 68 deaths per 1000 (almost four-fold reduced), mainly attributable to early childhood survival programs and interventions including treatment for diarrhoea, pneumonia, malaria, insecticide-treated bed nets, immunisations, reductions in wasting and stunting, facility birth care, and prevention and treatment of HIV [249].

Population by regions & location (urban vs. rural)

As can be seen from table 13, only 16% of the total populations live in urban areas.

Table 13: Population by regions (urban vs. rural)

*Region where from	Living in Urban areas		Living in Rural areas		Total	
	No.	%	No.	%	No.	%
North	240,515	1.8	1,468,415	11.20	1,708,930	13
Central	832,113	6.4	4,678,082	35.8	5,510,195	42
South	930,681	7.1	4,927,354	37.7	5,858,035	45
Total	2,003,309	15.3	11,073,851	84.7	13,077,160	100

*2008 census results by regions

The population is estimated to be growing by 2.8% per year.

Age and Sex distributions

Table 14 shows the age distribution of Malawi inhabitants and table 15 shows the sex distribution.

Table 14: Age distribution

Age (yrs)	Number in age group	Percentage (%)	Cumulative %
<1	503,385	3.8%	3.8%
1-5	2,302,610	17.6%	21.5%
6-10	1,898,782	14.5%	36.0%
11-15	1,601,152	12.2%	48.2%
16-49	5,558,067	42.5%	90.7%
50-69	866,356	6.6%	97.3%
70+	346,808	2.7%	100.0%

As shown in tables 14 and 15, 48.2% of the population are children aged 15 years or below.

Table 15: Sex distribution

Age (yrs)	Sex		Total
	% Males	% females	
<1	1.9%	2.0%	3.9%
1-5	8.7%	8.9%	17.6%
6-10	7.2%	7.3%	14.5%
11-15	6.1%	6.2%	12.2%
16-49	20.6%	21.9%	42.5%
50-69	3.1%	3.5%	6.6%
70+	1.1%	1.5%	2.7%
Total	48.6%	51.4%	100%

1.6.3 Health services

General medical services

Health services are mainly provided by the government and faith based non-profit organizations (Christian and Muslim health facilities), with a few health facilities being run by private institutions. The services provided by government public health system are completely free of charge while that provided faith based organizations (still considered public) require patients to pay a very minimal fee. The majority of sick patients move from their villages and are first seen at the health centres (HC) which offer PHC, and refer to the district hospitals those patients that need advanced treatment not offered at the facility. The district hospitals see and manage most referred cases (from health centre) and also mange cases that come directly to the hospital. If cases cannot be effectively managed at the district hospital (due to complications or lack of expertise), they are referred to tertiary hospitals known as central hospital where specialized treatment is available. Figure 17 shows the flow of patients and cadre of staff at each level within the Malawi Health system.

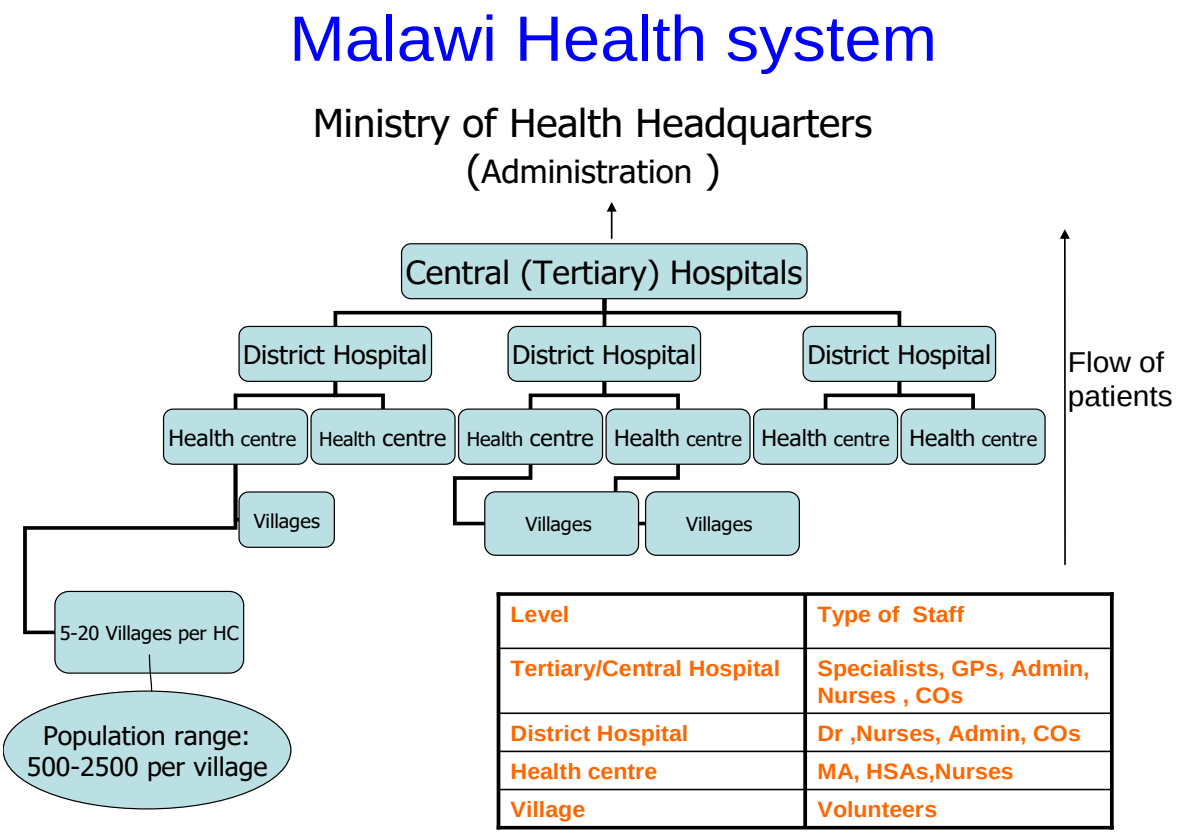


Figure 17: Malawi Health system

There are currently 4 tertiary hospitals (at least 1 in each region), 24 district hospitals and 328 public health centres in Malawi, as of 2015 [250]. The distance from one health centre to nearest one varies markedly between districts with some being only 5 km apart while others can be up to 30 km apart. The Ministry of Health plan, as part of the initiative to achieve Millennium Development Goals by 2015, recommended one health centre per every 5km. Currently each health centre serves a catchment population of approximately 10-40,000 persons usually resident within the 5-20 surrounding villages. The typical health centre is headed by a medical assistant who is a paramedical who has attended and completed a two years' certificate course in clinical medicine after completing secondary school. He is responsible for examining, diagnosing and managing all illness that present at a health centre and also for ordering drug supplies and prescribing medicines. There is also usually one enrolled nurse (a high school graduate who has attained a 2-year certificate in nursing), who assist the medical assistant and usually handles childhood immunizations and maternity cases. One to two patient attendants (who are usually local residents and recruited and trained on the job) assist in managing logistics involving patients and occasionally they diagnose and manage patients' illnesses (though not allowed by the medical and nursing regulation authorities). A large number of community health workers (approximately 5-20 in number) known as health surveillance assistants (HSA's) are attached to each health centre and conduct primary health care activities in the community.

Health surveillance Assistants (HSAs)

Health surveillance Assistants (HSAs),officially employed by ministry of Health (MOH) as primary health workers in Malawi, are the largest cadre of health workers (at least 12,000 employees).These were first recruited as temporary 'smallpox vaccinators' in the 1960's and as 'cholera assistants' in mid-1970's[251]. Their skills were limited and their main role was in health promotion and surveillance. The origin of HIV/AIDS in the early 80's and the pandemic in late 1990's and the emergency of other childhood diseases coupled with the severe crisis in human resource for health made the government of Malawi officially recognized HSAs as an important group and started scaling up their numbers to aid with community health programs[252]. By 2008 approximately 6,000 HSAs had been recruited in Malawi. With the launching of the Global Fight for TB, HIV and Malaria, a strategy to train more HSAs using global funds was adopted and within the next 3 years, a further 6,000 HSAs were recruited[253]. HSAs are high/secondary school leavers who do not go to college and they undergo a 3-month classroom training in primary health care and then learn skills on the job usually from experienced HSAs. It is not uncommon for HSAs to be recruited and stay 2 or more years before being sent for the 3 months training and usually by that time they would have mastered most of the skills without knowing the theory. Currently the delivery of most preventive and some curative health services rely on the roles of HSAs, who form an extensive network of workers that bridge the gap between the community and formal health

services. It is said that HSAs are responsible for about 60% of all vaccinations that are given to under-five children in Malawi and that they also perform several other roles concurrently[251].

HSA's roles, duties and the population they cover

As new diseases continue to emerge and challenges in the health sector in Malawi continue to increase, the job description of an HSA has constantly changed to cope up with the health needs of the community. Initially the job of an HSA was mainly health promotion and disease prevention in the community[251]; but recently the provision of curative and rehabilitative services have been added. HSAs have the following tasks at community level: conducting child and maternal vaccinations; growth monitoring, sanitation, water source protection and water treatment, disease surveillance, village and business inspection, health and nutrition talks and supervising traditional birth attendants and village health and water committees, providing family planning, implementing the community drug revolving funds, distributing community mass drugs administration (MDA), following up chronic patients needing palliative care in the community (TB patients, AIDS patients and cancer patients). In addition, almost all health NGO's in the community rely on HSAs to implement their activities[251].

Allocation of duties and supervision of HSAs

In terms of time allocation, immunization, growth monitoring and health talks occupy over 60% of HSA's time, followed by sanitation and water protection activities (25%)[254]. The rest of the activities are carried within the remaining 15% of their time. The average population being served by individual HSAs is between 1,000-2,000 persons, usually allocated in 1-2 villages but there is a large variation. HSAs are meant to live in one of their allocated villages and the village is usually 5-8 kilometres from the health centre. They are given a bicycle. Each health centre will have approximately 10-20 HSAs; 1-2 nurses and a medical assistant. The medical assistant is the overall in-charge but does not allocate or supervise HSAs. This is done by one experienced HSA at the health centre, who assigns duties and organizes a monthly work schedule. They will draft a weekly schedule of where they will be and what they will doing and give it to the HSA supervisor who will check and approve. A copy of the approved time schedule and activities is given to the medical assistant and sent to the zonal environmental officer who is the overall supervisor of all HSAs in the zone (1 zone has 8-10 health centres). HSAs only go to the health centre when there are antenatal clinics; but for the rest of the days they work in their community and submit monthly reports. A zonal supervisor will probably visit them once every 3-6 months in their village. Health Surveillance Assistants are usually called to the district hospital for refresher workshops about twice a year.

Productivity and attrition rates among HSA's

In regard to human resources for primary eye care, it is not only the numbers that matter but also the productivity of staff[255]. Few studies that have assessed the productivity of HSAs in Malawi but specific disease target goals have given an indication of their productivity [251]. For example, by 2013, Malawi had reached measles immunization coverage of over 90%[63] and the Ministry had attributed this to the high productivity of HSAs. However, a number of constraints still affect the performance of HSAs namely: mobility (transport) problems in the community, poor remuneration, lack of career development, irregular supply of essential items and lack of training and skills to perform some of the desired tasks.

Attrition is measured by the number of health workers who leave their posts [203]. Attrition can be resignation (voluntary), retirement, dismissal or death. The commonest form of attrition in the government sector is voluntary resignation, many of whom leave to work in the private sector [256-258]. Reasons why health workers leave are complex and include low compensation, lack of practical and education opportunities, poor working environment, lack of basic supplies, inadequate health infrastructure, social amenities and living environment, and lack of supervision and feedback[259]. Attrition rates among HSAs in Malawi are unknown, but are likely to be similar to the 5% attrition rates per year, among health workers, as reported by Chankova et al in Tanzania[256]. Health surveillance assistants are usually young persons who have just completed secondary school and are looking for other opportunities to advance in their lives. HSAs are known to be overworked, underpaid and often disgruntled, all reasons which can them leave. Some of these reasons were explored in the pre-pilot phase and are described in chapter 2.

Eye services

Infrastructure

Malawi has five dedicated eye hospitals that offer specialised eye services. Four of these are owned by Ministry of Health (MOH) and one is owned by churches. The four MOH owned eye hospitals were built by the Lions Club International in each of the major city (Blantyre, Zomba, Lilongwe and Mzuzu) and donated to the government of Malawi. The eye hospitals in Blantyre and Lilongwe have a 100-bed patient capacity while the hospitals in Zomba and Mzuzu have a 50-bed patient capacity. All the 4 hospitals have basic eye equipment but in addition the hospital in Blantyre is fully equipped with paediatric eye surgical equipment while the hospital in Lilongwe has vitreoretinal equipment. The fifth eye unit owned by churches is the Nkhoma eye unit (in Lilongwe) which is part of the Nkhoma mission hospital. The eye unit is supported by Christofel Blinden Mission (CBM). Nkhoma eye hospital is situated at a distance of only 32 from the Lilongwe. Each of the five facilities is headed by an Ophthalmologist.

Human resource for eye care

Coordination

Malawi is a signatory to the VISION 2020 initiative. Through this initiative a National Prevention of Blindness committee (NPBC) was established within the Ministry of Health headquarters in Lilongwe and this committee is responsible for overseeing and directing all eye activities within the country. The committee meets quarterly but there is a full-time position in the Ministry of Health headquarters for a focal person (deputy director) responsible for Ophthalmology. This focal person coordinates day to day activities that involve eye care, and liaises with supporting partners that are involved in eye service delivery.

Eye supporting partners

As far as support to eye services is concerned, Malawi is very fortunate in that there are many non-government organizations (NGO's) who support eye care services (some specifically for eye care while others support eye care as part of a comprehensive approach to health). To avoid duplication of services and unnecessary waste of resources, different partners in eye care support specific zones in the five administrative health zones of the country (table 16).

Table 16: Main zonal Eye supporting partners in Malawi

	Zone	Main Supporting MOH partner
1	Northern Zone	Lions AID Norway (LAN)[1]
2	Central West zone	Sightsavers (SS)[2]
3	Central East Zone	Christoffel Blinden Mission (CBM) [3]
4	South West Zone	Sightsavers (SS)
5	South East Zone & Ministry of Health headquarters	Blantyre Institute for Community Ophthalmology (BICO)[4]

1.Lions Aid Norway (LAN) is an NGO from Norway that belongs to Lions Club Members of Norway but is mainly funded by the Norwegian government.

2.Sightsavers (SS) is a UK registered dedicated eye care charity for developing countries.

3.Christoffel Blinden Mission (CBM) is an International NGO with headquarters in Germany and USA.

4 Blantyre Institute for Community Ophthalmology (BICO) is a local charitable organisation.

Levels and numbers of eye care workers in Malawi

Malawi faces a great challenge in that it has a severe shortage of eye health workers at all levels and these cannot effectively provide services in the excellent facilities that are available. There are only 9 Ophthalmologists (8 native Malawians, 1 expatriate) covering the entire population of approximately 16 million inhabitants (1 Ophthalmologist per 1.8 million) and this figure is below the WHO/VISION 2020 minimal desired number of Ophthalmologist for this region (2 per million) and probably one of the lowest in southern Africa. In terms of midlevel ophthalmic workers there are approximately 50 Ophthalmic clinical officers/nurses and 4 cataract surgeons for the entire country. The cataract surgeons and some of the clinical officers/nurses are based at the central hospitals to support the Ophthalmologist, but there is at least one ophthalmic clinical officer or nurse in each district that offers eye services to an average district population of 400,000 persons. There are 4 optometrists working in the Lions eye hospitals (one in each) and who do refractions, and low vision services are carried out by clinical officers in the central hospitals.

Training courses for eye care workers

Ophthalmologists

Prior to 2005 there was no training institution for ophthalmologists within Malawi and all the Malawian ophthalmologists were trained at the Department of Ophthalmology, University of Nairobi in Kenya which had strong links with the University of Munich in Germany. In 2005 the Department of ophthalmology, College of Medicine, University of Malawi based at the Lions Sight First Eye hospital in Blantyre approached University of Munich to help to establish the capacity to train local ophthalmologists in Malawi as was the case with Kenya. Later that year a twinning programme was established with the Department of Ophthalmology, University of Tubingen in Germany upon recommendation by Munich, and the first two Malawian ophthalmologists residents were recruited in 2006 to jointly train in Malawi and Germany for four years. Both residents graduated with Masters in Ophthalmology and have increased the number of Ophthalmologist from 7 to 9.

Cataract surgeons, ophthalmic clinical officers (OCO's) and nurses

The training of this cadre takes place at the School for Health Sciences based in Lilongwe. Since 1980s Malawi has trained midlevel ophthalmic personnel and the school has produced over 650 graduates from more than 20 African countries. Unfortunately, since the school was set up to cater for the entire region, the number of Malawians that could be enrolled was limited and hence only a few Malawians graduated. Most of the countries that were sending paramedicals for training in Malawi have started their

own training schools, and this has given Malawi an opportunity to increase the number of local candidates. This should result in an increase in the numbers of midlevel ophthalmic personnel in Malawi.

In regard to the optometrists, the four that are working in Malawi are private expatriate optometrists working in private optical shops at Lions Eye Hospitals. However, in 2008, a school of optometry was set up offering a four- year degree programme tenable at Mzuzu University, which uses the Lions Eye Hospital in Mzuzu for teaching. The increase in optometrists should result in availability of optometrists in district hospitals, and the future possibility of having readily available refractive services.

Eye care service delivery

Almost all the eye service delivery in Malawi has been supported by NGO's, and their particular interest in a specific area has guided how the service delivery has been implemented. Until recently the focus on eye care was on adult cataracts surgery, with an average national cataract surgical rate (CSR) of 600 surgeries per million per population[260]. Community services for children were limited to health promotion and school screening for refractive errors, but there were no mechanisms on how the children identified with refractive errors could readily access glasses. With VISION 2020 listing blindness in children as one of the priority diseases, the previous strategies of blindness prevention were reviewed. Blindness in children has now been prioritized and a national paediatric eye unit has been established at the Lions Sight First eye hospital in Blantyre to cater for the entire Southern Malawi (total population nearly 6 million, 48% children) and also for children from other areas of Malawi [242]. A paediatric oriented team has already been trained and is currently managing blind children (mainly with cataract) using the recommended guidelines. Routine health centre visits by the ophthalmic clinical officer, community based rehabilitation (CBR) workers, eye camps; self-referral to hospital, school screening, and other methods have been used to get children with cataract to the hospital.

However, less than 80 cataract cases per year attend the hospital in Blantyre which indicates that parents do not bring children. Reasons for poor uptake are likely to be similar to those reported from Tanzania [115] (gender relations and decision making within the household, local cultural beliefs about effects of surgery in children, long distance from hospital, transportation costs, low social education status of the mother and lack of skills among health care professionals to adequately counsel parents about surgery) and hence proactive case finding is needed.

The MOH plans to integrate primary eye care (PEC) into primary health care (PHC) through training of community health workers called Health Surveillance Assistants (HSAs) (see section 1.4.3). It is hoped that these will assist in identifying and referring more blind and visually impaired children in accessing services in Malawi.

Other services for blind and visual impaired children in Malawi

Through NGO and government partnerships, Malawi has adopted the comprehensive eye services (CES) approach to blindness in children through involvement of the health, education and low vision/rehabilitation sector. The country coordination of the program is based at the tertiary eye hospital in southern region of Malawi (Lions Sight first eye Hospital- Blantyre); where the blindness in children coordinator is responsible for referring children for appropriate eye care, education, low vision and rehabilitation needs.

In terms of eye care all children needing specialist clinical treatment are dealt with at the hospital while those children needing functional low vision services are sent to a resource centre for the blind and visually impaired that is located 30 km from the hospital. After obtaining clinical and low vision/rehabilitation therapy, most children are integrated in normal schools where they are coached by specialist itinerant teachers (IT's), while some are referred to blind schools and special resource centers. There are two blind schools in Malawi (one in southern region and the other in central region) which have approximately 95 children, and 14 resource centers which take approximately 172 children attending primary education[248, 249]. For secondary education over 17 secondary schools offer services to approximately 120 visually impaired children. More boys than girls (64% vs. 36%) attend blind schools and resource centers[249, 261].

Referral of eye patients

Malawi health systems has a referral process that allows eye patients to move from the community (after being identified by volunteers, HSAs, other health workers, or self) and be seen either at the first level health facility (health centre), secondary level (district hospital), or tertiary level (central referral hospitals). Once a patient has arrived at a health centre a nurse or medical assistant assesses and gives the first line of treatment (free antibiotic eye drops/ointment plus analgesics) or the patient is referred to the district hospital for further treatment. If it is an emergency such as ocular trauma and childhood cataract, the patient is transported for free by hospital ambulance from health centre to district hospital. Non-urgent cases are counselled to seek their own means to the district hospital. Health centres do not have facilities for admitting eye patients. At the district hospital, there is a trained mid-level ophthalmic personnel (ophthalmic clinical officer) that assesses the referred patient and provides additional treatment that may not be available at health centre (dilating drops, steroid eye drops, minor surgical procedures etc.). Patients are usually admitted at district hospital for a few days until the eye condition has recovered. In case of children, they can stay up to months until complete recovery has occurred. Upon discharge patients go through the same process, by ambulance from tertiary hospital to district hospital, then by ambulance

again from district hospital to health centre. From the health centre, they walk or take a bicycle (using their own money) back to their village (which can be up to 10 kilometres). Patients are given a return date to be reviewed either at health centre, district hospital or tertiary hospital. Health Surveillance assistants can be a useful source of information when it comes to reminding communities regarding health related issues.

CHAPTER 2

2 Pre pilot and pilot studies

This chapter starts with a summary of the chapter, then describes the rationale and approach, pre-pilot and pilot studies that were undertaken in southern Malawi between 2007 & 2008, as a follow up to the original key informant work that was conducted in 2006, and how the information obtained was used to develop the study questionnaires and methodology for the main study.

Summary of the chapter:

The pre-pilot and pilot studies presented here were conducted in the first year of the PhD between 2007 and 2008, in three separate districts, Mulanje, Chirazulu and Mangochi, in order to establish baseline information about any eye care work that was been conducted, and the willingness of HSAs and key informants to be involved in the project. As a background, in 2006, I pilot tested the key informant method(KIM) in Chikwawa district, as part of my Masters in community Eye Health at the London School of Hygiene and Tropical Medicine(LSHTM), and the results were encouraging, with key informants identifying up to 151 blind and visually children, over a four-week period of field work. Papers that were published as part of this work are attached at the end, as appendix 34. At that time, the suggestion was that this cadre of key informants (KIs) would have been an alternative to the primary health workers (Health surveillance Assistants), who were being advocated by the Ministry of Heath as the main group that would be involved in primary eye care work, including childhood blindness. I decided to provide evidence through research, by comparing the two groups.

I first had to register an NGO to recruit staff and administer the study, using the grant that I obtained from the British Council for Prevention of Blindness. As very minimal research work had been done on primary eye care among HSAs, and how that led to case identification, the plan was to conduct pre-pilot, followed up by pilot studies.

The 3 months' pre-pilot studies were designed to be qualitative in nature, and in-depth interviews and focus group discussions were conducted in 3 districts, primarily to generate baseline information on the knowledge, skills, roles and responsibilities of KIs and HSAs. Skills in qualitative research were obtained after I attended a qualitative research methodology training at LSHTM.

Qualitative interviews (16 in total), comprising of 8 focus group discussions (FGD's) and 8 in-depth interviews sessions were undertaken with potential KIs (community members), HSAs, parents of blind children, blind and normally sighted children. I designed tools (appendix 1-5), to assess levels of knowledge, attitudes and practices among HSAs, potential KIs, and parents of blind children in regard to

blindness in children, and generate information which would be useful in designing the training curriculum for key informants and HSAs. Interviews were tape recorded using a digital recorder and were transcribed, translated, and coded for emerging themes, using a coding framework shown in appendix 6. Key findings from the pre-pilot studies were that both KIs and HSAs had very little knowledge and skills in blindness in children, even though both groups were already involved in community health programs. The terminology of eye diseases in the community was confusing, with sometimes two separate eye diseases known by the same name. Parents of blind children has a sense of hopelessness, as they mostly did not know where to take their children, or what to do, and this was worsened by the negative way the community treated them. Blind children had hope that given an education and opportunities, they had the potential to achieve similar goals as sighted children.
The findings were used to develop study tools that were pilot tested over a 6 months' period.

Pilot studies were conducted in Mulanje districts, using 6 clusters, 3 randomised to KIs and 3 to HSAs, and aiming to train an equal number of KIs and HSAs to identify blind children. In total 163 children were identified, with HSAs only identifying 5 children and the rest (158) identified by KIs. A range of barriers that limit KI and HSAs from identifying children were elicited, and are discussed in this section.
The findings of the pre-pilot and pilot were written up inform of an upgrading document, which was presented during the upgrading seminar that took place at LSHTM in November 2008, where the findings were discussed, and the justification to proceed with a full study was debated. A team comprising of four experts from LSHTM (experts in blindness in children, global health, statistics and epidemiology, and tropical diseases) were nominated as advisory panel. They guided me in the methodology: the study design, sample size and the number of clusters to be used, selection criteria, data collection and analysis including issues of quality control, and planned qualitative work and statistical analysis.
The panel approved the main study methodology described in chapter 3.

2.1 Rationale

Using the WHO estimates for prevalence of blindness in children (derived from under-five mortality rates: of 133 death per 1000 live births in Malawi), by 2008, there were expected to be at least 2,500 blind children in southern Malawi, and up to a third were expected to be blind from cataract[54]. However, less than 80 cataract cases per year attended the only paediatric eye hospital in Blantyre. This suggested that either the WHO estimates were too high, or that current mechanisms for identifying blind and visually impaired children were inadequate. Parents may not have been bringing children, and reasons

for this were likely to be many and similar to those reported from Tanzania[115], and include parents unaware that treatment for childhood cataract is available, gender differences (girls less likely to be brought to hospital),complex decision making within the household, local cultural beliefs about effects of surgery in children including fear, long distance from hospital, transportation and other indirect costs, low education status of the mother and lack of skills among health care professionals to adequately counsel parents about surgery.

VISION 2020 has listed blindness in children as one of its priorities. If the desirable goal of controlling blindness in children is to be reached by the year 2020, more proactive methods for identifying blind and visually impaired children need to be explored. The Ministry of Health in Malawi advocated training of HSAs and their use in primary eye care (PEC), and this would include being responsible for identifying blind and visually impaired children. There was not much evidence as to whether using HSAs would be effective in identifying blind and visually impaired children. On the other hand, evidence gathered from studies in Bangladesh[50, 54] Ghana[53], Malawi[162] and Iran[52] had shown that key informants (community volunteers) could be effectively trained to identify blind and visually impaired children.

The question for Malawi was whether there was adequate evidence to advocate for change in policy to train volunteer key informants instead of HSAs, or to continue training HSAs and observe their effectiveness. In the absence of information comparing the effectiveness of the two groups, there was no justification to choose one group over the other. A comparison of the two approaches in identification and referring of blind and severely visually impaired children in Malawi and their effectiveness was, therefore, desirable.

A randomized cluster community study to compare two approaches of ascertaining blind children in the community i.e. training HSAs versus training Key Informants (KIs) was, therefore, planned and conducted to address this question in southern Malawi. The study was designed to provide evidence for and against each method.

Approach

Since very little previous similar research on blindness in children had been done in Malawi and there was limited baseline information about the work and willingness of HSAs and volunteers to be involved in the eye care, a phased approach to the research question was adopted, and implemented within 5 years (2007-2012).

Phase 1:3 months' pre-pilot studies in 3 districts to generate baseline information on the knowledge, skills, roles and responsibilities of KIs and HSAs and then use the data to develop study tools.

Phase 2:6 months' pilot studies in one district to pilot the study tools, analyse and refine them using the information obtained.

Phase 3: 15 month's data collection in two districts.

Phase 4: Data analysis.

Phase 5: Write up and discussion.

Research Team & ethical approval

The Blantyre Institute for Community Ophthalmology (BICO), registered as a charitable non-Government Organisation (NGO) in 2008, based at the Lions Sight First Eye hospital (LSFEH), was formed to administer the study. Two full time personnel were recruited under BICO: a research assistant /project coordinator and a data entry clerk. The main team implementing the fieldwork in Malawi involved five personnel: the lead investigator (K Kalua, an ophthalmologist and PhD research student), 2 ophthalmic clinical officers (acting as trainers and interviewers), a research project assistant, and a data entry clerk. Ethical approval for the study was obtained from the College of Medicine Research Committee (COMREC) in Malawi, and the Ethics Committee at LSHTM in UK.

2.2 Pre-pilot studies

Pre-pilot studies were undertaken between December 2007 and Feb 2008 in 3 districts (Mulanje, Chirazulu and Mangochi) in southern Malawi (Figure 18).

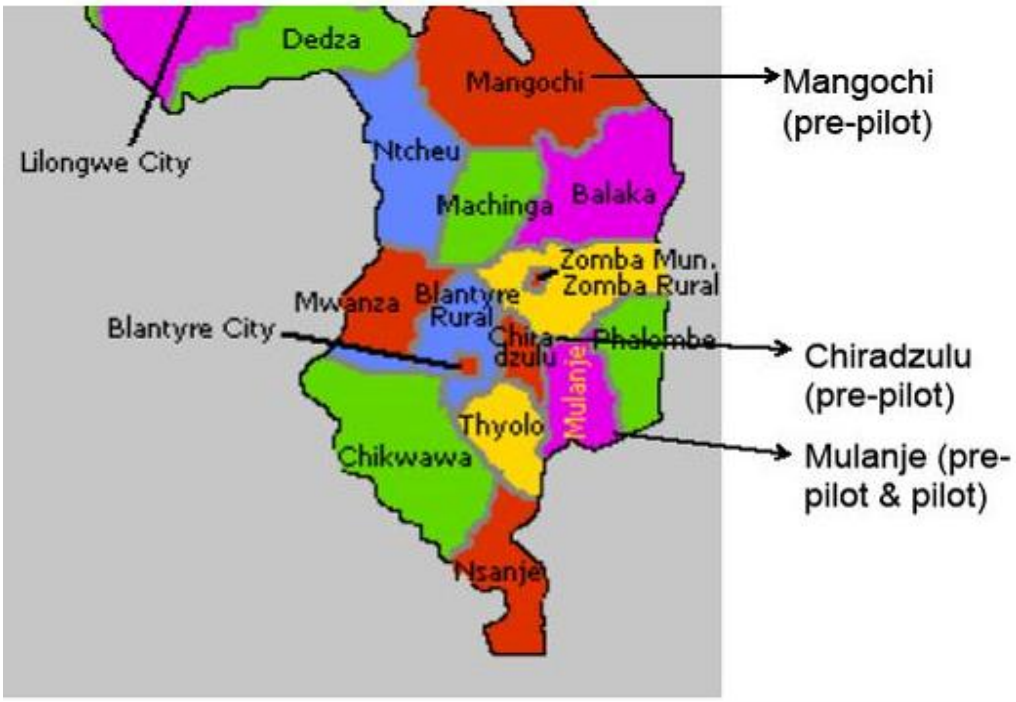


Figure 18: Map of southern Malawi showing pre-pilot and pilot studies districts

The districts were specifically chosen to capture social and cultural differences that may exist and explain challenges in identifying blind and visually impaired children. Mulanje is predominantly Christian; Mangochi is predominantly Muslim, while Chirazulu has a mixture of Christian and Muslim.

Aim

To assess levels of knowledge, attitudes and practices among HSAs, potential KIs, and parents of blind children in regard to blindness in children, and generate information which would be useful in designing the training curriculum for blindness in children for key informants and HSAs.

Objectives

1. Determine the knowledge and attitudes among HSAs and potential key informants towards blindness in children.
2. Assess obstacles that might limit HSAs and key informants in being involved in activities involving blindness in children.
3. Assess willingness of potential KIs and HSAs to be trained and involved in identification of blind children.
4. Determine challenges that blind children in blind schools and in the community face, and determine challenges that parents of blind children face regarding taking care of their blind child.
5. Develop training curricula for KIs and HSAs using information obtained from pre-pilot studies.

Methods and findings

Qualitative interviews (16 in total) comprising of 8 focus group discussions (FGD's) and 8 in-depth interviews sessions were undertaken with potential KIs (community members), HSAs, parents of blind children, blind and normally sighted children in 3 districts. The method of interviews, number of events and who was interviewed is shown in table17.

Table 17: Method and number interviewed per session

Method	Sessions	Participant groups	Number interviewed
Focus Group Discussions (FDG's)	8	2 FDG's KI 2 FDG's HSA's 2 FDG's Parents of Blind/VI children 2 FDG's Blind/VI children/Normal children	31 25 13 12
	Total		81
In-depth interviews	8	Parents of blind children Visual impaired children Normal sighted children	2 3 3
	Total		8

A team of 3 research assistants trained in qualitative research conducted the interviews. Key informants and Health surveillance assistants were interviewed in the health centres, while parents, blind and normal children were interviewed in the integrated boarding school, which is where children lived.

All the participants were randomly selected. Topic guides were developed as per protocols for conducting FGD's in developing countries, suggested by Hennink [216, 262] (appendix 1-5). Interviews were tape recorded using a digital recorder. Three facilitators who attended training on semi structured interviews were present for each session, one doing the interviews, the other taking hand written notes and the last person recording the sessions (Figure 19). Each session lasted for up to one and half hours. Key findings were summarized at the end of the session and discussed with participants for validation. The recordings were transcribed, translated, and coded for emerging themes [263], as shown in appendix 6.

Figure 19**:** Focus group discussion session with HSAs in Mulanje

Key findings from HSAs and potential key informants:

Health surveillance assistants reported that their basic training did not cover PEC and expressed willingness to be trained and involved in identifying blind children. They wanted to know more about the anatomy of the eye and what causes blindness. When asked about what they felt were causes of blindness in children and how to find the children, HSAs showed very little knowledge. Even though HSAs main work involved immunization and supplementing under-five children with vitamin A, more than half did not know that vitamin A deficiency could lead to corneal blindness and that cataract can affect children. HSAs reported that while some duties in their village could be undertaken by individuals, activities such as immunization often involved team work of 3-5 HSAs. They undertook health promotion and disease surveillance, diagnosed and gave first line drugs for malaria, pneumonia and diarrhoea in children.

In addition, HSAs reported doing home based palliative care for people with HIV/AIDS but most did not like this aspect of their work. Their most enjoyable task was giving immunization followed by planning their own work and time schedule. Health Surveillance assistants felt they would be the appropriate cadre to be trained to find blind children as they were better educated than volunteers, were recognized by the government and were already implementing many other much more demanding health programmes.

Potential KIs e.g. traditional healers, those involved in community programmes (e.g. orphan care, nutrition) and religious leaders also expressed willingness to be trained on how to identify blind children in their communities and had similar misconceptions about the causes. Sexually transmitted diseases

affecting pregnant women were what they perceived as the commonest cause of blindness in children. Almost all the volunteers were already implementing other health related programmes in their community. They reported that they indirectly benefited from these projects mainly through being provided with free t-shirts, lunch and transport refunds. The special recognition they received in their own village gave them status and made them appear knowledgeable. Volunteers felt that since they lived in the villages and knew all the residents, they would be the right cadre to be trained to identify blind children. They thought that HSAs already had a lot to do and would not give much attention to blind children at the expense of other life threatening conditions.

Both KIs and HSAs believed there were at least 3 to 5 blind children in every village (child population 500) in their community but since they did not know that anything could be done to help them they were not being given attention. Traditional beliefs that blindness could be caused by witchcraft and other abominations (i.e. evil spirits) were common among both KIs and HSAs. They admitted that harmful traditional eye medication (TEM) or traditional remedies (e.g. mother's breast milk or urine as eye drops; crushed pepper or tomato leaves as a treatment for red eyes) were commonly used as first line treatment for eye conditions in the community. They believed some could permanently cure blindness. Members from both groups admitted using traditional remedies for their own eye conditions or had advised relatives to do so.

The concept that a child who can still "see some things including light" can be categorized as "blind" (if VA is poor <3/60) was difficult for KIs and HSAs to understand. Most said they would not list such a child with poor visual acuity as blind if the child could still see enough to move around on their own. In regard to causes, different communities used different names for the same eye diseases. Interestingly, some common vernacular words meant different eye conditions within the same community. For example, a common word "Ng'ala" that everyone knew was translated by one group as a "white spot on the eye", while for the other group it meant a growth in the eye that caused the eye to be red. Upon further discussion by KIs and HSAs, it was revealed that indeed it represented both. However, the hospitals/health department used the term "specifically for cataract". It was obvious from these FDG's that if KIs and HSAs were told to identify and bring children with "Ng'ala", all sorts of conditions would be brought. It would, therefore, be necessary during training to use specific and agreeable terminology and definitions.

<u>Key findings from parents:</u>

Parents of blind children often did not realize the nature and seriousness of the problem until the child was older and completely blind and some still hoped the condition would go away as the child grew. Most felt blindness was as a result of witchcraft resulting from family disagreements or jealousy and

occasionally as a punishment for the wrong things done by the mother or father. These beliefs meant that their first line of approach for help was traditional medicine and only after that failed did they take the child to hospital. Some parents said they wished they had taken the child to hospital earlier, but distance was mentioned as a major barrier. In terms of caring for the child, it was usually the mother who was responsible and sometimes with very little family support. One mother reported that upon learning that the child was blind at 6 months, the father left to marry another wife in the neighbouring village, and another reported that she and her husband were disowned and banned from visiting other family members for fear of spreading the diseases. Mothers reported that they were given and called by “nick names” in the community such as “mache saona” which means mother of the blind child and everyone would know who that person was. They said there was very little understanding or sympathy from the community.

Key findings from blind and normal sighted children:

Most of the blind children could not explain what eye condition they had and what caused their blindness, but said they did not care much about that. What they were most concerned about was the way normal sighted persons treated them and why normal sighted persons had such problems in understanding and accepting them as they were. They said people in the community would make rude jokes about them instead of feeling sorry for them, saying that they had no future and would end as beggars. They preferred to be an integrated school where normal sighted children /friends would assist them. Sighted children indicated that they were more empathetic about their blind friends and said they were always willing to assist them.

All children expressed high ambitions and felt that if they were given an education and opportunities they had the potential to achieve similar or better things as sighted children. The children loved being at school more than staying at home because, they said, while at school, they would be assisted by friends but when at home their parents would often lock them up to prevent them from harm and sometimes siblings would mock them. During the farming season, they could be forgotten and left all day, often without food. Children concluded by saying that blind children are “not dumb and deaf” and most of the times they will hear bad things being said about them hence there is need to inform society so as to change their attitudes.

Conclusions

Both KIs and HSAs had limited knowledge and skills in eye care and knew little about blindness in children. Each group expressed interest and willingness to be involved in blindness in children activities and felt that they would be the right cadre to be trained and this further justified the reason for comparing the effectiveness of the two groups. Issues arising from parents and blind children gave information on

the counselling skills KIs and HSAs needed to be taught to handle such children when identified in the community, and also gave important information to use to encourage other blind children that do not attend school.

Information obtained from this qualitative study was used to develop training curricula (on expected knowledge, skills and attitudes) which included a brochure on issues about blindness in children and a training manual for both KIs and HSAs. The training was evaluated and the curricula revised and updated following comments and further modified during the pilot study.

2.3 Pilot studies

Following the pre-pilot phase, pilot studies were done in southern Malawi between February and October 2008 in one district (Mulanje) in Southern Malawi (Figure 18).

Aim

To test and refine the objectives, methods and study tools that would be used in the main study districts

Objectives

1. Select and recruit 60 HSAs and 60 KIs for training
2. Conduct 6 trainings sessions for KIs and HSAs
3. Conduct 18 community eye examination sessions on children identified by KIs and HSAs
4. Refer and follow up children needing tertiary services
5. Revise the data collection forms and methodology based on information obtained

Methods

Selection of clusters and recruitment of KIs and HSAs:

The total population of Mulanje district was 435,753[264]. Based on existing geographical boundaries the district was divided into 6 clusters of similar population sizes (approximately 70-80,000 population per cluster, 35-40,000 children). Clusters were then randomly allocated to training of KIs or HSAs (3 each). Each cluster had 2-3 health centres located within it and approximately 60-70 villages.

Selection of KIs and HSAs

Approximately 20 KIs or HSAs were recruited per cluster for each training session. The health centres catchment population was used to determine how many KIs and HSAs were selected from that centre for training (proportional to size so that each KI and HSA covered a similar population area). Village leaders were asked to select persons (KIs) who were resident in the village, were acceptable to the community, had time to do the work, and who also knew how to read and write. Approximately 1/3 of all HSAs working in each cluster were selected for training using the KI and HSA selection criteria (appendix 7). Once selected, KIs and HSAs were communicated about dates and venues for training.

Training of KIs and HSAs and identification of children:

Groups of KIs and HSAs were trained separately on concurrent days and the training was done in a centre identified in the community. Training was conducted by 4 facilitators (the lead investigator, 2 ophthalmic clinical officers and a project coordinator). The aim of the training was that KIs and HSAs should be able to identify cases of blind and severely visually impaired children in the allocated villages. A KI and HSA training manual developed using the findings from the focus group interviews and other community eye health materials was used (appendix 7) for the training. HSAs & KIs were taught how to assess visual acuity using a single E chart at a distance of 6 meters in children aged 6 to 15 years, and how to take a standard history for children aged less than 6 years to determine if the child could be blind or visually impaired.

Each KI had 1-4 villages allocated to them, comprising of an approximate total population of 2,000 residents and were told to identify and list all children they thought to be blind. They had to do this within the 2- week period after the training. They were given brochures as reminders of what to do and how to measure visual acuity (appendix 8, 9 & 10) and forms to complete while identifying children (appendix 14-20). The methods they could use for identifying children included going from house to house to ask if there are any children with visual problems, making announcements during gatherings (markets, church, weddings, funerals, village and political meetings), going into schools and asking the teachers and talking to women's groups (e.g. orphan carers, home based carers). Key informants underwent half days training and they were told when and where the KI clinic would be held in their community where the children they had identified would be examined.

In contrast, the HSAs underwent a full day of training conducted at one of the Health centres in their community. This was because during the pre-pilot phase they had asked to be taught about the anatomy of the eye and the causes of blindness and it was felt this could not be covered in half a day. The KIs on the other hand did not need to know the details so it was felt half a day would be enough for them. The curricula for HSAs also included information on the management and prevention of other eye conditions.

HSAs were allocated villages also covering population of 2000 to visit and were given a single E letter visual acuity (VA) chart and forms (in English) to complete. The methods HSAs could use to find blind children included health talks at the health centre and asking mothers if they had any children with eye problems. If identified they were to take a more detailed history and examination. They also asked mothers if they had any concerns about their child's eyes during immunization clinics, during their routine village visits, if any members of households had eye problems and if they knew anyone with eye problems in their area. They were told to refer all children they suspected of having visual problems to the ophthalmic clinical officer (OCO) at the district hospital (he was part of the research team). The name and diagnosis of each child seen was recorded in duplicate: one copy was given to the parent and HSAs kept a copy for their records. Every time they referred a child, they would communicate with the OCO. They did not have a deadline for identifying children as this was supposed to be integrated into their normal work. In terms of enumeration and incentives, KIs and HSAs were not given any financial incentives but told they would be given a t-shirt for every blind child they identified. During the day of training, they received lunch and transport costs were reimbursed. All forms used during the fieldwork are shown in appendix 11-33.

Examination of identified children in the community:

For children identified by KIs, eye clinics were conducted in the community at agreed centres two weeks after the training. KIs were told the date, place and time to bring the children. The research team conducted the ophthalmic examinations during the clinics. Written consent was obtained from parents of children who had been brought to the examination centre and from the children themselves if they were able to understand. The clinical ophthalmic examinations involved measuring visual acuity with LogMAR charts for older children and LEA charts for the very small children, pinhole for best corrected visual acuity, cycloplegic refraction if warranted, anterior segment examination with a torch and portable slit lamp, florescence staining, tonometry when justified, and direct and binocular indirect ophthalmoscopy. Mothers were told of possible side effects for the eye drops used for diagnosis (amethocaine 0.5%, fluorescence 2%, tropicamide 0.5%, and cyclopentolate 0.5%) and treatment (antibiotic and anti-allergic eye drops) before installation.

A modified version of the standard WHO form was used to assess the causes of blindness in children (appendix 22). Children referred by the HSAs were examined by the OCO at the district hospital, or by an ophthalmologist if referred directly to the tertiary hospital in Blantyre, if the latter was the nearest. A register of children who had been referred by the HSAs was kept at the district hospital and by clinical staff at the tertiary hospital. These were reconciled for inconsistencies. After examination children were referred for treatment, as required e.g. for surgery, refraction, low vision services, special education, rehabilitation and community based rehabilitation (CBR).

Follow up and tracing of identified children

A database of all children coming to the district and tertiary hospital and their means of referral was compiled. Through working with the paediatric ophthalmologist at the tertiary hospital, registers of how to track all children reporting at the hospital were established and put in place so that every time a child from any of the clusters reported this could be recorded. Due to the complexity and challenges of tracking KIs, HSAs and the children identified, 14 separate quantitative forms were initially developed during the pilot phase for capturing data at various levels (appendix 12-25).

Results

The total population covered in the pilot study was approximately 436,000 of whom approximately 42% were children. The total number of children living in selected villages (target population) from the KIs clusters was approximately 85,000 while for HSAs clusters it was approximately 100,000. The total expected number of blind and severely visual impaired children (BL/SVI) children from population in the study area using WHO estimates of 0.8 blind per 1000 children was 148.

Characteristics of KIs and HSAs trained

Approximately equal numbers of KIs and HSAs were trained (64 and 59 respectively) and the sex distribution between the two groups was also equal. The average age was 29 years for HSAs and 34.5 years for KIs (Tables 18 and 19).

Table 18: Number of KIs and HSAs per training session

Session No	Numbers Trained		
	Health Surveillance Assistants	Key Informants	Total
Session 1	16	20	36
Session 2	20	23	43
Session 3	23	21	44
Total	59	64	123

Table 19: Gender distribution between KIs and HSAs

Sex	Health Surveillance Assistants		Key Informants		Total	
	N	%	N	%	N	%
Male	29	49	34	53	63	51
Female	30	51	30	47	60	49
Total	59	100	64	100	123	100

Key informants (KIs) were asked to state their social roles and these are shown in table 20.

Table 20: Social roles of KIs

Social roles	Number	%
Local farmer	16	25
Village committee member	13	17
Community Based organization	10	16
Religious leader	9	14
Health committee	9	14
Human rights	2	3
Orphan carer	2	3
Traditional Birth attendants	2	3
Peer educator	1	2
Total	64	100

75% of the KIs played active roles in several community projects.

Baseline characterizes of children identified by KIs & HSAs

From each of the 3 training sessions, KIs and HSA identified 163 children of whom 22 were confirmed to be blind on examination. KIs alone identified 158 children of whom 20 (13%) were blind while HSAs identified 5 children and 2 (40%) were blind (Table 21). Using the estimates of 8 blind children per 10,000 there were expected to have been 148 children in the catchment area and both groups combined only identified 15% of those expected. Key informants (KIs) alone identified 29% of expected children in their catchment area while HSAs only identified 2% of blind children in their catchment area.

Table 21: Children identified by KI and HSAs per each session

	Health Surveillance Assistants			Key Informants			All		
	Total listed	Confirmed blind	Total child pop	Total listed	Confirmed blind	Total child pop	Total listed	Confirmed blind	Total child pop
Session 1	1	1	42,253	58	2	30,733	59	3	72,986
Session 2	1	1	20,649	39	3	22,339	40	4	42,988
Session 3	3	0	39,633	61	15	31,766	64	15	71,399
Total	5	2	102,535	158	20	84,839	163	22	187,374

In regard to schooling, 14 of the 22 children were of school going age (5 and above) but only 7 (50%) were in school. Three had dropped out of school due to being blind while the other 4 had never been. Those who dropped were happy to go back to school, and through support from this project they were sent to a school for visual impaired children. The children's age ranged from 1-15 years, the mean age being 6.8 years (Table 22).

Table 22: Age range of children & frequency

Age range	No of blind/SVI children	Percentage
	N	%
<5	8	36.4
5- <10	8	36.4
10-15	6	27.2
Total	22	100

Among all children, 13 (59%) were blind, 7 (32%) were severely visually impaired, and 2 (9%) were believed Blind/SVI but could not be primarily tested. The causes of visual loss (diagnosis) among the children identified are shown in Table 23.

Table 23: Causes of visual loss by sex

Clinical Diagnosis	Boys		Girls		Total	
	N	%	N	%	N	%
Cataract	10	59%	1	20%	11	50%
Cornea scarring	2	12%	1	20%	3	14%
Glaucoma	2	12%			2	9%
Cortical blindness	1	6%	1	20%	2	9%
Optic atrophy	1	6%	1	20%	2	9%
Refractive error		0%	1	20%	1	5%
Amblyopia	1	6%			1	5%
Total	17	100%	5	100%	22	100%
% Boys	77%		23%		100%	

Of all blind children 77% were boys. Un-operated cataract was the leading cause of blindness (50%).

Findings on barriers: KI and HSAs perspectives:

A total of 3 in-depth interviews and 2 focus group discussion were conducted with KIs.

Key Informants said they had to travel long distances between villages, taking up to 2 hours to visit all the villages allocated to them. Once they heard there was a child suspected of being blind they usually went to their home to talk to the parents and check the child. Motivating factors included the knowledge

they acquired and wanting to help their communities. Key informants reported that the majority of older children they saw with eye problems had red eyes and itching. Key informants reported that they needed to have proper identification cards to be accepted in their communities especially in the neighbouring villages.

As most HSAs did not identify any children, a larger proportion of them were included in qualitative research to find out why they didn't. Therefore 5 focus groups (6 HSAs in each) and 2 in-depth interviews were conducted. HSAs reported that the commonest method they used to identify children was health promotion (making announcements) and this was done mainly in their own work village.

It was difficult for them to work in other village with HSAs who had not been trained which was contrary to what was reported in the initial qualitative studies. A misunderstanding about incentives for identifying blind children led to their non-trained colleagues being jealous and not willing to assist. HSAs reported that they had not been given long enough time to identify children (the visit done was 4 weeks after training) as they were busy with other duties. They said they needed a minimum of 2-3 months to do the job in the allocated villages. HSAs also wanted to be given bicycles and motorcycles. Most HSAs admitted that after the training they had not searched for the children as agreed. Reasons included immunizations keeping them busy and they did not think it was appropriate to screen for blind children at the same time. HSAs said they would prefer to have a specific day to attend to eye patients in their villages. Some senior HSAs admitted they were involved with other programmes that gave better incentives such as bicycles. To assess whether HSAs had acquired the right knowledge and skills after training and whether they still remembered, we asked questions about what was taught to HSAs at random, and all of them correctly recalled the causes, and how to identify and refer blind children.

Discussion of findings:

From these findings, it was noted that both KIs and HSAs are capable of acquiring knowledge and some skills in identifying blind children after a short period of training. Key informants were more willing than HSA's to be involved in identifying blind children and this may be because HSAs have other demanding duties. However, the numbers of blind and severely impaired children identified by both groups (and particularly HSAs) were very low. There were a number of possibilities for the low numbers: both groups may have not covered the entire areas, they may have covered the area but there were fewer blind children than expected, or parents of blind children were not wanting to acknowledge the person to strangers, either through fear, shame, or through belief that nothing could be done. The last possibility was very unlikely as residents from these villages lived a much more communicable life which would make it harder to hide the blind children. On the whole, the

discrepancies in the numbers between KIs and HSAs suggested more to the fact that they did do the exercise well and that perhaps the villages allocated were too large or the distances between them too great. Some HSAs admitted not to have done the job because of lack of time due to engagement with other activities but in the absence of supervisory records it was difficult to verify this. The observation that the person in charge of health centres had very little supervisory role meant that before moving into the remaining districts it would be necessary to interview several people at health centres and district hospitals to find out how HSAs spend their time, who allocates tasks and supervises them and also 'how much time' is allocated to different activities.

More boys (77%) than girls (23%) were identified and this suggest that girls were possibly being missed, and this would be in agreement with observation made in Bangladesh[54] and Tanzania[160]. The large proportion (50%) of children identified with cataract could either be explained by the fact that emphasis during the training was on finding children with cataract (which is treatable). It was therefore decided that during the main study the training of KIs/HSAs needed focus on listing all children regardless of the cause and particularly advising the KIs/HSAs to look for the girls.

Recommendations by advisory panel

The findings of the pilot studies were presenting to the upgrading committee at LSHTM on 28th November 2008, which approved that the main study should be conducted in the remaining two districts taking into account suggestions and revisions that were discussed. The following weaknesses were identified in the methodology:

1. Differences in the length of trainings periods between KIs and HSAs (half a day for KIs and full day for HSAs) and the content of the curricula (basic for KIs but a bit more advanced for HSAs) would bias results of the study.
2. Different methods of referral and clinical examination mechanisms between the two groups (KIs referring children to the KI clinic set in the community at agreed dates while HSAs were requested to identify and send children to the district hospital at their own time) were likely to lead inbuilt study differences that would bias the results.
3. Qualitative interviews after the identification period mainly focused on the service provider (KI or HSAs) and the problems associated with identification of children; but barriers to service uptake on the side of the consumers (blind children, parents and community) that were not addressed are equally important and need to be addressed in the remaining districts.

Revisions and commencement of main study:

The concerns and advice of the advisory panel were addressed during the main study that took place in 2 districts (Zomba and Mulanje) for a period of 17 months from December 2008- April 2010. In brief, the following actions were taken:

1. The training was standardized to one full day for both groups and the curricula were revised and only addressed basic skills in identifying blind and severe visually impaired children.
2. All eye examinations sessions were done in the community at given dates.
3. Qualitative interviews to address non-financial barriers that parents and blind children face while accessing services were factored in the main study.

After the pilot study, tools were revised and finally 17 forms were used in the two districts (appendix 12-29). Clinical data were captured using a modified version of the WHO form for childhood blindness [100] (appendix 22). A semi structured qualitative questionnaire used for in-depth and FGD's was designed and administered to selected KIs and HSAs during follow up (appendix 26) approximately 4-6weeks after the training.

CHAPTER 3

3 Main study aim, objectives, and methodology

3.1 Aim

To compare two methods of ascertaining children who are blind or severely visually impaired by training Health Surveillance Assistants (HSAs) and Key informants (KIs) to identify BL/SVI children, assess and describe positive and negative factors that are associated with the use of each method and give guidelines on optimal approaches to identifying blind children in southern Malawi.

3.2 Objectives

1. To compare the number of blind and severe visually impaired children identified by Health Surveillance Assistants (HSAs) and Key informants (KIs).
2. To list the causes of visual loss in children confirmed blind /severely visual impaired among the children identified by KIs and HSAs.
3. To identify constraints and problems that limit KIs and HSAs in identifying blind and severely visually impaired children.
4. To identify barriers that limit blind and severely visually impaired children from accessing eye services.
5. To provide guidelines on optimal approaches of identifying blind and severely visually impaired children.

3.3 Methodology

3.3.1 Study setting

This was a cross sectional randomized community study conducted in 2 districts in southern Malawi: Zomba (population 670,533), and Mangochi (population 803,602), with a total population of 1,474,135 [264], among whom 43% (633,878) are children. Figures 20 and 21 shows Zomba and Mangochi districts

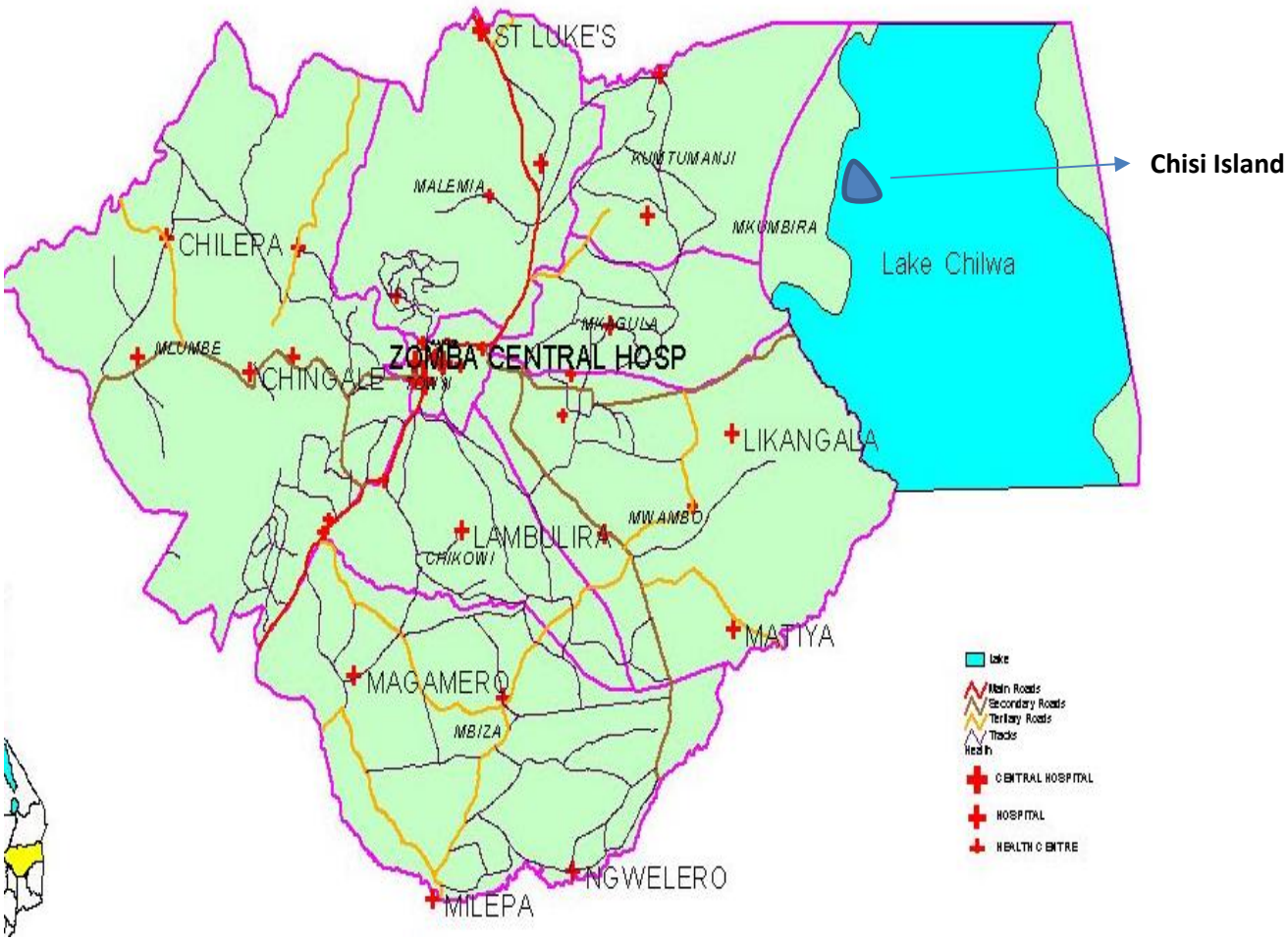


Figure 20: Map of Zomba showing health facilities

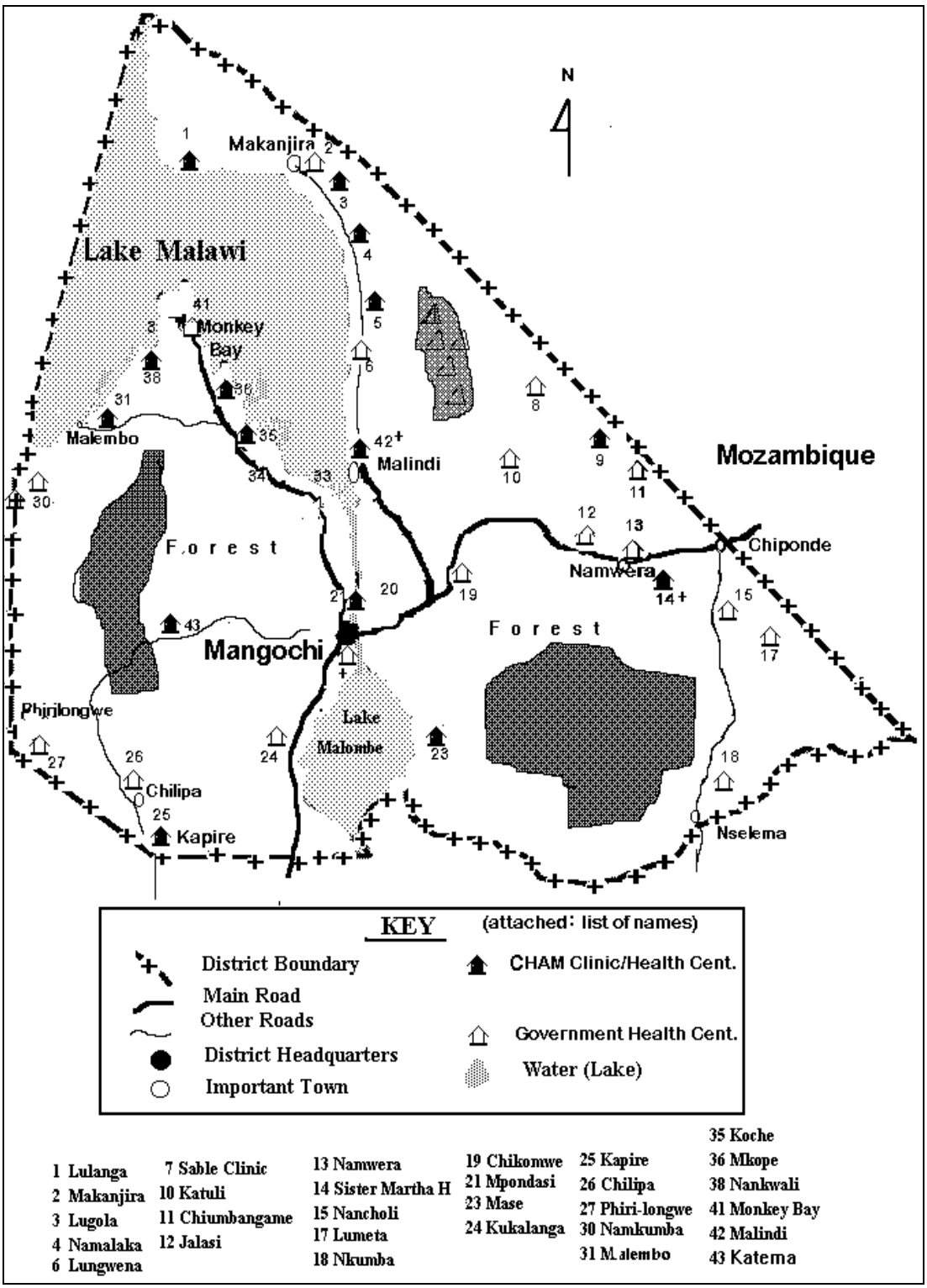


Figure 21: Map of Mangochi showing health facilities

Both districts are located in the Southern Region of Malawi (Figure 16). Zomba is located 70 Km from Blantyre (the administrative city), while Mangochi is located further east at a distance of 180 km from Blantyre. It is reported that the social economic levels and the education levels between the two districts are similar (demographic and health survey, 2013). In-terms of religion, Zomba has a mixture of Muslim and Christian, while Mangochi has predominantly, Muslims.

Selection of districts

Southern Malawi has a total of twelve (12) districts. Eight (8) of them were planning to launch a comprehensive eye service (CES) project that would involve training of HSAs, and this would bias the study if those districts were chosen. One district was newly demarcated and had no district hospital, which would make referrals from health centres, difficult. The remaining 3 districts (Mulanje, Zomba and Mangochi) were therefore selected for the project and Mulanje was selected for the pilot study because it was near Blantyre (where the research coordination was based) and logistically it was easier to start there.

3.3.2 Sample size

Sample Size calculation

The results of the pilot study suggested that KIs were better at finding cases that HSA's and that the prevalence calculated from numbers of blind children found by KIs would be higher than HSA's. The sample size is based on the null hypothesis that there is no difference in the case finding rate (proportions) obtained using the two identification methods (HSAs vs. KIs)[265, 266]. To calculate the sample size needed to reject this hypothesis and support the alternative hypothesis (that KIs were better than HSAs) the following parameters were used:

Test Ho: p1 = p2, where p1 is the proportion of blind children identified in population 1 and p2 is the proportion of blind children identified in population 2, with assumptions that:

Alpha =0.0500 (two-sided)

Power =0.9000

p1 = x

p2 =y

and n1/n2 = 1.00 where n = population

Using these parameters and the various values of x and y that would give a difference of either 40%,30% and 20% in the two groups with WHO childhood blindness prevalence estimates (0.9 per 1000) obtained using of 2005 under-five mortality rates for Malawi as a proxy, the range of sample sizes was generated using Stata 10.0. Since randomization was based on clusters rather than on individuals, a design effect of

1.6 (commonly applied in trachoma and other eye prevalence surveys) was used to adjust for sample size calculation. The final calculated sample sizes are shown in table 24.

Table 24: Sample size calculation

Prevalence estimate of childhood blindness	Difference in prevalence between KIs and HSAs	Number of children* needed for each group	Number of children after correction for clustering design effect (1.6)	Total population needed (adults + children) *
0.9 per 1000	0.4	122156	195450	454534
0.9 per 1000	0.3	227703	364325	847267
0.9 per 1000	0.2	535998	857597	1994411

*Children comprises 43% of total population

Based on this information a middle level of 40% difference was chosen and 12 clusters of approximately 40,000 population each (total 480,000; 206,400 children) were planned to be selected for the HSAs and KI training and case detection (6 clusters for each group) from the two districts. The figure of 40,000 per cluster was based on the minimum sample size for surveys of blindness in children (between 30-60,000), needed to estimate cluster prevalence and causes. The expected number of blind children from all these clusters was 185.

3.3.3 Overview of planning and protocol

The research team visited the two districts a number of times before training sessions were arranged. During the visits, the District Health Management Teams (DHMT) were briefed about the research project, several health centres were visited as part of familiarization with the districts and key contact persons were interviewed to obtain district baseline information (maps, names and distances between health centres, health centre and village population, number of HSA's, and health projects in the area using key informants). This was followed by selection and randomization of clusters, selection of KIs and HSAs, organizing and conducting the training and finally conducting the eye examinations sessions in the community. Each cycle of training for one group of KIs and HSAs took six weeks to be completed from the time of training to conducting eye examination sessions. Activities carried out in one cycle are shown in appendix 30.

Planning

The study was designed to have equal number of clusters (6) in each district. The distance from Blantyre (where the research team were based) to Zomba was 60 kilometres and to Mangochi it was 190 kilometres. It was decided that the first district should Zomba (for ease of logistics) followed up by

Mangochi. Zomba district had one district hospital and 32 other health facilities which were either managed by government or churches. Mangochi district had one hospital with 43 health facilities.

Protocol

Letters explaining the purpose of the research were sent to the District Health Medical Officers (DHO's) who were in charge of the government district hospitals and other allied health facilities in the district. This was followed by arranging planning visits and meeting the district Health Management Team (DHMT) in their districts. The DHMT members included the medical doctor in charge of administration (chairman), medical officer in charge of clinical services, a matron, an administrator, head transport and finance, and head of public and environmental health. During the first visit, all members of DHMT were briefed about the aims of the research, and several persons were separately interviewed about their role and what they thought would be the challenges in conducting such a research. Since there was need for one Ophthalmic Clinical Officer based in the district to be part of the survey team (for conducting training and follow up of children), two were chosen, but it was agreed that they would swap roles so that for each week, only one of them would be in the field.

Logistical support

Maps of the district and all health facilities (Figure 20 & 21) were obtained from the district Health Management Information System (HMIS) office. The office also provided detailed information about all health NGO's working in the district and those that used volunteers, names of villages and village leaders (headmen), names of health centre, person's in-charge and their contact telephone numbers. The DHMT from the two districts agreed to provide utility vehicle throughout the entire period of the survey as long as the vehicles were provided with fuel and the drivers were given a lunch allowance.

Summary of study Protocol

The summary of the study protocol and all the stages from the selection of clusters, training of KIs and HSAs, identification and referral of children, eye examination sessions, numbers of corresponding forms used, and interviews for access and service barriers are summarized in the flow diagram shown in Figure 22,23 and 24.

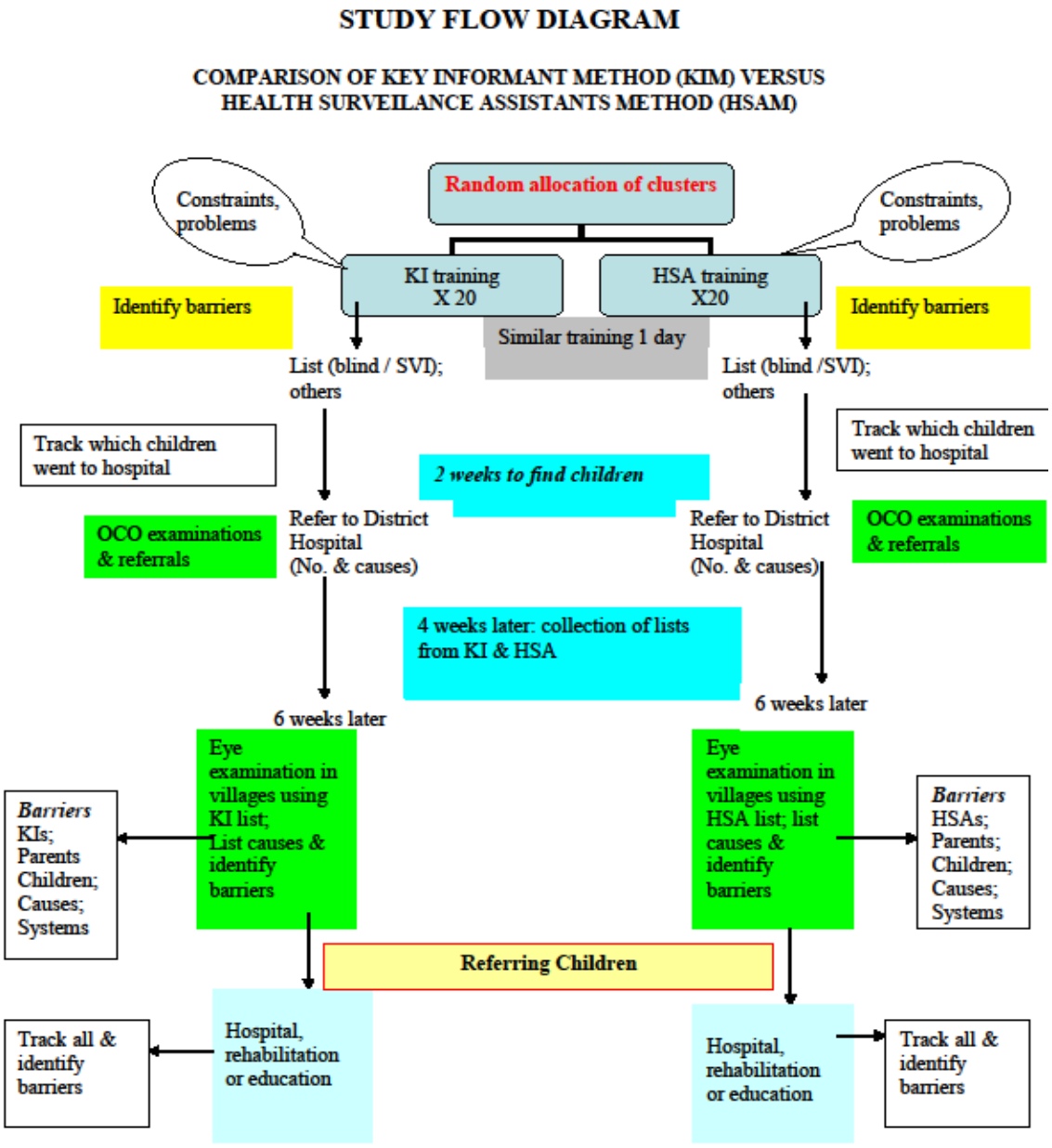


Figure 22: Flow diagram summarizing study protocol

Figure 23 shows what questionnaires were used at different levels of Figure 22 (training, listing, eye examination and referrals), and Figure 24 shows where information for access and service barriers (linked to last part of Figure 22), were collected during the study period.

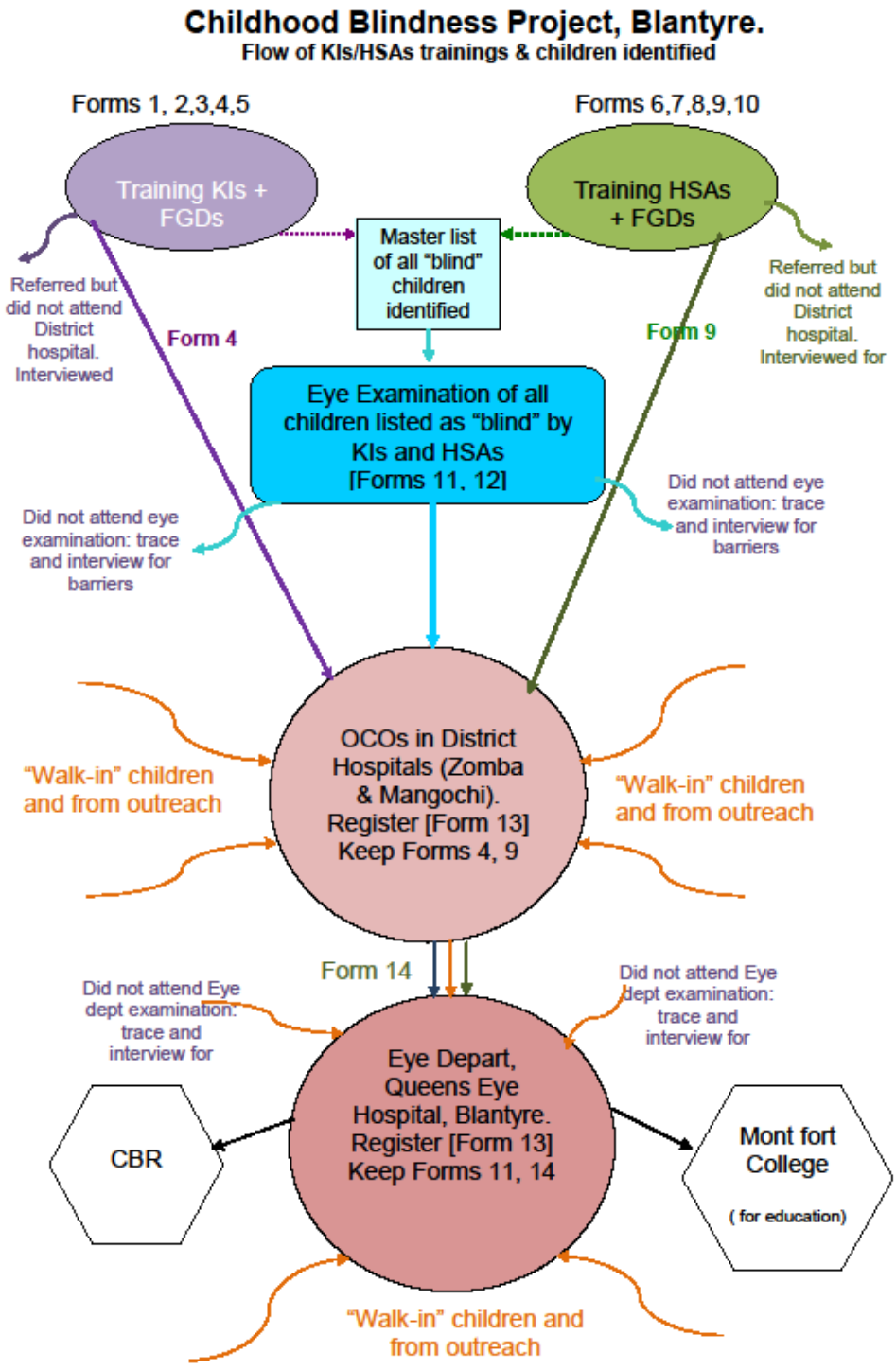


Figure 23: Flow diagram showing where and which questionnaire forms were used

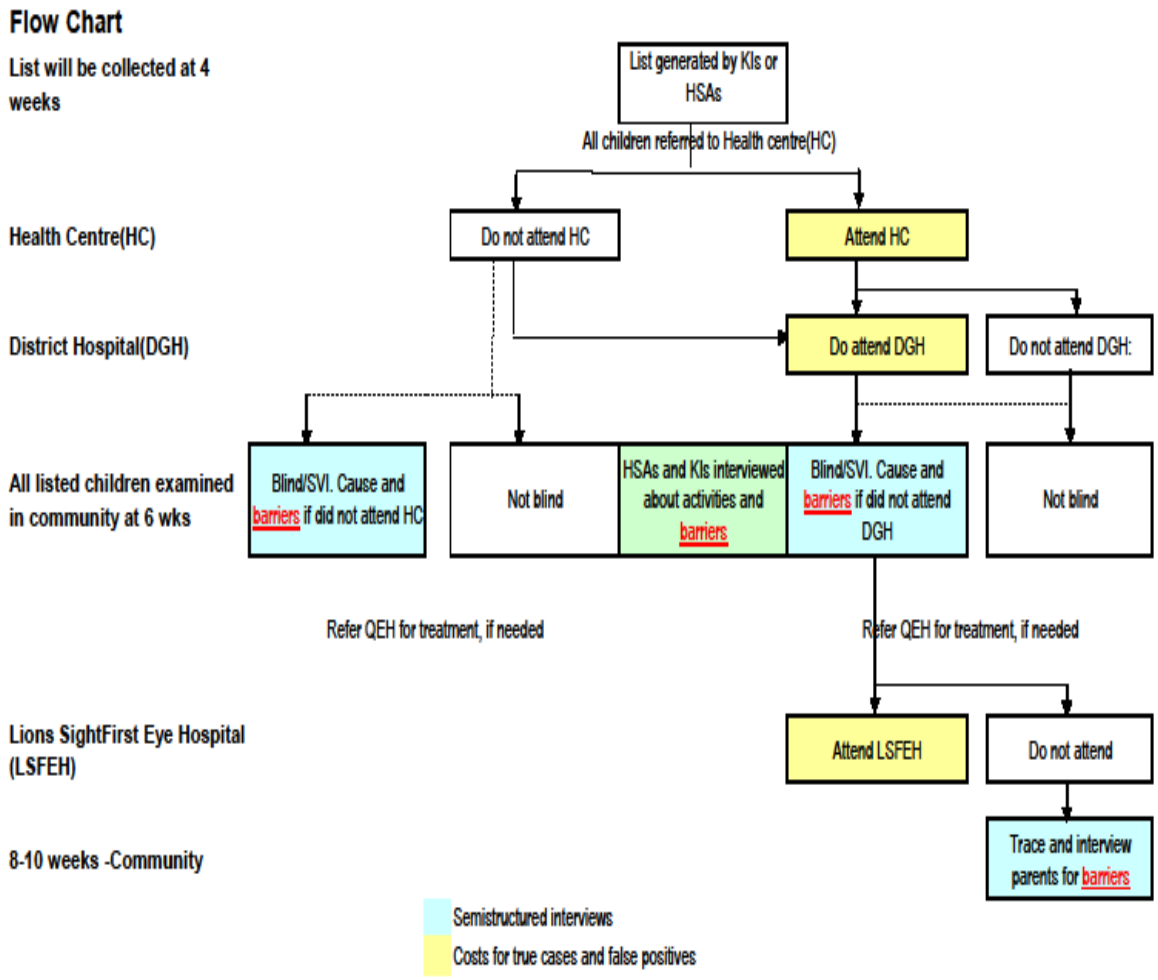


Figure 24: Flow diagram showing levels where access and service barriers were collected

3.3.4 Selection and allocation of clusters

Selection of clusters (zones)

Zomba district was already divided into 10 clusters called zones with populations ranging from approximately 50-80,000 persons, while Mangochi was divided into 5 much larger zones. Each zone had a zonal environmental health officer (EHO) who was responsible for supervising HSAs located in the health centres and contacting group leaders for all health-related issues. The EHOs regularly visited the district hospital for meetings with the district environmental health officer (DEHO), who was their line manager and a key member of the DHMT. The DEHO's were appointed by DHMT to assist in the logistics of the survey and selection of the clusters. For Zomba after inspection of the map and looking at several factors (proximity of the zones, size and population, whether located urban or rural, geographically demarcation, similarities in terms of infrastructure and road access), 6 clusters (zones) were selected from the 10 zones and paired according to similarities (similar population size, age distribution, similar development and infrastructure, distance to the main hospital, and services offered

within the surrounding health centre). For Mangochi, since there were only 5 existing zones; one very large zone was split into two to make a total of six and these were paired as per same criteria used in Zomba. Contact information for EHO's (HSA's zonal supervisors) from the selected zones was obtained.

Allocation of clusters to KI or HSA method

In regard to random allocation of the 3 paired clusters (6 clusters) from each district to either the KI or HSA method, 6 small pieces of folded papers were put in the basket (numbered 1-6; with half indicated as HSA and half as KI). EHO's from each pair of clusters selected head or tails for a coin tossed by the DEHO. The winner was asked to pick one paper from the basket which indicated which group (HSAs or KI) would be trained from his area and the sequence of training, with the number indicating the order of the training. The paired EHO who did not choose had the opposite group to be trained. This was done until all the 6 clusters were allocated. The EHO's from the selected clusters were visited in their zonal area and interviewed on how often they supervised the HSA's. The questionnaire used is attached in (appendix 29).

During visits to the zones, information on the characteristics of each cluster (condition of roads, distance to hospital, accessibility, and infrastructure) was discussed with the zonal manager and some of the farthest health centres were visited to assess travelling time and whether the team needed to stay overnight on the training day. In Zomba, the farthest health centre was 72 kilometres away, needing one and half hours travelling time. One health centre, Chisi (Figure 20) was located on an island between Malawi and Mozambique, only accessible by boat. In Mangochi distances from Mangochi town (where research team stayed) to some areas were long and took over 3 hours to reach.

Selection of KI /HSAs villages

The plan was that one HSA or KI would cover a population of 2-3,000 (1-3 villages) so 20 KIs or HSAs covering a population of approximately 40-50,000 would be selected from each cluster. Assuming that 10-15% of those invited would not attend the training session, 22-25 were selected for each training session. This meant that those selected would cover the entire cluster, which in principal had approximately 60 HSAs in total. Therefore, the number selected represented approximately one third of all HSAs in the chosen clusters.

In each cluster a list of villages with their population sizes was drawn up as the sampling frame, using data from the 2008 census. 25 initial villages were selected through probability proportionate to size sampling (PPS). A column was created with the cumulative population across the enumeration areas and the total population was divided by the number of HSA/KIs (25) required to derive the sampling interval. The first village was selected by multiplying the sampling interval with a random number

between 0 and 1, the resulting number was traced in the cumulative population column, and the first village was chosen. Consecutive villages were identified by adding the sampling interval to the previous number. Depending on the population of the villages selected, other villages were added during the training session to ensure that the catchment population of an area covered by an individual HSA/KI was approximately 2-3,000.

Recruitment of KIs and HSAs

The second stage of selecting KIs and HSAs in the selected villages was done by the zonal supervisor. For the HSAs, since each village had an HSA allocated to them, if the HSA was resident in the village, he or she was selected for training. Where there were no HSAs the nearest HSA to the village was chosen.

For the KI clusters, the zonal manager met the village headmen of each selected village and asked them to give one volunteer who was already involved in health issues, knew the village well, was able to read and write, and had the time to identify children. Half the villages were asked to choose a male and the other a female, this was done in-order to be able to compare gender differences in identification, as earlier work had suggested there could have been a gender difference. Once the lists of KIs and HSAs were obtained and complied by the zonal supervisor, they were forwarded to the project coordinator.

Upon agreement with the zonal coordinator, the dates and venues for the training sessions were organized and the KIs/HSAs were informed to report at the chosen venue on the date specified.

3.3.5 Training sessions

Training curriculum and materials:

The manual used for training the KIs and HSAs is shown in appendix 33. It is a 24-page document and goes step by step starting with an introduction about VISION2020 and blindness in children, the aim of the research, and the main topic for the one- day training i.e. structure and function of a health eye, how to tell whether a child is blind or visually impaired, causes of BL/SVI, what advice to give and where to refer children and their parents, and what health promotion messages to be given to the community. This manual which was originally developed from findings from qualitative interviews and other child eye health information that was available was modified after the pilot testing to add in other emerging issues which were known to be important. The final manual was user friendly and can be used by any health workers in training KIs and HSAs and other health workers in regard to issues of blindness in children. A number of materials were available for illustration of conditions and also for use in practical sessions which was a

major component of the training. The materials included flip charts, markers, torches, visual acuity charts, measuring ropes, and pictures of children's eyes with different conditions.

Organization and planning

All training sessions were planned to start at 8.00am and finish at 5.00pm. The team travelled from Blantyre a day earlier to plan the session in detail (appendix 31). KIs and HSAs were trained on consecutive days so 3-4 nights were spent in the field for each cycle of training. The zonal coordinator for the selected area was invited to attend the training and in most cases, they either came or they sent a representative. A copy of the training manual was handed to the zonal officer and all research team members a week before the training so that each facilitator would read guiding notes regarding their section and be familiar with their role. The main persons conducting the training were the ophthalmic clinical officer from Blantyre who was assisted by the ophthalmic clinical officer from the district where the training was taking place. The Ophthalmologist (lead investigator) was available mainly as a workshop facilitator. The people in charge of the health centres (either a medical assistant or a nurse) within the cluster were invited and present at the training; this was necessary because all children identified by either KIs or HSAs had to be referred to them so they had to know what to do when they got a referral. Training took place at a communal place in the cluster, usually a school or church, or health centre, as shown in Figure 25.

Figure 25: A training session in progress

Training methods

Training methods involved classroom lectures, small group discussions, case studies, participatory rural appraisal techniques [218, 267], plenary and practical.

Content of training

The training sessions started with registration and introduction of the participants which was facilitated by the zonal supervisor. This was followed by explanation of the aims and objectives for the gathering, and a background to VISION 2020 and the childhood blindness research. The structures of the eye were explained followed by prevalence, causes and impact of blindness on the child, their family and community. Participants were asked to list all possible ways of finding blind children and debate which methods would yield more blind and visual impaired children. A brochure and instructions on how to identify blind/SVI children and measure visual acuity in younger children aged 1-5 years was provided as is shown in Figure 26.

1. **How might we know if a child cannot see properly?**

Adults complain if they lose vision, but children do not usually complain. We have to ask some questions first and go by what the parents, teachers or others have observed, or noticed. The following are some important indications that a child cannot see properly: Clues to telling that a child is blind:

- Child not following light /objects
- Child not looking /smiling back as mother/other people smiles at the child
- Child bumping into objects
- Child not able to see objects across the room
- Child playing well during the day but refusing/all afraid at night
- Older child not able to read/see letter at a distance of 6 metres
- Mother convinced that child is not seeing
- Child with white pupil

Standardized history for blind children <6 years

Babies:0-6 months

- The mother notices that the child does not look at her face, does not smile when she smiles at her baby, and the baby does not watch her as she moves around
- The mother may also have noticed a "white spot" in her babies eyes, or some other abnormality
- The baby's eyes may "wobble" from side to side and they cannot hold them still

Toddlers and young children:6months-4 years

- The child is reluctant to walk around, particularly in the evenings when the light is not good
- The child bumps into things or falls over objects on the floor

Older children:4 years and above

- They stop doing what they used to do
- They start holding the things they want to look at very close

Important message: If the mother, father or other family member thinks the child cannot see properly they are nearly always right, even if they are not well educated. They know their child very well!

CHILDHOOD BLINDNESS PROJECT

BICO

Blantyre Institute for community Ophthalmology
Excellence in Community eye Health

Contact: Project coordinator
Blantyre Institute for community Ophthalmology
Lions Sight First Eye Hospital

Tel: 00265 999242019

Figure 26: A KI/HSA brochure on how to identify children aged 1-5 years.

Measuring visual acuity

KIs and HSAs were taught to attempt to measure visually acuity in all children that they suspected as being blind. For children aged from up to 5 years they were taught to ask the mother questions or to assess the child's functional vision by observation. For children aged 6-15 years they were trained to test distance visual acuity using single E optotype (Figure 27) according to the instructions in the brochure (Figure 28).

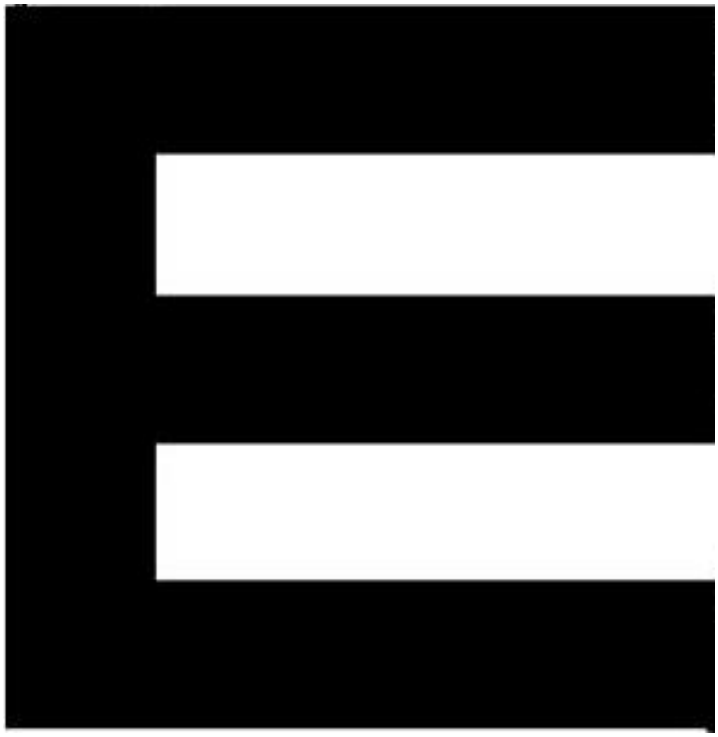


Figure 27: A single E letter chart and instructions for measuring VA in older children

How to measure vision in children

1. Explain to the child and the parent that you would like to measure the child's vision as they may have "some problem with their vision". Explain that this is not painful and will only take a few minutes

2. Measure out 6 meters by taking the number of paces you need to take for 6 meters (women = usually 8 paces, men= 7). Mark the beginning and the end of the 6 meters

3. Hold the E about 30cm away from their eyes make sure the child understands that you want them to show the direction the "arms" of the E are pointing in. Rotate the E chart several times until you are sure they understand.

4. Once you are sure the child understands what they should do, ask the child to go to the 6 meter mark and face you.

5. Show the E chart 4 times. Change direction of the E each time. Give the child one chance to show the direction of the E.

6. Count how many times the child correctly shows the direction of the arms of the E.

7. Refer all children who get the direction of the arms of the E wrong one or more times.

What to tell the parents:

Do NOT tell them their child is blind – this will worry them and you may be wrong

DO tell them that their child needs to be examined in a clinic which will be set up in the community shortly

What I should do now:

Complete the details of the child on the form I have been given

Motivate the parents to take the child to the clinic.
Accompany the child and their guardian to the clinic

Childhood Blindness Project

BICO

Blantyre Institute for Community Ophthalmology
Excellence in Community Eye Health

Queen Elizabeth Central Hospital, Blantyre

Project Co-ordinator, Blantyre Institute for Community Ophthalmology (BICO)
Cell phone number: 09241019/08302232

Figure 28: How to measure visual acuity in older children 6 years and above

The afternoon session covered the number of children expected to be blind in the area. They were taught to list children and refer them to the nearest health centre. The person in-charge of the health centre were present during training and were introduced at this point. HSAs/KIs were advised to identify, list and refer all children within two weeks after training and that after they would be called to find out how the exercise went. The detailed training manual is shown in appendix 33.

How to approach a family?

The plenary session involved simulating a family with a blind child. Trainees were divided into groups of 4, one member acting as a blind child, the second as a parent, the third as KI or HSA and the 4th as an observer. The scenario was that the family was at home and the HSAs/KI had been given a hint by a

villager (who did not want to be named) that this family had a blind child. The HSA/KII had gone to their house and indeed found that the child was there. They were asked to demonstrate/act how they would approach the family. Observations were discussed in the larger group.

Where to find blind children

The methods discussed were: door to door visits; making announcements at gatherings within the community (market place, church, weddings, funerals, village and political meetings); going into schools and asking teachers; talking to community groups (e.g. orphan carer, home based carers, women's groups); checking children in immunization clinics; organizing village talks; checking with registers of disability groups, and other social mapping techniques such as "snow balling"[263] which involves asking an affected family whether they know any other family with similar condition. It was emphasized during training that even though it may not be possible to go door to door in all villages this method had been successful in identifying blind and visually impaired children in other areas. KIs and HSAs were asked to document the method they used for each child listed.

A poster in Chichewa, with an image of a child with cataract was developed for the project, and 10 posters were given to each HSA/KI (Figure 29). They were asked to display them up in their allocated villages. The text on the poster says that if anyone in the village had seen a similar child they should take the child to the clinic.

Figure 29: Poster of a child with cataract (for display by KIs/HSAs in villages)

A substantial amount of time was spent outside the classroom in small groups of 3 facilitated by the ophthalmologist and the two ophthalmic clinical officers on role play and practical that involved techniques on how to approach a family suspected of having a blind child and to and how to measure visual acuity in a child.

Allocation of villages

The last part of the day involved confirming and allocating each trainee the required number of villages to cover an average population of approximately 2,000. The database for population of all the villages in the cluster was available. Using the original randomly selected list of villages, each KI/HSA was asked to indicate which village belonged to them, and the total population was checked from the database and recorded for them. If the randomly selected village had a population of less than 2,000, additional adjacent villages belonging to same HSA or KI were selected and added, and the total population in the database was adjusted, while retaining the same HSAs/KI name.

Forms and brochures

KIs and HSAs were taught how to complete forms for each child identified and how to refer them to the health centre. Table 25 shows all forms used during the study.

Table 25: Forms used during the study

Form number	Data collected	Who collected it	*Duplicates?
1 & 2	Demographics for KIs	Research assistant	No
6 & 7	Demographics for HSAs	Research assistant	No
3 & 8	Demographics of children listed	KIs and HSAs respectively	No
4 & 9	Referral form for children	KI and HSAs respectively	Yes
5 & 10	KI and HSAs data & lists for all children	Research assistant	No
11	Children's eye examination findings	Ophthalmologist	Yes (only if referred)
12	Daily eye examination summary	Research assistant	No
13	Registers	Research assistant	No
14	Children referral information	Ophthalmic clinical officer	Yes
15	Information about KI/HSAs post identification period	Research assistant	No
16	Interviews with parents of blind children	Research assistant	No
17	Interview with supervisors of HSAs	Research assistant	No

**these were forms that were printed and filled in duplicate by KI/HSAs. A copy was kept by the KI/HSAs, while the other one was sent to the Research assistant.*

All forms were printed in English except form 4 (KI referral form) which was translated into Chichewa because it required more information from the KIs/HSAs. KIs were required to be able to read and write but their education levels were not known before training. Because of this it was felt that if form 4 was in English some KIs may not have used the form properly.

Brochure

A brochure was given to all KIs and HSAs and had reminders of the main things taught during the training, and instructions on what to do if a child was identified (Figure 30).

Brochure with instructions on things to remember and what KIs/HSAs had to do after identifying children.

What to tell the parents:

Do NOT tell them their child is blind – this will worry them and you may be wrong

DO tell them that their child needs to be examined in a clinic which will be set up in the community shortly

How to find children who are blind:

Put up posters in public places

Talk to villages leaders

Talk to teachers

Go from house to house asking if there is a child "with problems with their vision" living there

Ask people attending men and women's groups

Make announcements in public places e.g. church, funerals, markets

What I should do now:

Complete the details of the child on the form I have been given

Motivate the parents to take the child to the clinic.

Accompany the child and their guardian to the clinic

Blantyre Institute for Community Ophthalmology

BICO

Excellence in Community Eye Health

Queen Elizabeth Central Hospital, Blantyre

Project Co-ordinator, Blantyre Institute for Community Ophthalmology (BICO)

Contact :

Childhood Blindness Project Coordinator

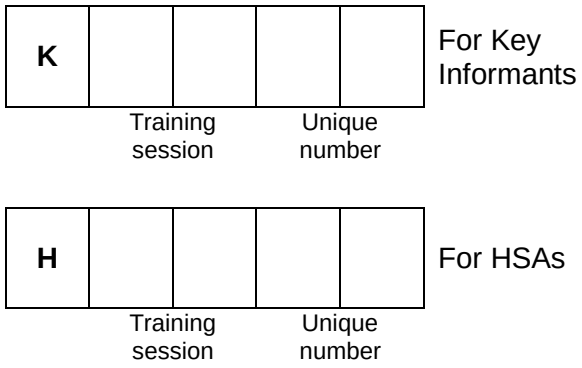
Cell phone number: 0999241019/0888302232

Figure 30: Things to remember from training

Identify cards

At the end of the training session each KI and HSA was given an identity card (ID) on the basis of the need for recognition raised during the pilot studies. The ID clearly stated that the KI/HSA had been trained in identifying blind and severe visually impaired children, giving the date of training, so that when in their assigned villages, they had evidence to back up what they said. Each KI or HSAs was allocated a unique ID number which could easily be linked to the master database that was created. The ID number had five boxes comprised of letters and numbers, starting with either “K” or “H” followed by 2 boxes for the training session number (from 01 to 06) and two boxes for the KI/HSA number (from 01 to 25). This is shown in table 26 below.

Table 26: Unique ID number



Information about the examination of children:

KIs and HSAs were told that the children they identified would be examined in the community but they were not told the date when this would take place. They were advised that they should try to finish identifying and referring children by end of the second week after training. Even though all eye examination sessions were planned to be conducted at 6 weeks after the initial training, this information was deliberately not communicated during training, for participants not to wait until 6 weeks before starting the identification, as this may have compromised their skills. The date when the team would visit the community for examination was communicated through the selected team leaders (see below).

KI/HSA team leaders

Four or five KI/HSAs from each cluster who had mobile phones were identified as team group leaders who would be the contacted person for the project coordinator.

Incentives

KIs and HSAs were given snacks and lunch during the day of training and transport costs were reimbursed. They were told they would get a t-shirt for every bilateral cataract correctly identified. Each trainee was given a certificate issued by BICO indicating that they had acquired skills.

Post training period

One week after the training the project coordinator sent text and telephone reminders to the team leaders to remind them to inform all trained KIs and HSAs to refer children they had identified to the health facility and submit their lists to the team leaders before the end of the second week. The protocol of the referrals for the identified children was that KIs/HSAs would refer children from the community to the health centre where the medical assistant/nurse would record, examine, treat and/or refer the child on to the district hospital though form 14 (appendix 25) for the ophthalmic clinical officer to examine the child, if necessary.

Compiling a master list of children identified by KIs/HSAs

At the end of the week two, the project coordinator called the group leaders to ask whether they had completed the exercise and referred all the children and had to arrange with them to get all the lists from the other KIs/HSAs so that she could compile a master list by the end of week 3 through phone calls. Week 3 and 4 were spent collecting and compiling the master's lists on forms 5 and 10 (appendix 16 and 21). The information collected during the telephone conversation included the guardian's name, child's name, age, sex, whether the child was listed as blind or not and whether they had already been to the health facility

Once the master list had been compiled, the project coordinator informed the HSA/KI group leaders at week 5 that the research team from Blantyre would visit communities at week 6 to examine all the children they had listed and referred. They were advised to bring all the children, including those who had already been to the health facility or district hospital and new ones with eye problems, to prearranged examination sites within the community.

3.3.6 Eye examination sessions

Protocol

Eye examination sessions took place from 6-7 weeks after the KIs/HSAs training, and temporary clinics were set up in schools, churches or health centres. Due to the large areas covered, several eye examination sites were required for each training session. Where KI/HSAs reported that a child could not attend the session an attempt was made to visit the child at home. For each cluster the examination team spent up to one week in the field. Examination sessions were run by an ophthalmologist (KK), two

clinical officers, and the project coordinator. Each attending KI/HSA was called to bring their updated lists of children they had identified and brought and the master list was updated. The KI/HSAs referral form for each child was then collected.

Eye examinations

Written consent (appendix 32) was obtained (signed or thumb print) for examination from the parent or guardian of each child. Verbal consent was asked from older children. Each child was given an eye examination form (appendix 11) which had a unique child code number that linked the child to the KIs/HSAs who identified them. The eye examination form used was adapted from the standard WHO clinical examination form for childhood blindness that uses the anatomical and etiological classification of causes of blindness and visual impairment in children [100].The form had additional information that was collected which included information about where the child had gone after being identified earlier on, parents level of education, and details of schooling if the child was of school going age (5 years and above).The parents were asked whether the child was in school, if so whether it was a normal or integrated school, whether the child had never started school, or dropped out of school. The clinical officer filled out the top part of the eye examination form which had general demographic data (name, age, sex, child code number, parents level of education, etc.), and then each child was referred to the Ophthalmologist who did the eye examination.

Equipment and consumables used in the examination included LogMAR illiterate E and number visual acuity charts, Lea picture charts, 6 meter rope for measuring distance, torch, batteries, 4 dioptre loupe, direct ophthalmoscope, retinoscope, retinoscopy bars, portable slit lamp, binocular indirect ophthalmoscope, + 2.2 Dioptre panretinal loupe, +20.0 Dioptre loupe, Perkins hand-held applanation tonometry, refraction box, amethocaine 0.5% and fluoresence drops 2%, cyclopentate drops 0.5%, tropicamide drops 0.5%, homatropine 2% and additional theraupeutic drops gentamyicin 0.3% eye drops; tetracycline ointment 1%, chloramphenicol 0.5%, and dexamethasone 0.5%eye drops.

Examination procedure

Examination started with a history taken from the parent or guardian, or if not present, the KI/HSA, asking about the child's eye condition. Other questions related to the age of onset, previous treatment and any associated family history or other disability. Visual acuity was then measured using a LogMAR illiterate E or number chart for older children aged 4 years and above and Lea charts for younger children. Vision was measured in each eye separately at 6 meters, using a paediatric frame and occluding lens to cover one eye at a time. If the child could not see any letters/numbers/symbols at 6

metres they were retested at 3 meters. If they could not see at this distance, perception and projection of light was assessed. Children with a visual acuity of less than 6/18 but better than 3/60 were tested with a pinhole by the clinical officer (who was a trained refractionist and low vision therapist) and subjective refraction to determine whether the problem was due to refractive error. When there was evidence of a refractive error, cycloplegic refraction was undertaken.

Anterior segments were examined with a torch or direct ophthalmoscope, a 4-dioptre loupe and a portable slit lamp. Fundi were examined, when possible, using a direct and binocular indirect ophthalmoscope. Pupils were dilated only when indicated by the history and clinical findings e.g. when retinal pathology was suspected, or a child was reported to have poor visual acuity but no abnormality could be detected on refraction and anterior segment examination. If the vision was normal and no abnormality was seen on examination pupils were not dilated. Intraocular pressures were measured in all children suspected of having glaucoma after applying amethocaine 0.5% and fluorescence 2% eye drops and using Perkins tonometry. Where this was not possible, children were referred to the eye unit in Blantyre.

Causes of visual loss and referral:

At the end of the examination an anatomical and aetiological cause for each eye was identified and the main anatomical and aetiological cause for the child was established, using guidelines given in the Coding Instructions which accompany the WHO classification. A decision was taken whether to refer the child to the hospital for refraction, surgery, medication, low vision assessment or other further assessment tests, and/or counsel the parents. In cases of referral a duplicate eye examination form was completed and the parents were counselled to give it to staff at the district hospital where they would be provided with transport reimbursement. When there was no reason for referral, parents were counselled and eye drops were dispensed, if required.

Examination forms were collected and checked by the ophthalmologist for inconsistencies or gaps before giving them to the project coordinator. The daily eye examination summary form (appendix 23) was used to reconcile the total number of forms collected with the number of children expected from the updated master list. After completing the examination sessions, selected parents of children that were identified were interviewed qualitatively about their child's condition and KIs/HSAs were interviewed in focus groups and also individually by the project coordinator to find out how the identification and referral process had gone.

Tracking of children

If the child was found to be blind, parents were interviewed at the end of the examination session. The interview asked whether the child did or did not attend the health centre after being identified and the possible reasons. Where the children were of school going age, they were interviewed regarding whether they were attending school and if so the difficulties they were facing. All children referred to Blantyre were tracked and if they attended, they had a second interview. Those that did not attend were tracked and interviewed.

KIs and HSAs interviews

The interviews were done in two phases: individual in-depth interviews (IDI's) to all HSA's and KI's present at time of eye examination at the eye examination centre, and focus groups discussion (FDG's) with groups of HSA's and KIs.

Firstly a questionnaire (appendix 26) was administered by either the clinical officer and/or childhood blindness coordinator verbally and individually to all KIs and HSAs who had attended the eye examination sessions, asking them how many children they had identified and who had/had not come for eye examinations; and the challenges faced: not able to visit all villages and the reason why, whether any parents were refusing the children to be listed, whether the time period to identify children was adequate, whether they had engagements with other more pressing issues after the training that prevented them from doing the job, and whether training they had obtained was lacking in other areas in regard to identifying blind and severely visually impaired children.

The second part of the interview involved conducting a focus group discussion session lasting 30-45 minutes with all KIs/HSAs present at a large examination centre, usually a total group of between 9 and 11 per each eye examination session. One person conducted the interview while 2 note takers took notes and summarized important findings at the end. The interviews were also recorded on a digital recorder for transcription and translation. The purpose of the discussion was to generate additional information that could not have been obtained through one to one interview but could come up in a group. Issues discussed focused on five main areas highlighted on the topic guide (appendix 26) followed by other probing questions. The areas were: how the identification process went on in general, what could make the process easier, whether they thought any blind children were missed in the allocated villages, whether any of the children they had identified and referred had been helped, and whether they thought the training was adequate.

3.3.7 Data entry and analysis

Quantitative data entry

Data collected using all the forms were centrally located and manually checked by the researcher (KK) before being processed for entry. Databases for forms 4, 5, 9, 19, 11, 14, 15 & 16 were prepared in Epidata 3.1 by the researcher and the research assistant entered the data which was then checked by the researcher. The data was then imported into STATA software (STATA 10.0, Texas) where all inconsistencies were checked and queries were referred back to the research assistant to check the original forms. The research assistant and researcher then went through original forms for corrections. Since data collected from various forms had similar information, it was usually possible to correct the inconsistency/missing data by checking similar information collected in other forms. Where required information could only be obtained in the community the KIs/HSAs or the clinical officers in the health centres and districts were contacted through telephone. Data from forms 1, 2, 3, 6, 7, 8, and 12 had basic demographic information which was entered into an Excel spreadsheet by one research assistant and checked by another research assistant. The researcher then checked the entered records versus the original data and corrected any inconsistencies. After cleaning, data from Excel were imported into software (STATA 10.0, TEXAS) and analysed for inconsistencies.
Form 13 was used as a check list and record keeping so was not entered for analysis. Finally, Form 17 had two parts: quantitative information which was entered into Epidata/ STATA and qualitative data which was analysed differently (see below).

Qualitative data entry

The study explored social -cultural factors that deter KI and HSAs from identifying blind and severely visual impaired children, and children and families of blind children from attending services even when services are offered within the community. Qualitative data collection methods, specifically focus group discussions and in-depth interviews were used to collect data from the respondents, who included children and parents of blind children, KIs and HSAs, and zonal environmental health officer.

i. To understand the social, psychological and physical impact of blindness on blind children, their families and the wider community.
ii. To understand reasons why some families with children who are blind do and do not access the services.
iii. To explore factors within families that are related to decision making processes and factors within the community and cultural barriers that deter people from accessing the health care services.
iv. To understand challenges faced by key informants and Health surveillance.

In-depth interview guides were used for the parents of blind children, children, KIs and HSAs, and environmental health officers, while Focus Group Discussion (FDG) guides were used for the families, KI and HSAs. All interviews were conducted in Chichewa, the local language. Notes were taken during the actual interview, and the conversation was recorded on a digital voice recorder. The recorded information was transcribed verbatim into Chichewa and then translated into English. Thematic analysis was used as a tool for data analysis. Most of the data was descriptive; major themes from individual in-depth interviews and FDG's were coded & triangulated by two staff, and findings were compared between the two; where there was a disagreement, the joint review of the material settled the matter. The analysis was done by identifying recurrent patterns and themes from the conceptual coding framework (appendix 6) and the transcripts. All English transcripts were read in their entirety to identify themes that re-occurred across the focus groups and in-depth interviews. Reports were produced from the analysed data with direct quotations from the participants (appendix 6).

Statistical analysis

Information from training sessions, eye examination sessions and post training interviews were analysed separately using STATA/ SE 10.1 (Texas, USA). Chi squared tests were used to derive associations between different variables and their significance. Paired t test was used to compare the means. Linear regression was used to predict factors that were associated with healthy facility attendance, using the following variables: age, sex, whether blind or not district, who identified the child (KI or HSAs), and mothers educational level. Where the association between two variables was significant on chi square, the variables were inserted in the model for Univariate logistical regression and statistically significance was derived (P values & Odds ratio). Based on statistical advice at that time (by International Centre for Eye Health -ICEH statistician), only variables that remained statistically significant at 95% on univariate logistical regression were put in the model for multivariate regression. It is important to state that the current practice is that all variables should be inserted in the model.

The following definitions were used during the analysis:

- Normal vision: visual acuity of 6/18 or better in the better eye
- Visual impairment (VI): visual acuity of less than 6/18 but >=6/60 in the better eye
- Severe visual impairment (SVI): visual acuity of less than 6/60 but >=3/60 in the better eye
- Blind: visual acuity of <3/60 in the better eye
- Not Blind: visual acuity of >= 3/60 in the better eye
- Couldn't determine: children believed not to be blind but visual acuity could not be categorized
- Unilateral blindness: visual acuity of <3/60 in one eye

- Education levels
    I. None or informal-refers to not attending any classroom formal education that can make one read or write
    II. Some education-refers to attending primary education up to level 8
    III. A lot-refers to attending secondary or tertiary education

<u>The following information was obtained from training and identification sessions.</u>

1. Details of training sessions (total number of clusters, where, who trained)
2. Comparison of the following variables between KIs and HSAs trained: Sex, age, education levels, villages covered, and number of blind children identified by each group.
3. Characteristics of listed children who did and did not attend eye examination sessions.
4. Logistical regression
    a. factors associated with attendance at eye examination sessions
    b. characterizes of KIs and HSAs who did and did not attend eye examination
5. Barriers to identifying children

<u>The following information was obtained from eye examination sessions.</u>

1. Demographics of children examined and parents' educational levels
2. Number of blind children identified by KIs and HSAs
3. Mean age of children identified by KIs versus HSAs
4. Proportions of prevalence and causes of blindness
5. Characteristics of children that did and did not attend health centre
6. Frequency and cumulative distribution (bar charts and histograms):
7. Categorical associations (chi square)
8. Univariate and multivariate analysis

Literature search strategies

A variety of sources provided the literature that has been used in this thesis. These include known paediatric ophthalmology and epidemiology books, and online searches of published and peer reviewed articles. The database used included the following Pub Med, Web of science, Embase, Central, Medline, the Cochrane library (eye and vision group) and other educational resources. The detailed search on articles on blindness in children covered the period from 1987 to early 2014, as the thesis was expected to be submitted by end of 2014. This was unfortunately not the case, as I was involved in a series of accidents between 2011 and 2014. Firstly, a laptop with all the data was stolen in 2011, and the write up and analysis had to redone over a period of 6-12 months, in Malawi. This was followed up by trauma in 2013; I tripped and sustained a fractured right arm, that required 3 months of immobilisation with plaster of Paris. After I recovered and started catching up with the thesis write up, I was involved in a much more serious accident: a fire accident that took place in a hotel in Malawi in the middle of 2014; resulting in a life-threatening condition (second and third degree burns covering 32% of body weight), admission in intensive care burns unit for many days, followed up by skin grafts, and psychological trauma. The long-term hospital admission, and rehabilitation, took two years to fully recovery, before I could submit the thesis in 2016. The 2016 search update mainly focused on new articles that mentioned blindness in children.

The following search terms were used for the original and updated search:

For prevalence, incidence and causes

-blindness, low-vision, vis* impair, vis* disab, sight impair*, partial sight, global

-child*, schoolchild, infant, childhood, adolescent, juvenile*, new born

-cataract, lens*, near opacity*, congenital*, inherit*, juvenile*, paediatr*, pediatr*, child*, adolesc*, juvenile*, minor*, infant*, lensectomy, phacoemulsif*, operat*, surg*, implant, heriditary, genetics, genes, autosomal*

-key informant, key*, informant*

-Trial, random*, blind*, clinical trial

For Health systems, primary health care, primary eye care and education interventions

-PHC, PEC, eye clinic*, eye-clinic, special needs, inclu*, inclusive*, CBR, rebabilat*, community based rehab*, magnifiers*, low vision*; alma ata, health seeking behaviour, glasses, spectacles, read*, visual*, acuity*, delays, follow up, obstacles.

Outcomes-Key informant, randomised, community study, disability, trial*, examination*, referral, clinical*

Areas

low income country*, middle income country*, developed countr*, developing countr*. devel*

In addition, the websites of the following organisations that have several articles that deal with blindness in adults were searched and accessed for some of the facts: International Centre for Eye Health, Community Eye Health Journal, Kilimanjaro centre for community ophthalmology, open resource centre for east Africa, International Agency for the prevention of blindness (IAPB), and Sightsavers.
Although no major systematic research was conducted from 2014 to 2015, there was a search for open access journals that mentioned review of blindness in children or primary eye care and had been published in Pub-med. In particular, all peer reviewed article that mentioned key informant and blindness in children were accessed and reviewed.

CHAPTER 4

4 Results

Overview:

This section shows results from the two districts included in the main study (Zomba and Mangochi), presented in eight sections (Section 4.1.to 4.8). These include 1) training findings; 2) overall eye examinations findings; 3) causes of blindness and severe visual impairment; 4) referrals and action taken; 5) barriers; 6) attendance of children at a health centre; 7) interviews with parents of blind children; and finally, 8) school attendance.

Fieldwork in the two districts took 15 months, from February 2009 to April 2010. Fieldwork in Zomba took 6 months from February to July 2009 during the dry season. A short break in August was used by the field team for meetings to reflect on the challenges that were encountered in Zomba and strategize on how they could be overcome in Mangochi. Fieldwork in Mangochi took 9 months, from September 2009 to 2010, some of which was during the rainy season. No fieldwork was possible in December as roads were impassable. The rains made it difficult not only for the survey teams to travel to rural areas in Mangochi but also for the HSAs/KIs and the children they identified to travel to the examination sites. A section of one cluster was not accessible due to flooding and screening was not conducted.

4.1 Training

12 training sessions, (6 for HSAs and 6 for KIS) in 12 clusters were conducted as planned, 6 in Zomba district and 6 in Mangochi district. The total population of villages covered by the KIs was 263,802 (52.2% of the total) while that of HSAs was 279,618 (53.7%% of the total) (Table 27). In Mangochi coverage was higher than in Zomba (58.9% vs 47.2%), but the difference was not significant (P>0.05).

Table 27: Population covered by KIs and HSA

	Key Informants				Health Surveillance Assistants				Overall			
	Population of all ages			Child pop	Population of all ages			Child pop	Population of all ages			Child pop
District	Total all	Villages covered	% covered	In villages covered	Total all	villages covered	% covered	In villages covered	Total all	Pop. of villages covered	% covered	In villages covered
Zomba	253902	121149	47.7	50883	270751	126692	46.8	53211	524653	247841	47.2	104093
Mangochi	251705	142653	56.7	59914	249863	152926	61.2	64229	501568	295579	58.9	124143
Total	505607	263802	52.2	110797	520614	279618	53.7	117440	1026221	543420	53.0	228236

310 individuals were trained: 151 (48.7%) were KIs and 159 (51.3%) were HSAs. 167 (54%) were males. The cluster sizes, HSAs and KI numbers for each cluster, and for each district, are shown in Table 28.

Table 28: Training sessions, location and who trained

Training session	Location (District)	Cluster name	Who trained		Male		Female		Total
				population	N	%	N	%	N
1	Zomba	Likangala	KI	40,086	18	58%	13	42%	31
2	Zomba	Mayaka	HSA	50,596	16	52%	15	48%	31
3	Zomba	Chingale	KI	39,233	15	52%	14	48%	29
4	Zomba	Jali	HSA	39,418	15	50%	15	50%	30
5	Zomba	Domasi	KI	41,830	15	58%	11	42%	26
6	Zomba	Thondwe	HSA	36,678	17	57%	13	43%	30
7	Mangochi	Chilipa	KI	57,509	12	46%	14	54%	26
8	Mangochi	Malombe	HSA	52,392	11	37%	19	63%	30
9	Mangochi	Nkumba	KI	40,454	10	53%	9	47%	19
10	Mangochi	Namwera	HSA	46,534	14	70%	6	30%	20
11	Mangochi	Lungwena	KI	44,690	13	72%	5	28%	18
12	Mangochi	Monkey Bay	HSA	54,000	11	55%	9	45%	20
Total KIs				263,802	81	54%	70	46%	151
Total HSA				279,618	86	54%	73	46%	159
Zomba				247,841					
Mangochi				295,579					
Grand Total					167	54%	143	46%	310

Even though the target was to have an equal number of male and female KI, community leaders selected more males than females. The number of KIs and HSAs trained per 100,000 children in each district and overall is show in Table 29.

Table 29: Total numbers of KIs and HSAs trained from each district

	Key Informants			Health Surveillance Assistants			Overall		
District	Trained	Child pop	Trained per 10,000 children	Trained	Child pop	Trained per 10,000 children	Trained	Child pop	Trained per 10,000 children
Zomba	86	50,883	16.9	91	53,211	17.1	177	104093	17.0
Mangochi	65	59,914	10.8	68	64,229	10.6	133	124143	10.7
Total	151	110,797	13.6	159	117,440	13.5	310	228236	13.6

The rate of trained personnel / 10,000 children was almost one and half times higher in Zomba than in Mangochi. The average cluster size was approximately 45,000 and 22-25 HSAs/KIs were trained per cluster to cover a catchment population of 2,000-3,000. For the same number of KIs/HSAs sessions slightly more KIs/HSAs were trained in Zomba (177) in comparison to Mangochi (133). The average number of KIs/HSAs per training session in Zomba was 30 in Zomba while in Mangochi it was 22. The gender, median age and the age range of the HSAs/KIs from the two districts are shown in Table 30.

Table 30: Age summary of KIs and HSAs

	Zomba		Mangochi		Total
Total HSAs trained	N	%	N	%	159
	91	57.2	68	42.8	
Median age (yrs)	27.5		30.4		28.7
Range (yrs)	22-45		20-52		20-52
% Male	52.7		57.4		54.7
Total KIs trained	No.	%	No.	%	151
	86	57.0	65	43.0	
Median age (yrs)	34.2		33.8		34
Range (yrs)	21-60		21-62		21-62
% Male	55.8		51.5		53.9
Total HSA's & KI's	No.	%	No.	%	310
	177	57.1	133	42.9	

KIs tended to be on average older (median age 34 yrs.) than HSAs (median age 28.7 yrs.). The educational levels of KIs and HSAs are shown in Table 31.

Table 31: Education levels of KIs and HSAs

Education level	Key Informants		Health Surveillance Assistants		Total		Chi2	P value
	N	%	N	%	No	%		
Post-secondary	0	0	19	11.9	19	6.1		
Secondary	56	37.1	137	86.2	193	62.3		
High primary	77	51.0	3	1.9	80	25.8	139.3	0.001
Low primary	16	10.6	0	0	16	5.2		
None	2	1.3	0	0	2	0.6		
Total	151	100	159	100	310	100		

HSAs had much higher qualifications than KIs and this was statistically significant (Chi squared test, P=0.001). HSAs with only a higher primary (25.8%) were of an older generation before minimum qualification (secondary school certificate) was introduced. 37.1% of the KIs attained secondary education. Despite having strict selection criteria that required them to be able to read and write, 2 KIs reported having no formal education and when tested, could not read and write. The education levels of KIs and HSAs were further analysed to see whether there was a gender difference in educational levels among KIs and HSAs and as Table 32 shows there was no statistically significant difference among both groups (KIs: P=0.082; HSAs: P=0.183).

Table 32: Comparison of education levels between males and female KIs and HSAs

	Key Informants (N=151)							
	Male		Female		Total		Chi square	P value
Education level	N	%	N	%	No	%		
Post-secondary	0	0%	0	0%	0	0%		
Secondary	38	46.3%	18	26.1%	56	37.1%		
High Primary	35	42.7%	42	60.9%	77	51.0%	6.7	0.082
Low primary	8	9.8%	8	11.6%	16	10.6%		
None	1	1.2%	1	1.4%	2	1.3%		
Total	82	100%	69	100%	151	100%		
	Health Surveillance Assistants (N=159							
	Male		Female		Total			
Education level	N	%	N	%	N	%		
Post-secondary	14	16.1%	5	6.9%	19	11.9%		
Secondary	71	81.6%	66	91.7%	137	86.2%		
High Primary	2	2.3%	1	1.4%	3	1.9%	3.39	0.183
Low primary	0	0%	0	0%	0	0%		
None	0	0%	0	0%	0	0%		
Total	87	100%	72	100%	159	100%		

There was no significant difference in education levels by district between KIs and HSAs. The community occupational roles of the KIs, which were all mutually exclusive, are shown in Table 33.

Table 33: Existing roles of KIs in the community

	Male		Female		Total	
	N	%	N	%	N	%
Village development committee (VDC) member	6	7.3	1	1.4	7	4.6
Religious leader	2	2.4	4	5.8	6	4.0
Health volunteer	69	84.1	51	73.9	120	79.5
Community based organization	1	1.2	3	4.3	4	2.6
Orphan carer	0	0	1	1.4	1	0.7
Human rights	1	1.2	0	0	1	0.7
Other	3	3.7	9	13.0	12	7.9
Total	82	100	69	100	151	100

79.5% of the volunteers were already health volunteers involved in other projects.

4.2 Eye Examinations

Characteristics of children listed

The number of children listed and those that attended the eye examination sessions is shown in Table 34. Children on the master list refers to those who were identified by HSAs/KIs up to 4 weeks after training and who had submitted the names by telephone to the childhood blindness coordinator. Children on the KI/HSA list were either identified by 4 weeks but their details were not submitted, or they were identified between the end of week 4 and week 6, after being told the team would visit community. Children labelled as “new not listed” refers to those that attended for examination but whose name was not on any list.

Table 34: Children listed and examined

	KI		HSA		ALL	
	No	%	No	%	No	%
Master List	265	56	181	57	446	56
KI/HSA List	203	42	110	35	313	39
New Not listed	10	2	26	8	36	5
Total	478	100	317	100	795	100

A total of 795 children were listed or newly identified, 550 (69%) of whom were examined. KIs listed 478 children (60%, average 3.1 / KI) while HSAs listed 317 children (40%, average 2.1 / HSA). Only 5% of children overall were examined but not listed. Among the listed children 440 (55%) were from Zomba

and 355 (45%) from Mangochi. Table 35 shows how the children were listed by KIs and HSAs (blind /not blind).

Table 35: Whether listed as blind by KIs or HSA's

	KI		HSA		ALL	
	No	%	No	%	No	%
Listed as blind	79	16.5%	59	18.6%	138	17.4%
Listed Not blind	383	80.1%	234	73.8%	617	77.6%
Not indicated	16	3.3%	22	6.9%	38	4.8%
Total	478	100.0%	317	100.0%	795	100.0%

Only a small proportion (17.4%) of all children was listed as blind (16.5 for KIs and 18.6% for HSAs).

Table 36 shows the characteristics of KIs & HSAs who did and did not list any children.

Table 36: Characteristics of KI/HSAs associated with listing of children

		Did not list any children		**Did list children**		**Total**		**Chi square**	**P value**
		N	%	N	%	N	%		
By cadre	KIs	30	20%	121	80%	151	100		
	HSAs	65	41%	94	59%	159	100	16.09	0.001
By gender	Males	49	29%	118	71%	167	100		
	Females	46	32%	97	68%	143	100	0.29	0.59
By cadre and gender	KI males	18	22%	63	78%	81	100		
	KI females	12	17%	58	83%	70	100	0.61	0.435
	Subtotal	30	20%	121	80%	151	100		
	HSA males	31	36%	55	64%	86	100		
	HSA females	34	47%	39	53%	73	100	1.81	0.178
	Subtotal	65	41%	94	59%	159	100		
By district	Zomba	50	28%	127	72%	177	100		
	Mangochi	45	34%	88	66%	133	100	1.11	0.291
	Total	**95**	**31%**	**215**	**69%**	**310**	100		

20% of all KIs and 41% of all HSAs trained did not list any children. HSAs were significantly less likely to list children than KIs (Chi2, P<0.001). Gender of the KIs/ HSAs and the district where KI/HSAs came from was not associated with listing of children. Some of those that did not list children reported that they did not find any in their allocated catchment area, while others reported they had not completely covered

all their villages. Unfortunately, this information was obtained during interviews, and only selected KI and HSAs were involved. The age group of all children listed and their gender are shown in Table 37.

Table 37: Age group, gender of children listed and whether listed by KIs/HSAs

	Key Informants				Health Surveillance Assistants				All	
	Male	Female	Total		Male	Female	Total		Total	
	N	N	N	%	N	N	N	%	N	%
<1 year	9	11	20	4.2%	6	9	15	4.7%	35	4.4%
1 to 5 years	72	65	137	28.7%	62	51	113	35.6%	250	31.4%
6 to 10 years	77	72	149	31.2%	45	53	98	30.9%	247	31.1%
11 to 15 years	100	72	172	36.0%	54	37	91	28.7%	263	33.1%
Total	258	220	478	100%	167	150	317	100%	795	100%

Only 4.4% of all children listed were aged less than 1 year. Of all children listed 33.1% were older than 10 years of age. The mean age of children listed by KIs was 8.2 years while mean age of children listed by HSAs was 7.4 years but the difference was not statistically significant. Males contributed to 54% of children identified by KIs and 53% of children identified by HSAs. There was no significant difference in gender of children between those listed by KIs and HSAs (P=0.72, Chi2). The proportion of children listed by KIs aged <6 years was 32.9% compared with 40.3% of those listed by HSAs, but the difference was not significant. KIs were more likely to list older children (11-15 years), than HSAs.

Examination sessions:

Table 38 shows the total planned and conducted number of eye examination sessions and how many children were examined.

Table 38: Planned versus conducted eye examination sessions

Examination Sessions	Planned	Conducted	Total children examined	%
KI	29	27	326	59%
HSA	19	19	224	41%
Total	48	46	550	100%

Eye examination sites were only organized in week 4 after knowing the number of children that had been listed on the master list. The target was to have one examination site for every 10-12 children reported listed. Using the information obtained 29 examination sites were organized for the 6 KI clusters and 19 sites for the 6 HSAs clusters. Only 27 out of 29 sites (93.1%) of the 6 KIs clusters had eye examination sessions while all 19 sites of the 6 HSAs clusters all had eye examinations. Among the KI sites that were not visited, one in Zomba (Chisi Health post) was a small island on Lake Chilwa (Figure 20), that was only accessible by boat. Unfortunately, hiring a boat was going to be very expensive, and therefore it was decided not to visit the island. The other site not visited was Nankhwali health centre in Mangochi, as it had experienced floods during the planned screening dates.

Among the 795 children listed (as shown in Table 37), only 550 reported for the eye examination session within the community. The age group of children examined, who identified them and their sex and district are shown in Table 39.

Table 39: Age groups of children examined, by sex, district, and who identified them.

	<1 years		1-5 yrs		6-10 yrs		11-15 yrs		All			
Who identified	N	%	N	%	N	%	N	%	N	%	Chi	P
HSAs	9	4.0%	82	36.6%	69	30.8%	64	28.6%	224	100	5.9	0.115
KIs	20	6.1%	98	30.1%	96	29.4%	112	34.4%	326	100		
Sex of children	N	%	N	%	N	%	N	%	N	100		
Males	12	4.0%	98	32.8%	83	27.8%	106	35.5%	299	100	5.5	0.138
Females	17	6.8%	82	32.7%	82	32.7%	70	27.9%	251	100		
District												
Zomba	21	7.0%	95	31.7%	79	26.3%	105	35.0%	300	100	8.78	0.03
Mangochi	8	3.2%	85	34.0%	86	34.4%	71	28.4%	250	100		
Total	29	5.3%	180	32.7%	165	30.0%	176	32.0%	550	100		

There was no difference in age groups among children examined, between children identified by KIs and HSAs (P=0.115), and between boys and girls (P=0.138). There were more children in the younger age groups in Zomba than Mangochi (P=0.03).The age distribution of males and females were similar, with mean age of boys being 7.8 and girls 7.3. The least number of children was in the group aged less than 1 year (5.3%), and this is what would be expected. Children less than one year are too young to have cornea scarring related Vitamin A deficiency disorders (VADD). Key Informants identified more children aged below 1 years than HSAs (20vs 9), but overall the mean age of children identified by KIs was not statistically significant from the mean age of children identified by HSAs (7.7 versus 7.4 years), (P=0.41).

The characteristics of children who attended eye examination sessions (at 6 weeks) are shown in Table 40.

Table 40: Characteristics of children that did and did not attend eye examination session

		Total	Attended		Didn't attend			
		N	N	%	N	%	Chi2	P
Who listed the child	KI	478	326	68.0	152	32.0		
	HSA	317	224	71.0	93	29.0	0.8	0.37
Gender of who listed the child	KI Male	257	177	68.9	80	31.1		
	KI Female	221	148	67.0	73	33.0		
	HSA Male	177	123	69.5	54	30.5	1.41	0.7
	KI Male	257	177	68.9	80	31.1		
Gender of child:	Male	425	299	70.4	126	29.6		
	Female	370	251	67.8	119	32.2	0.59	0.44
Age of child:	0-5 years*	285	210	73.7	75	26.3		
	6-10 years	247	156	63.2	91	36.8	5.7	0.59
	11-15 years	263	184	70.0	79	30.0		
District	Zomba	440	300	68.2	140	31.8		
	Mangochi	355	250	70.4	105	29.6	0.46	0.5
	Total	795	550	69.2	245	30.8		

*among the children aged 0-5, 35 were aged <1: 30 attended and 5 did not.

Among all the children that attended the eye examination, 54.4% (CI 50.0-58.5) were boys and 45.6 % (CI 41.4-49.9) were girls. Attendance at an eye examination centre was not associated with who listed the child whether KI or HSAs (P=0.37), or the gender of the KI/HSA (P= 0.70), gender of the child (0.44), age of child (0.59) or by district (P=0.50). The proportion of male children listed who attended eye examination was the same as the proportion of female children listed. There was no statistically significant difference in the mean age between those that attended and those that did not attend examination sessions (mean 7.6 and 8.2 respectively, P=0.09). Information on how the children that attended eye examination sessions were identified is shown in Table 41.

Table 41: How children were identified

Method used	Key Informants		Health Surveillance Assistants		Total	
	N	%	N	%	N	%
Door to door	299	91.7%	183	81.7%	482	87.6%
Under-five clinic/immunization day	7	2.1%	22	9.8%	29	5.3%
School visit	17	5.2%	4	1.8%	21	3.8%
Village meeting	3	0.9%	13	5.8%	16	2.9%
Church announcement			1	0.4%	1	0.2%
Market visit			1	0.4%	1	0.2%
Total	326	100.0%	224	100.0%	550	100.0%

Door to door visits were the most successful method used to identify children, 91.7% of all children identified by KIs and 81.7% by HSAs. Table 42 shows the summary of the children examined by case finder and district.

Table 42: Summary of children examined

Who Trained	Children examined, by case finder			Children examined, by district	
	N	%			%
KI	326	59%	Zomba	300	55%
HSA	224	41%	Mangochi	250	45%
Total	550	100%		550	100%

The proportion of children examined who were found to be blind/SVI from the total number of children listed by KIs and HSAs is shown in Table 43. The success rate has been defined as the percentage of children that were listed/identified as blind/SVI and who were confirmed as blind by the examiner (KK). The accuracy rate has been defined as the percentage of the children confirmed blind among those listed as blind, which reflects the ability of the KIs and HSAs to assess the child's visual status. In comparing false positive (children identified as blind but who were not blind) between KIs and HSAs only children that were listed as blind were considered for analysis. Table 43 shows success and accuracy rates.

Table 43: Success and accuracy rates

	Key Informants	Health Surveillance Assistants	Total	P Value
Total Examined	326	224	550	0.85
Confirmed blind/SVI	50	33	83	
% Blind/SVI (success rate)	15.3%	14.7%	15.1%	
Total listed as blind	51	32	83	0.88
Confirmed blind	37	22	59	
% confirmed blind (accuracy rate)	72.5%	68.8%	71.1%	
False positives	27.5%	31.2%	29.9%	

There was no difference in proportions of children examined versus children confirmed blind between KIs and HSAs (P=0.85) and also in total children listed as blind versus confirmed blind (P=0.88).In other words neither group had better skills in listing children as blind. The table shows that only 15.3% of

children identified by KIs and 14.7% identified by HSAs were confirmed blind/SVI on examination. Among the children that were listed as blind by KIs. 27.5% were not blind (false positives) while among children listed as blind by HSAs, 31.2% were not blind. The number of HSAs or KIs that needed to be trained (NNT) to identify one blind/SVI child was calculated and results are shown in Table 44.

Table 44: Number of HSA's/KI's needed to train per blind child

	Total trained and contacted	Number identified blind/SVI	Number needed to train (NNT) /per blind child	Number of blind/SVI children per 10 trained
HSAs	159	33	5	2
KIs	151	50	3	3
Total	310	83	4	

Fewer KIs than HSAs needed to be trained to detect one blind child (3 KIs vs 5 HSAs). 6 KIs that were not contacted and did not give their children's list have been included in the analysis. The prevalence of blindness in children was calculated, by method of case detection and overall, from the numbers of children confirmed as blind/SVI divided by estimates of the child population covered. As shown in Table 45 both groups identified fewer children than expected.

Table 45: Expected versus confirmed number of blind children by district

Who trained	Adult pop covered	Child pop covered	Blind children expected	Blind children identified	% of expected
Zomba					
KI	121149	50883	41	29	71.2
HSA	126692	53211	43	10	23.5
Subtotal	247841	110797	83	39	46.8
Mangochi					
KI	142653	59914	48	8	16.7
HSA	152926	64229	51	12	23.4
Subtotal	295579	124143	99	20	20.1
Both districts					
KI	263802	110797	89	37	41.7
HSA	279618	117440	94	22	23.4
TOTAL	543420	228236	183	59	32.3

*comprises of 42.0%of adult population.

**Extrapolation of prevalence estimate (8 per 10,000) using 2008 Malawi under-five mortality rates (110 per 1,000)[28].

Table 46 shows the obtained prevalence of blindness.

Table 46: Prevalence estimates of blindness

Who trained	Blind found	Child pop covered	Prevalence estimate /1,000 children	95% CI	P value
Zomba					
KI	29	50883	0.57	0.50-0.64	0.01
HSA	10	53211	0.19	0.15-0.23	
Subtotal	39	104093	0.37	0.33-0.41	
Mangochi					
KI	8	59914	0.13	0.10-0.16	0.46
HSA	12	64229	0.19	0.16-0.22	
Subtotal	20	124143	0.16	0.14-0.18	
Key Informants					
KI Zomba	29	50883	0.57	0.50-0.64	0.001
KI Mangochi	8	59914	0.13	0.10-0.16	
Both districts					
KI	37	110797	0.33	0.27-0.39	0.03
HSA	22	117440	0.19	0.13-0.25	
TOTAL	59	228236	0.26	0.19-0.32	

The prevalence of blindness calculated using the number of blind children found by KIs was significantly higher than that of children found by HSAs (3.3/10,000 versus 1.9 /10,000) (P=0.03), but both figures were lower than the expected figure (8/10,000) obtained using under-five mortality rates as a proxy. More people trained per head of child population leads to a higher prevalence.

4.3 Causes of blindness and severe visual impairment

This section describes the visual acuity findings in the children examined and the causes of visual loss in other one or both eyes.

Bilateral blindness and severe visual impairment

Visual acuity described here referred to the presenting visual acuity in the better eye (Table 47).

Table 47: Visual acuity

Visual acuity better eye*	N	Percent
Normal (6/18 or better)	401	72.9
Visual impairment (<6/18-6/60)	41	7.5
Severe Visual impairment (<6/60-3/60)	24	4.4
Blind (<3/60)	59	10.7
Believed sighted but could not be tested	25	4.6
Total	550	100

*Presenting visual acuity in the better eye

72.9% of all children examined were normal and only 10.7% were blind. A further 11.9% had severe visual impairment or were visually impaired. The association between categories of visual acuity and gender, age, who listed, district, and history of previous surgery is shown in Table 48.

Table 48: Association between categories of VA and gender, age, who listed, and district

	Normal		VI		SVI		Blind		Others*		Total	
	N	%	N	%	N	%	N	%	N	%	N	P value
Who listed:												
KI	163	72.8%	13	5.8%	11	4.9%	22	9.8%	15	6.7%	224	
HSA	238	73.0%	28	8.6%	13	4.0%	37	11.3%	10	3.1%	326	0.216
Gender:												
Boys	224	74.9%	20	6.7%	12	4.0%	33	11.0%	10	3.3%	299	
Girls	177	70.5%	21	8.4%	12	4.8%	26	10.4%	15	6.0%	251	0.525
Age:												
<1 yr	10	34.5%	0	0.0%	0	0.0%	8	27.6%	11	37.9%	29	
1-5 yrs	134	74.4%	7	3.9%	1	0.6%	24	13.3%	14	7.8%	180	0.001
6-11 yrs	130	78.8%	15	9.1%	9	5.5%	11	6.7%	0	0.0%	165	
11-15 yrs	127	72.2%	19	10.8%	14	8.0%	16	9.1%	0	0.0%	176	
District:												
Zomba	208	69.3%	24	8.0%	17	5.7%	39	13.0%	12	4.0%	300	
Mangochi	193	77.2%	17	6.8%	7	2.8%	20	8.0%	13	5.2%	250	0.107
Previous surgery												
None	400	73.4%	41	7.6	22	4.1	56	10.3	24	4.4%	543	
Cataract	0	0.0%	0		2	33.3%	3	50.0%	1	16.7%	6	
Removed	1	100.0%	0								1	
Total	401	72.9%	41	7.5%	24	4.4%	59	10.7%	25	4.5%	550	

*refers to children that could not be ascertained for various reasons.

Not all children could have accurate visual acuity assessment. Among the children that could be examined, visual acuity was associated with age (P=0.001, chi2), with the youngest age group (<1years) being the age group with the highest proportion of children who were blind (27.6%). Visual acuity was not associated with gender (P=0.525), who listed the child (P=0.216), and district (P=0.107).

Anatomical and etiological findings

The anatomical causes by level of visual loss are shown in Table 49.

Table 49: Anatomical causes categorised according to visual acuity

Anatomical site of abnormality		Visual impairment		Severe visual impairment		Blind		Total	
		N	%	N	%	N	%	N	%
Whole eye	Phthisis					6	10.2	6	4.8
	Microphthalmos			1	4.2	2	3.4	3	2.4
	Disorganized			0	0	3	5.1	3	2.4
Cornea	Corneal scar	9	22.0	2	8.3	5	8.5	16	12.9
	Keratoconus	1	2.4			0		1	0.8
	Cornea - other	1	2.4			1	1.7	2	1.6
	VKC*	1	2.4					1	0.8
Lens	Cataract	2	4.9	4	16.7	11	18.6	17	13.7
	Pseudophakia			2	8.3	1	1.7	3	2.4
Uvea	Aniridia					1	1.7	1	0.8
	Coloboma			1	4.2			1	0.8
	Uveitis	1	2.4					1	0.8
Optic nerve	Optic atrophy	1	2.4	5	20.8	5	8.5	11	8.9
Retina	Retinal dystrophy	1	2.4			0		1	0.8
	Retinoblastoma					2	3.4	2	1.6
	Albinism	6	14.6	2	8.3	0		8	6.5
	Retina, other	1	2.4	1	4.2	2	3.4	4	3.2
	Refractive error	12	29.3	4	16.7	2	3.4	18	14.5
Eye appears normal	Amblyopia	1	2.4					1	0.8
	Cortical	1	2.4	1	4.2	17	28.8	19	15.3
	Nystagmus	3	7.3	1	4.2	1	1.7	5	4.0
Total		41	100.0	24	100	59	100	124	100.0

*VKC=Vernal keratoconjunctivitis

Refractive error was the commonest cause of visual impairment (29.3%) followed by corneal scar (22.0%) and albinism (14.6%). Optic atrophy (20.8%), refractive errors (16.7%) and cataract (16.7%) were the commonest causes of severe visual impairment (SVI). Cortical blindness was the commonest cause of blindness (28.8%) followed by cataract (18.6%) and phthisis (10.2%). Overall cortical was the number one cause of visual loss (15.3%), followed by refractive error (14.5) and un-operated cataract (13.7%). Despite having cataract surgery, 3 children remained blind or severely visual impaired. The anatomical sites of abnormality among children who were blind or severely visually impaired were categorized by age group (<6 years and >=6 to 15years), and this is shown in Figure 31.

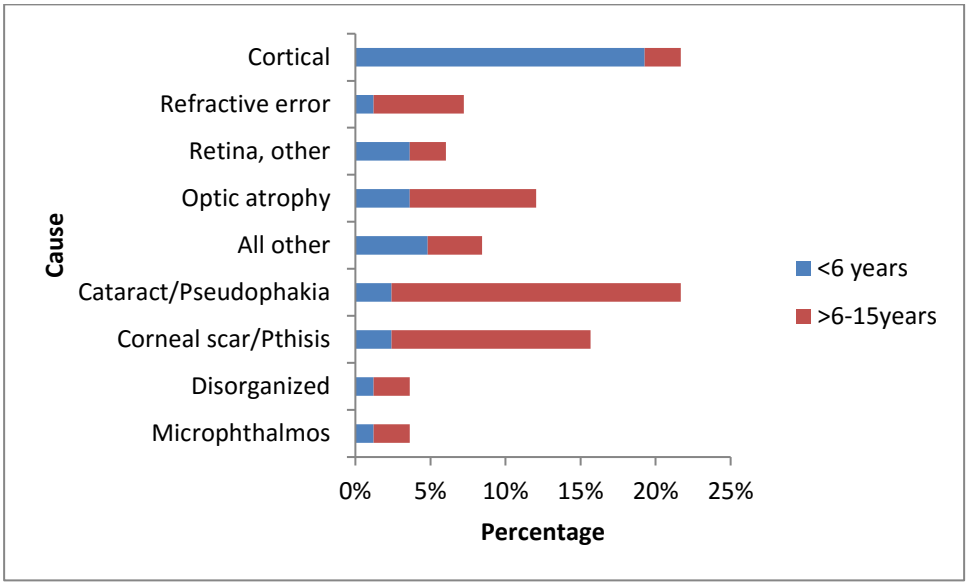


Figure 31: Causes of blindness by anatomical site, according to age groups

Cortical blindness seconded by cataract/pseudophakia was the commonest causes in all age groups. Cortical blindness was commonest in infants (75%), but was rare in the oldest age group (1 child, 3.3%). There was a total of 13 cases of corneal scar and phthisis (which is often secondary to corneal pathology). Among these, 8 children were older aged 11-15 years and only 1 child was less than 6 years. Only 6 children had refractive errors. Figure 32 shows anatomical causes among the blind children, categorized according to their gender.

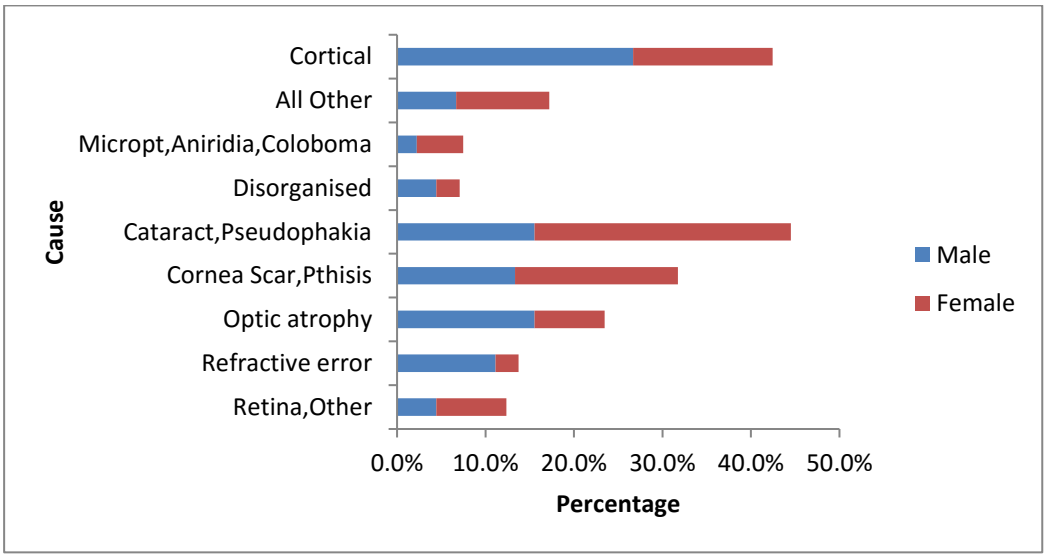


Figure 32: Causes of blindness by anatomical site, categorized according to gender

Cortical blindness was more common in boys than girls (26.7% vs. 15.8% respectively) while cataract/pseudophakia was common in girls than boys (28.9% vs. 15.6% respectively) but the numbers were too small for statistical significance analysis.

Figure 33 shows the anatomical site of abnormality in blind and severely visually impaired children, according to who identified the child (KIs vs HSAs).

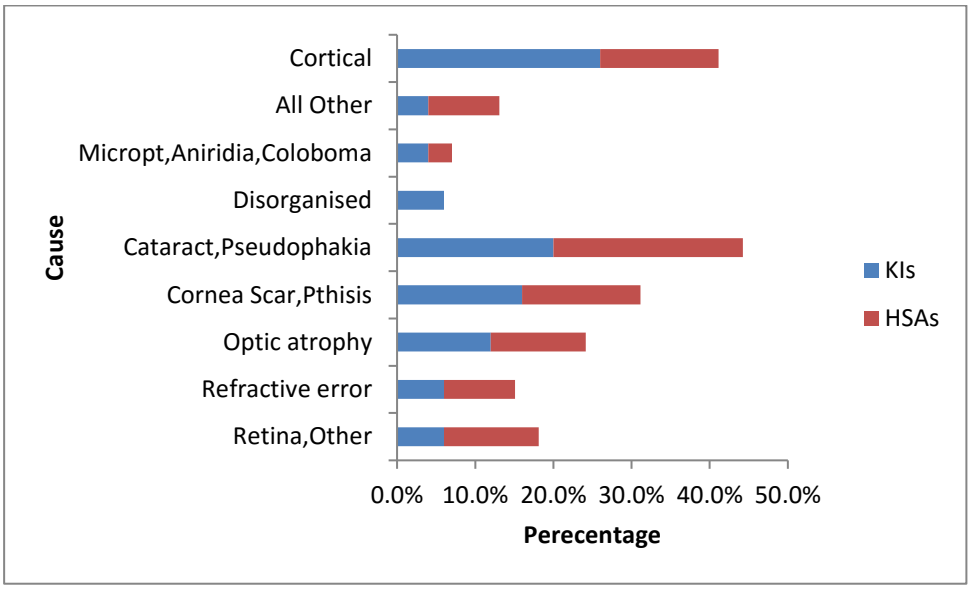


Figure 33: Causes by anatomical site and according to who identified the children

There was no difference in the anatomical abnormalities of children identified by that KIs and HSAs, except for cortical blindness where KIs identified more children than HSAs. However, the numbers were small for individual comparisons among the anatomical diagnoses between the two groups. Table 50 shows which cases were potential avoidable (preventable or treatable) based on the anatomical diagnosis.

Table 50: Potential avoidable causes of blindness

Preventable or treatable	No	%
Definitely preventable (phthisis, disorganized, cornea scar)	17	20.5
Definitely treatable (cataract, pseudophakia)	28	33.7
Not preventable or treatable (all other causes includes cortical blindness) *	38	45.8
Total	83	100.0
Total avoidable	45	54.2

*some cases of cortical blindness had a clear history of being potentially preventable.

54.2% of all causes were avoidable, with a large proportion being treatable. The underlying aetiological diagnosis among the 83 blind and severely visually impaired children is shown in Table 51.

Table 51: Diagnosis according to aetiology

Aetiological category	Severe visual impairment		Blind		Total	
	N	%	N	%		
Hereditary	1	4.2	2	3.4	3	3.6
Intrauterine	2	8.3	2	3.4	4	4.8
Perinatal	1	4.2	15	25.4	16	19.3
Childhood	7	29.2	17	28.8	24	28.9
Unknown	13	54.1	23	39	36	43.4
Total	24	100	59	100	83	100

Unknown aetiology was the commonest, followed by conditions occurring in childhood. Perinatal and childhood factors (either potentially preventable or treatable) contributed to almost half of all aetiological causes.

Unilateral blindness and severe visual impairment

In this section, factors that were asscoiated with unilateral visual acuity loss have been reported by using findings from each eye examined. Table 52 shows the visual acuity obatined from each eye, among all children examined.

Table 52: Visual acuity

	Visual acuity in RIGHT eyes						
Visual acuity in LEFT eyes		Normal	Visual impaired	Severe visual impaired	Blind	Could not be tested	Total
	Normal	271	12	10	46	0	339
	Visualy impaired	8	29	2	4	0	43
	Severe visually impaired	13	1	18	3	0	35
	Blind	41	5	3	59	0	108
	Could not be tested	0	0	0	0	25	25
	Total	333	47	33	112	25	550

Among all children examined approximately 50% had a completely normal vsiual acuity in both eyes.Using the table above, calculations of how many children, and also eyes which were unilaterally blind/SVI, were done, and these are shown in Table 53 .

Table 53: Unilateral and bilateral blindness

	No	% out of 550(persons)	Total Eyes*	% out of 1100(eyes)
Unilateral SVI/blind	122	22.2%	122	11.1%
Bilateral blind/SVI	83	15.1%	166	15.1%
Unilateral VI	32	5.8%	32	2.9%
Bilateral VI	29	5.3%	58	5.3%
Unilateral normal	130	23.6%	130	11.8%
Bilateral normal	271	49.3%	542	49.3%
Could not be tested	25	4.5%	50	4.5%
Total children			1100	100.0%

22.2% of all children were atleast blind or severely visuallly impiared in one eye and 49.3% of children brought had normal visual acuity.The causes of visual loss in children who were unilaterally blind/SVI (N=122) are shown in Table 54 .

Table 54: Causes of visual loss

Anatomical site of abnormality			
		N	%
Whole globe	Phthisis	7	5.7%
	Microphthalmos	4	3.3%
	Disorganized	1	0.8%
Cornea	Corneal scar	65	53.3%
	Corneal other	3	2.5%
Lens	Cataract (unoperated)	12	9.8%
	Pseudophakia/aphakia	4	3.3%
Iris	Uveitis	2	1.6%
Optic nerve	Optic atrophy	6	4.9%
Retina	Retina, other	3	2.5%
Eye appears normal	Refractive error	1	0.8%
	Amblyopia	11	9.0%
Others		3	2.5%
Total		122	100.0%

Cornea scarring was the comonest cause of unilateral severe visual impairment/blindness contributing to 53.3% of all cases.Refractive error was a very rare cause of unilateral blindness (0.8%). Avoidable causes (whole globe,cornea and lens related) contributed to more than 75% of all causes of unilateral blindness.Childhood factors contributed to the majority (79%) of cases of unilateral blindess/SVI, followed by unknown(18%) and heriditary(3%).

Table 55 summarizes the main differences in anatomical causes of blindness and severe visual impairment between bilateral blindness and unilateral blindness and 3 main causes, listed according to order of importance.

Table 55: Summary of differences in anatomical causes between bilateral and unilateral BL/SVI

Diagnosis	Cause 1	Cause 2	Cause 3
Bilateral blindness/SVI	Cortical	Cataract	Phthisis
Unilateral blindness/SVI	Cornea scar	Cataract	Amblyopia

Cortical causes was the commonest causes of bilateral blindness/SVI, while cornea scarring was the commonest cause of unilateral BL/SVI.

4.4 Referrals and action taken

Figure 34 shows the numbers and where the children were referred to after eye examination.

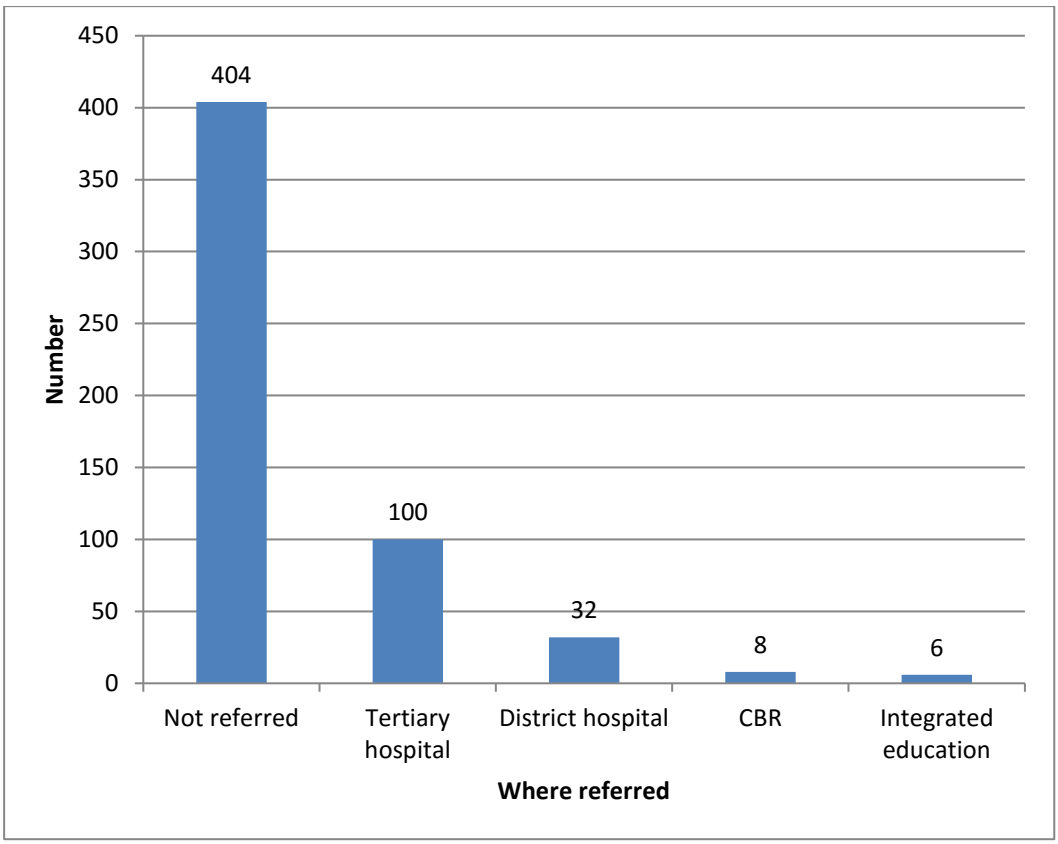


Figure 34: Referrals after eye examination

Of all children examined 404 (73.5%) were not referred, 100 (18.2%) were referred to a tertiary eye hospital in Blantyre, 32 to a district hospital and 14 (2.6%) to CBR/Integrated education. All parents were counselled about their child's condition, some had other action taken about their condition. Where children needed to have eye medication in addition to another action, that action was stated as the "main action". It was only among those who received medication that the "main action" was taken as medication at the site. The main actions are shown in Figure 35.

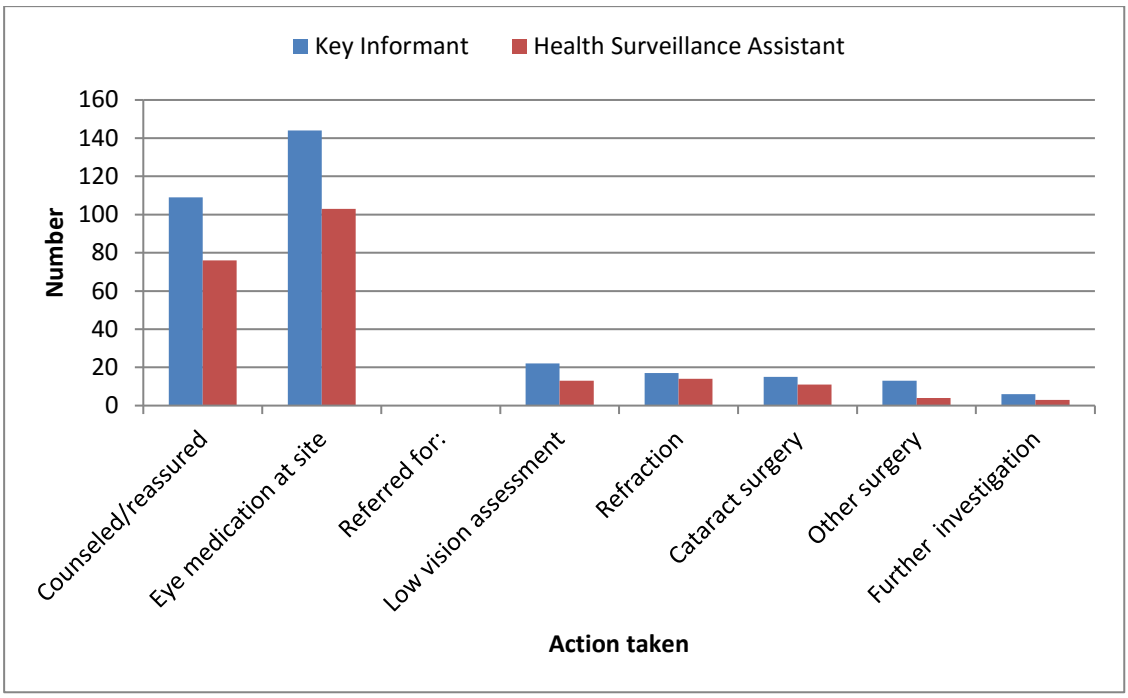


Figure 35: Action taken after eye examination, by case finder

The commonset action taken was provision of eye medications at the examination site (N=247,44.9%), followed by counselling/reassurance(N=185,33.6%). The main resons for providing medication was to treat conjunctivitis (bacterial, vernal and allergic).

4.5 Barriers

167 (54%) of the trained HSAs/KIs (310) had in-depth interviews. A total of ten (10) focus group discussions were conducted (5 for HSAs & 5 for KIs. The characteristics of the KIs and HSAs that had in-depth interviews are shown in Table 56.

Table 56: Characteristics of HSA's & KI's interviewed

	Key Informants			Health Surveillance Assistants			Total		
	Trained	Interviewed		Trained	Interviewed		Trained	Interviewed	
	N	N	% of those trained	N	N	% of those trained	N	N	% of those trained
Male	81	39	48.1%	87	57	65.5%	168	96	57.1%
Female	70	42	60.0%	72	29	40.3%	142	71	50.0%
Zomba	86	46	53.5%	91	39	42.9%	177	85	48.0%
Mangochi	65	35	53.8%	68	47	69.1%	133	82	61.7%
Total	151	81	53.6%	159	86	54.1%	310	167	53.9%

Overall 53.6% of all KIs trained and 54.1% of all HSAs trained were interveiwed. More males than females were interviewed, due to the fact that more males came for the interview . KIs and HSAs were individually asked to indicate whether they visited all villages allocated to them. Almost two thirds (64.7%) managed to visit all the allocated villages within the agreed period of time, while the rest (35.3%) did not visit all the allocated villages. There was no statistically significant difference according to who was trained (P=0.44, chi2). The 59 KIs and HSAs that did not visit all villages were asked to indicate reasons that prevented them from visiting all the villages and these are shown in Table 57.

Table 57: HSAs/ KIs Reasons for not visiting all allocated villages

	KI		**HSA**		**Total**	
Reason	No	%	No	No	%	%
Other commitments	7	22.6	12	42.9	20	33.9
More time needed	10	32.3	8	28.6	18	30.5
Long distance between villages	9	29.0			8	13.6
Lack of adequate incentives			5	17.9	5	8.5
Prevented by illness	1	3.2	1	3.6	2	3.4
Finished all the given forms	2	6.5			2	3.4
Refused/delayed by village leader	2	6.5			2	3.4
Sent messages on health promotion			1	3.6	1	1.7
Prevented by heavy rains			1	3.6	1	1.7
Total	**31**	**100.0**	**28**	**100.0**	**59**	**100.0**

The commonest reasons given by both groups were other commitments (33.9%) followed by “more time needed to visit the villages” (30.5%).

Challenges common to both KIs and HSAs:

- Some HSAs/KIs stated that after visiting 1-2 villages and not finding any blind and visual impaired children, they were convinced that the other villages would be the same and were reluctant to continue.
- Some villages were large and had difficult access and 2-3 days were needed to cover the entire village.
- HSAs/KIs reported that despite identifying some children, cultural and traditional beliefs among families of BL/SVI had prevented them from being listed and attending eye examination sessions.

Challenges specific to HSAs:

- They felt incentives were inadequate and that providing both financial and non-financial incentives (such as bicycles for easy mobility) would increase motivation and productivity.
- Due to regular involvement in other health related activities, HSAs reported that they did not have time to go door to door on a regular basis. They felt that it would be more effective to allow them to identify and train volunteers who should be identifying children while HSAs supervise them.
- Regarding using under-five immunization clinics as regular places to look for blind children, HSAs reported that the clinics were busy as many children needed to be weighed and immunized and then have different forms filled for each, such that it would not be practical to check the children eyes at the same time.
- They felt that there was need to identify a separate day (not during immunizations) when they could do the eye work in the community but this would increase their work load. They reported they already had separate days for different activities: collecting village registers, conducting village inspection and health promotion.
- HSA's were supposed to be supervised by senior HSAs. However, these supervisors also had their own villages to look after, so it was not possible for them to check whether all the HSAs in his catchment area were doing their job.
- Approximately half of all the HSAs interviewed reported that this was the first official classroom training/workshop that they had attended since being appointed (2008) and that they had not had their 3 months formal training. They reported that they spent more time learning on the job skills from other trained HSAs whenever they went for immunization clinics in the community and that this further reduced the time they could spend on identifying blind children.

Challenges specific to Key Informants:

- Despite being provided with an identity card that detailed their involvement in this project, some village leaders were reluctant to give permission to KIs to identify children in villages where the KI was not a resident. This was often as a result of suspicion as to why the project did not select a KI resident in that village and that perhaps they were benefits that this KI was getting. It was only after a lengthy explanation of why each village could not have had its own KI that some leaders allowed the KIs to proceed while others refused and said they knew there were no blind/SVI children in their village.

- Since the government only recognized HSAs as the official health worker in the village, some residents in the village could not accept that KIs could have the skills to correctly identify children and hence did not bring children despite getting the announcements. KIs felt that if the government officially recognized the role they played in the community and encouraged the community to take advantage of them in all health-related issues they may be more productive and complement the work being done by HSA's and other health workers.

Other additional comments:

- Both the KIs and HSAs indicated that the knowledge and skills gained during the one day training was adequate to allow them to correctly identify blind and visual impaired children.
- Among the KIs that visited all the allocated villages, they did not think any BL/SVI children could have been missed because the main method they used was door to door.

Key informants and HSAs reported that in earlier training sessions that were conducted in the community for other health related projects, it was not common for the training team to come back to the community, track those that were trained and conduct follow-up/assessments. This impressed them as it indicated the projects team's motivation and commitment.

4.6 Attendance of children at a health centre

All children were supposed to have attended the health centre and the eye examination centre or have been referred to the nearest district hospital once they were listed. Table 58 shows whether children attended a health facility or were examined after being listed.

Table 58: Attendance at Health Centre

		Listed, attended, had eye examination		Listed, did not attend but had eye examination		Listed, no information on attendance, no eye examination		Total		Chi square	P value
		N	%	N	%	N	%	N	%		
Gender	Male	63	7.9%	236	29.7%	125	15.7%	424	53.3%		
	Female	58	7.3%	193	24.3%	120	15.1%	371	46.7%	1.09	0.58
Who listed:	KI	57	7.2%	269	33.8%	153	19.2%	479	60.3%		
	HSA	64	8.1%	160	20.1%	92	11.6%	316	39.7%	10.3	0.006
District:	Zomba	41	5.2%	259	32.6%	140	17.6%	440	55.3%		
	Mangochi	80	10.1%	170	21.4%	105	13.2%	355	44.7%	27.3	0.001
Total		121	15.2%	429	54.0%	245	30.8%	795	100.0%		

Only 15.2% of all children listed attended the District Government Hospital (DGH) and also had an eye examination at 6 weeks. However more than half (54%) who did not attend the DGH had an eye examination.30.8% of the children who were listed did not have an eye examination at 6 weeks and it was not possible to collect information as to whether they had attended the DGH or not nor any other clinical information. Figure 36 shows who brought the child to eye examination centre.

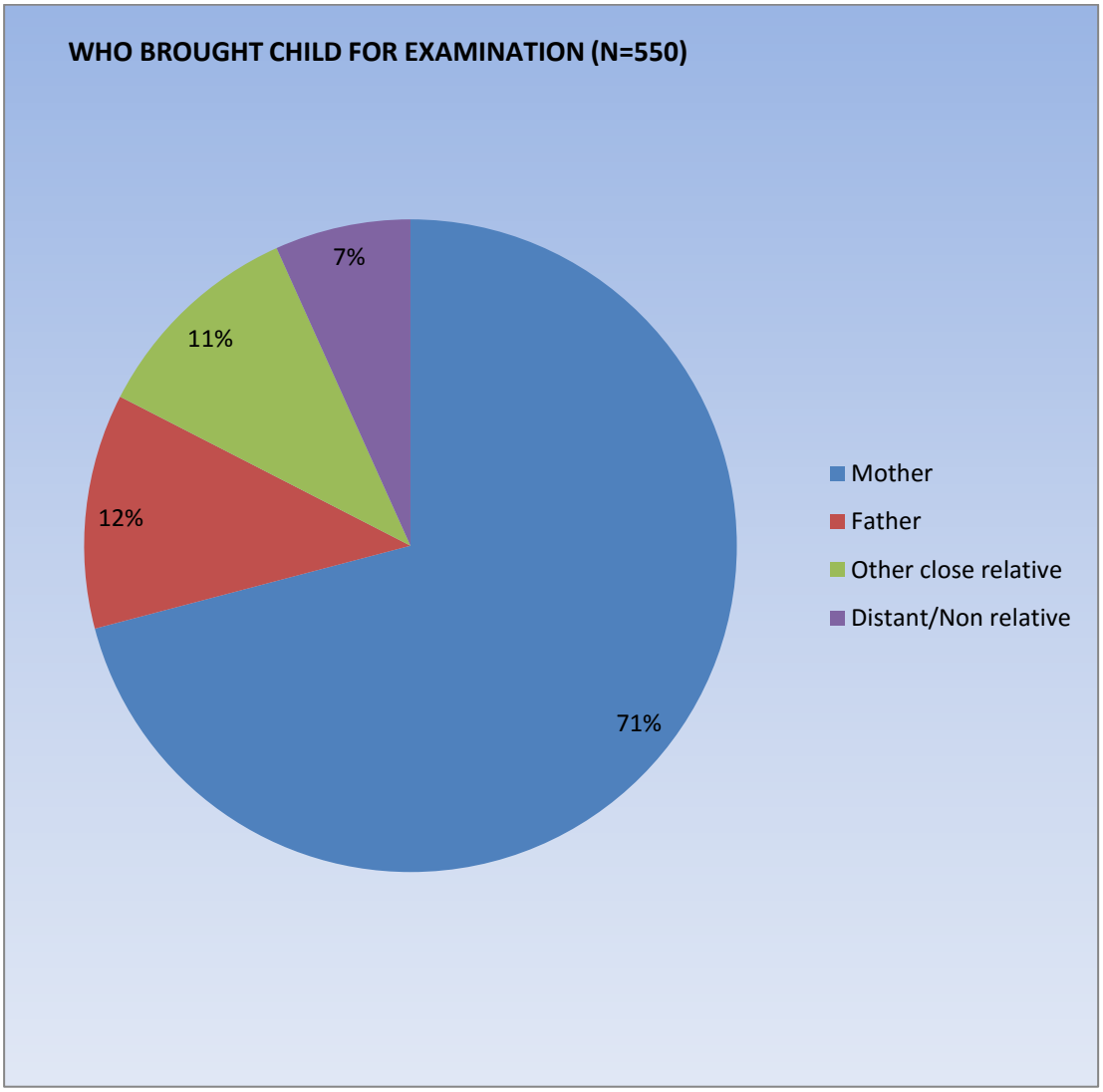


Figure 36: Who brought the child to eye examination centre.

Most of the children (71%, N=390) were brought by the mothers to the eye examination centres, while the rest were brought by fathers (12%), another close relative (11%), or non/distant relative.

Table 59 shows (only among the examined children) the characteristics of children that attended and those that did not attend the health centre after being detected by KIs and HSAs.

Table 59: Characteristics of children that attended and those that did not attend the health centre.

		Attended		Did not attend		Total Examined		Chi square	P value*
		N	%	N	%	N	%		
Gender:	Male	63	21.07	236	78.93	299	100		
	Female	58	23.11	193	76.89	251	100	0.33	0.56
		121	22.00	429	78.00	550	100		
Age:	<1 year	4	13.79	25	86.21	29	100		
	1-5 years	45	25.00	135	75.00	180	100		
	6-10 years	35	21.21	130	78.79	165	100	2.24	0.52
	11-15 years	37	21.02	139	78.98	176	100		
	Total	121	22.00	429	78.00	550	100		
Confirmed as blind:	Yes	15	25.42	44	74.58	59	100		
	No	106	21.59	385	78.41	491	100	0.45	0.5
		121	22.00	429	78.00	550	100		
Who listed:	KI	57	17.48	269	82.52	326	100		
	HSA	64	28.57	160	71.43	224	100	9.5	0.02
		121	22.00	429	78.00	550	100		
District:	Zomba	41	13.67	259	86.33	300	100		
	Mangochi	80	32.00	170	68.00	250	100	26.7	0.001
		121	22.00	429	78.00	550	100		
Mothers education[1]	None or informal*	49	38.28	79	61.72	128	100		
	Some**	40	17.54	188	82.46	228	100	20.04	0.001
	A lot***	6	17.65	28	82.35	34	100		
		95	24.36	295	75.64	390	100		

1. Mothers were 390 in total

*refers to not attending any classroom formal education that can make one read or write

**refers to attending primary education up to level 8

***refers to attending secondary or tertiary education

Among the children that attended the eye examination session (N=550), only 22% had attended a health facility after being identified and referred. Attendance at a health facility was not associated with gender of the child (P=0.560), age group (P=0.520), and whether child was blind or not (P=0.500). However, attendance at a health facility seemed to be significantly associated with who identified the child (children identified by KIs were less likely to attend the health facility P=0.020, chi2); the district where the child came from (children from Zomba less likely to attend P= 0.001) and education of the mother (children from uneducated mothers were more likely to attend the health facility P=0.001).

The factors associated with attendance were tested in a univariate logistical regression and the results are shown in Table 60.

Table 60: Factors associated with health facility attendance on univariate logistical regression

	Health facility attendance	Odds Ratio	95% Confidence Interval		P value
Who identified	HSA	1.9	1.3	2.8	0.002
	KI	1.0			
District	Mangochi	3.0	1.9	4.5	0.001
	Zomba	1.0			
Education	No education	3.7	1.9	7.2	0.001
	Some education	1.4	0.7	2.8	0.293
	Well educated	1.0			

The odds of health facility attendance for children identified by HSAs were 1.9 times the odds to the health facility attendance for children identified by KIs (P=0.002), the odds of health facility attendance for children from Mangochi district were 3 times the odds to the health facility attendance for children from Zomba (P=0.001), and the odds of health facility attendance for children from mothers with no education were 3.7 times the odds to the health facility attendance for children from well-educated mothers (P=0.001).

The factors were further tested on multivariate logistical regression are the results are shown in Table 61.

Table 61: Factors associated with health facility attendance on multivariate logistical regression

	Health facility attendance	Odds Ratio	95% Confidence Interval		P value
Who identified	HSA	1.5	1.0	2.4	0.044
	KI	1.0			
District	Mangochi	3.7	1.5	4.5	0.001
	Zomba	1.0			
Education	No education	3.9	1.5	7.2	0.001
	Well educated	1.0			

Only district and education of the mother remained significant in the model (P=0.001), with odds of health facility attendance for children from Mangochi being 3.7 times the odds to the health facility attendance for children from Zomba; and the odds of heath facility attendance for children from non-educated mothers being 3.9 times the odds to the health facility attendance for children from well-educated mothers.

4.7 Interviews with parents of blind children

A total of 16 parents of blind and visually impaired children had in-depth interviews to find out why they had not attended the health centre after being listed and advised to attend. Table 62 shows the responses that the parents gave for non-attendance, by cause of visual loss.

Table 62: Parents reasons for children's non-attendance at health facility

	Cause of visual loss					
Response for not attending	Cataract	Cornea scarring	Other avoidable	Other unavoidable	Total	
	N	N	N	N	N	%
Previously told by health workers that nothing can be done	0	1	1	4	6	37.5%
Went to a health facility but was not referred to an eye hospital, sent back home by HC staff, no record kept at the health centre and no reason given to parents.	3	0	0	1	4	25.0%
No money for transport	1	0	0	2	3	18.8%
Other reasons/commitments	1	0	0	1	2	12.5%
Listed but misunderstood instructions	1	0	0	0	1	6.3%
Total	6	1	1	8	16	100%

Among the parents interviewed, 6 children (37.5%) had cataract, a treatable condition. Half of all children had avoidable causes of blindness while the other half had unavoidable causes. The commonest reason for children's non-attendance at the health facility was that the parents of the child had been previously told by a health worker that nothing could be done about the child's condition (37.5%). Indeed 4 of the children with unavoidable cases had been appropriately counselled /advised that nothing could be done. The second common reason was that they went to the health centre but were sent back by a health centre staff without being referred to an eye hospital helped, no record was kept at the health centre and no reason was indicated on their form or health book. This was unfortunately a missed opportunity, as 3 of the 4 children had cataract and needed to be referred to an eye hospital without delay. All 6 children with cataract were successfully referred to Blantyre where they had sight restoration surgery.

Case Study

A case story of the child and parents who did not turn up after being identified by an HSA is illustrated below:

The mother of an 8-year-old girl who had dense bilateral cataracts noticed since the first year of life was interviewed about why they did not attend the health centre after being identified. She reported that she did not know that her child's condition could be treated in a hospital. She thought that since the child was born like that, other family members had expressed fear about what would happen to the child if she was to be taken to the hospital and she respected the family decision. She said that if the health worker met the family and explained the child's condition to the family perhaps the family would agree. The HSA who identified the child was asked to go and counsel the family. In addition, the parent was assured that if they went to the hospital action would be taken to help the child see, and in addition the parent and child would be reimbursed for the cost of transport. They were told that after the surgery the child would be provided with a free pair of glasses. The HSAs successfully counselled the family who agreed to send the child to the hospital. The parents and child came to Blantyre after a few weeks. Cataract surgery was successful done in both eyes as some vision was restored (Figure 37).

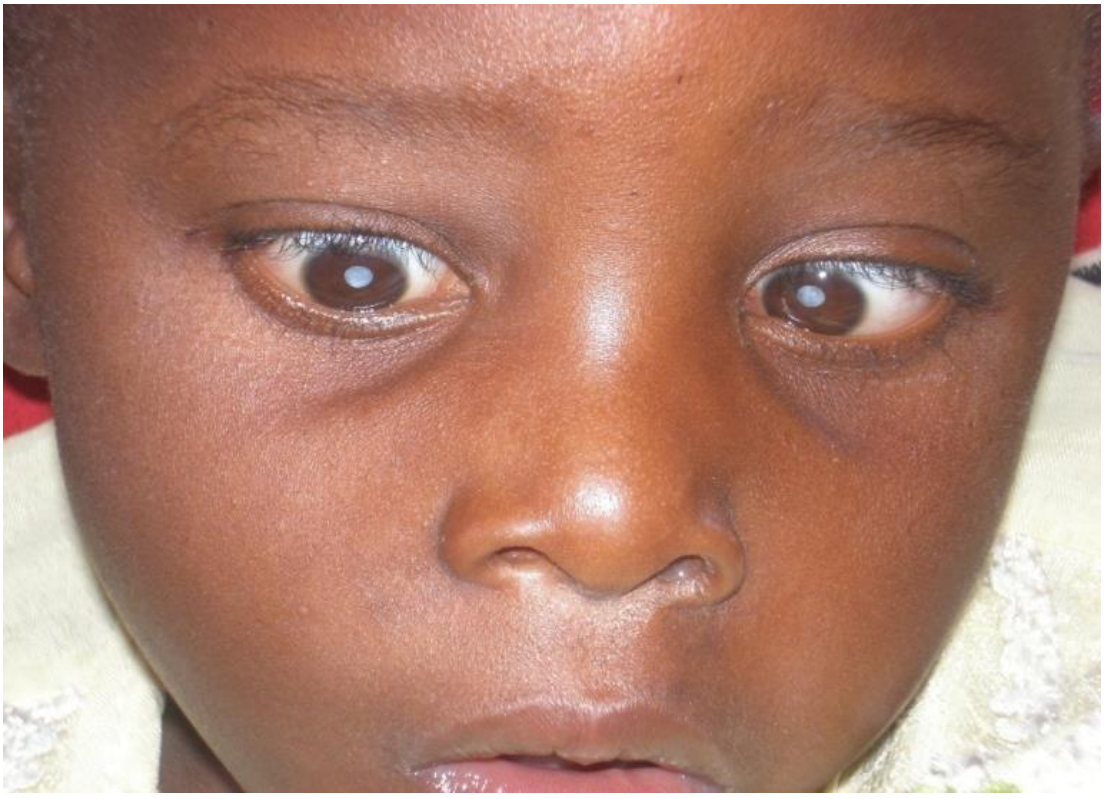


Figure 37: 8-year-old child with bilateral cataract

4.8 School attendance

The association between visual acuity of the children examined and school attendance (analysed only for the 387 children of school going age i.e. 5 years and above), is shown in Table 63.

Table 63: Association between visual acuity and school attendance

School attendance	Normal		VI		SVI		Blind		Total
	N	%	N	%	N	%	N	%	N
Never been	59	19.7	7	19.4	3	13.0	11	39.3	80
Dropped out	14	4.7	2	5.6	3	13.0	3	10.7	22
Integrated education	0	0.0	0	0.0	1	4.3	6	21.4	7
Normal school	227	75.7	27	75.0	16	69.6	8	28.6	278
Total	300	100%	36	100%	23	100%	28	100%	387

School attendance was lower among children who had poorer levels of visual acuity. Only 19.7% of normally sighted children of school going age had never been to school but this figure was twice as high for blind children (39.3%). In terms of school dropout, while only 4.7% of children with normal vision who started school dropped out, 10.7% of blind children dropped out. Overall, 50% of blind children had never been to school at all, or had dropped out. Risk factors for school attendance were investigated and the findings are shown in Table 64.

Table 64: Risk factors for not attending school among children of school going age (6 years and above)

		Never attended school, or dropped out		Attends normal school or integrated education		Total		Chi sq	P value
		N	%	N	%	N	%		
VA better eye	Blind/SVI	20	39.2	31	60.8	51	100		
	Normal	82	24.4	254	75.6	336	100	5	0.025
Gender	Boys	60	28.2	153	71.8	213	100		
	Girls	42	24.1	132	75.9	174	100	0.8	0.371
Age(years)	5-10	74	35.1	137	64.9	211	100		
	11-15	28	15.9	148	84.1	176	100	18.5	0.001
		102	26.4	285	73.6	387	100		
Mothers education	No education mother[1]	55	36.4	96	63.6	151	100		
	Educated mother	18	18.2	81	81.8	99	100	9.63	0.002
	Total[2]	73	29.2	177	70.8	250	100		
District	Zomba	51	24.5	157	75.5	208	100	0.782	0.376
	Mangochi	51	28.5	128	71.5	179	100		
	Total	102	26.4	285	73.6	387	100		

1. No education refers to not being able to read and write.

2.Total number is less because not all children were brought by mothers.

Better visual acuity, older age of the child, and having an educated mother were all associated with high school attendance, while gender and district of origin were not (Table 65).

Table 65: Factors associated with school attendance on univariate logistical regression

	School attendance	Odds Ratio	95% Conf. Interval		P value
Visual acuity	Blind/SVI				
	Normal VI	2.0	1.08	3.69	0.027
Age (years)	5-10				
	11-15	2.86	1.74	4.6	<0.001
Education	No education	1.0			
	Educated mother	2.08	1.34	3.2	<0.001

These factors were further explored through multivariate logistical regression ad the results are shown in Table 66.

Table 66: Factors associated with school attendance on multivariate logistical regression

	School attendance	Odds Ratio	95% Conf. Interval		P value
Visual acuity	Blind/SVI	1.0			
	Normal VI	2.4	1.25	4.6	0.008
Age (years)	5-10	1.0			
	11-15	2.9	1.74	4.9	<0.001
Education	No education	1.0			
	Educated mother	1.19	1.03	1.38	0.021

All the three factors: poor visual acuity (BL/SVI), younger age (5-10years) and an uneducated mother remained as predictors for not going to school.

CHAPTER 5

5 Discussion

Overview

This section discusses how the findings of this study relate to the aims and objectives of the study, how they compare and contrast with findings from other studies of blindness in children, the implications of the study findings for program planning, the limitations of the study and future research that need to be undertaken as a follow-up to this study.

The objectives of the study were to compare the number of blind and severely visually impaired children identified by KIs and HSAs, identify the causes of visual loss in children, identify constraints that limit KIs and HSAs in identifying children, identify barriers that prevent blind children from accessing eye services and provide guidelines on optimal approaches to identifying blind and severely visually impaired children. The key informants (local volunteers) were taken as the gold standard as they have been trained and used before in Malawi[51], and other countries to identify blind and visually impaired children and the HSAs were the comparative group. Malawi provided the opportunity to test the two methods because it is one of the few countries in Africa that has a large number of formal community health workers (HSAs).

5.1 Main findings

A summary of the main study findings relating to specific issues are listed below, and followed up by a general discussion.

Key Informants

i. Key informants were more effective than HSAs in identifying blind and visually impaired children.
ii. Key informants tend to spend more time in villages than HSAs in identifying children because they have fewer other tasks.
iii. Lack of recognition of KIs as official case finders (health worker) by community members prevented KIs from identifying more children.
iv. Incentives (financial and non-financial) play a major role in motivating KIs.

Health Surveillance assistants

i. Health surveillance assistants have many other duties that affect their productivity and prevent them from identifying blind children.
ii. Health surveillance assistants need more financial and non-financial incentives than KIs.

Method of case identification

i. Door to door method was the method that yielded most cases of blind and visually impaired children.
ii. Overall coverage was low by both groups.
iii. False positives were comparable among both groups.

Socio-Cultural factors affecting case identification

- Cultural factors, traditional beliefs, misinformation from health workers and other factors prevented parents and children from accessing eye health services in their communities.

Health seeking behaviour and impact of blindness on education of children

i. Mothers educational status, family income and distance to hospital influence health seeking behaviour.
ii. Blindness and visual impairment in children if not addressed are likely to interfere with the children's education.

Prevalence and causes of blindness and severe visual impairment

i. The number of blind and visually impaired children identified was less than expected, using available blindness estimates in children, and possible reasons are discussed below.
ii. A large number of children identified by KIs and HSAs did not have conditions that cause visual impairment or blindness, but had conditions requiring attention.
iii. The four main causes of bilateral blindness and severe visual impairment in descending order were cortical blindness, cataract, optic nerve disease and cornea scarring.

5.2 Discussion of findings

5.2.1 Key Informants better case finders than HSAs

Several factors may have played a role in making KIs better case finders than HSAs in identifying blind and visually impaired children and these include the method used, the time spent on identifying the

children, the incentives, levels of motivation of the two groups and the anticipated benefits. Key informants went door to door as that meant they needed more time to complete the allocated villages but at the same time, it meant they spent more time getting to know the family members and asking about their health status.

5.2.2 Incentives:

Both financial and non-financial incentives played a role in motivating the KIs to be more productive than HSAs. The HSAs are paid government employees who are paid on a monthly basis. They may not appreciate a day's extra pay for field work in comparison to the KIs who usually would not earn a salary and a day's pay may be a significant source of income. Non -financial incentives (certificate of recognition, identify cards, etc.) are also likely to play a much major role in increasing the motivational levels of KIs much more than the HSAs. According to WHO guidelines on incentives[268], financial incentives, though important, play a limited role in the long term motivation of staff. Non-financial incentives such as guarantee of sustained employment, positive working environment, flexible working conditions, support for career and developments, family support and other intrinsic rewards such as respect from colleagues and the community, the feeling of belonging to a particular group and feeling of personal achievement are equally important and play a major role in motivation. In this study, it is likely that intrinsic rewards motivated the KIs (who may be looking for favours for future jobs) more than the HSAs. The feeling that they were personally making a difference to children in their own community may also have motivated the KIs.

5.2.3 Recognition of key informants

One factor that needs to be addressed and which may have contributed to KIs not getting more children is the lack of recognition of KIs as official case finders (health worker) by the community. The fact that each village is Malawi has an HSA as an authorized health worker may make village members doubt the competence of known local members in identifying visually impaired children and other health problems. It may need the HSAs to endorse KIs as local workers to get approval of community members; however, according to information obtained during KI interviews, this has the potential to undermine/decrease the HSAs popularity in the village, so they may not be willing to do so.

In a systematic review of global experience of community health workers[269] , WHO argues that community health workers are a good way to reach disadvantaged populations and that they should be formally recognized as part of the health work force, and provided with adequate training and supervision. Currently many NGOs working with Ministry of Health in Malawi choose to use either community volunteers or HSAs in their projects, but there have not been any comparative studies in Malawi. For rare diseases, such as blindness in children, using KIs is recommended. Our findings in

support of using KIs are similar to those of three studies [270-272] in Malawi that have demonstrated that using community volunteers offer a good alternative to using health workers. Using community volunteers as a strategy in Tuberculosis management in comparison to using the recommended standard protocol not only reduces annual costs by 50%, but is also effective in improving treatment[273]. In another HIV/AIDS study in Malawi [274], use of community volunteers was associated with reduced death rate and a good antiretroviral therapy use among HIV positive patients. Finally, a study that looked at the role of traditional birth attendants (TBA's) in reducing maternal mortality in Malawi [272], suggested a positive role played by TBAs (they were able to conduct antenatal clinics where they screened pregnant women for danger signs, using the danger signs card provided by the TBA Program, and were able to refer those with complications), though it was not possible to quantify mortality reduction rates.

5.2.4 HSAs productivity

For HSAs, many factors could have contributed to them not being productive. They preferred to use immunization clinics but this only identified a small fraction of the children (Table 41). In the pilot study, HSAs reported that they spent 80-85% of all their time in under-five clinics, and they could use this chance to identify children. Immunization clinics, though an available source, only immunize children up to 5 years, and therefore are not good for identifying older children. In regard to time management, it should be noted that immunization clinics are busy and adding a simple task such as checking the children's eyes or asking the mother if the child cannot see adds a considerable time to their workload. In the end, HSAs may be demotivated to do these checks on a regular basis. Their work involvement in maternal and child health though an opportunity for childhood blindness is labour intensive such that specific innovative ways need to be factored into their routine work schedule for them to be productive in identifying visually impaired children.

The findings of the study agree with a recent study in Tanzania [275] which also found KIs to be better than health workers at identifying children with cataract.

It is logical to think that some factors and characteristics such as age, gender and education status may all play an important role in determining which cadres of HSAs or KIs would be more productive. Even though an earlier pilot study in another district in Malawi [51] suggested some characteristics of productive KIs, this study did not find any relationship between age, gender, education and the number of children listed among both KIs and HSAs (Table 36). Reasons why KIs were able to list less young children than HSAs (Table 37) include the fact that pathology such as cornea scarring may be more noticeable in the older than younger children, and that parents of older children may be able to give a much reliable history of the child's condition.

5.2.5 Other factors influencing the number of cases

The overall coverage was lower in Zomba than in Mangochi (47.2% versus 58.9%) (Table 27) yet the number of blind/SVI children identified in Zomba was almost twice as that in Mangochi. One explanation relates primarily to the number of trained personnel / 10,000 children and the coverage. The number of trained KIs/HSAs was almost one and half times higher in Zomba than in Mangochi (Table 29). The lower coverage coupled with the higher number of KIs/HSAs trained in Zomba meant that KIs/HSAs had less catchment area to cover in comparison to those from Mangochi, and this possibly enabled them to do a more effective job in comparison to those from Mangochi.

Another factor that could explain differences in number of cases would be the inbuilt socioeconomic differences between Zomba and Mangochi district. Zomba has a good network of roads that are easily accessible and all the health centres are closer apart, while Mangochi has some health centres areas that are difficulty to reach (poor road network). The timing of the fieldwork in the two districts also probably contributed to the number of blind/SVI children identified from each district. While as most of the fieldwork in Zomba was done during the dry season, part of the fieldwork in Mangochi was done during the rainy seasons, as this meant that KIs/HSAs had difficulties reaching some of the allocated areas, resulting in them not identifying all the children in their catchment population. Also, as KIs were volunteers, and this was the rainy season when there were supposed to have been farming, it was likely that the effort put towards this exercise in Mangochi was less than in Zomba, and this could explain why they had identified less children. However, within each district, there were no differences in socioeconomic structures between the KI and HSA clusters, which would potentially bias the results. The random allocation of clusters to either KIs or HSAs groups in each district ensured that inbuilt differences between clusters, within a district, were evenly distributed.

5.2.6 Social culture factors and traditional belief prevent some families from accessing services

Health workers often assume that once the community is aware of a problem and the solutions have been presented to them, appropriate actions will be taken. However, healthy seeking behaviours and factors that determine them are complex, and unless these are understood, a larger proportion of community members will continue not accessing services. The Health Belief Model (HBM) as developed by Rosenstock et.al [276]can be used to generate findings within the health community about the role that knowledge and perceptions play in personal responsibility, and to predict certain health behaviours. The HBM suggests that one’s belief in a personal threat together with ones belief in the effectiveness of the proposed behaviour will predict the likelihood of that behaviour[276].

In this study, it is important to understand why parents of 31% of all children that were identified and advised to attend the eye examination centre did not present themselves. One possibility would have been to expect differences between the characteristics of children (age range of children, mean age, gender of

children, who listed, gender of who listed, and district) that did attend the eye examination in comparison to those that did not (Table 40), but this was not the case. The fact that there were no significant differences between the two groups confirms the complexity of health seeking behaviours. The observation that overall more boys than girls were listed and attended eye examination sessions (Table 40) suggests that possibly some girls were missed during the listing period, as there is no biological explanation to indicate why more boys should suffer from blinding eye diseases than girls. This is in agreement with studies from other areas where gender differences in children accessing eye care services has been documented, with more boys attending than girls [277] and also in adults where women access services less than men [278-280]. It should be noted in regard to age, parents with the very young children (<1years) may not attend to the health services due to the belief that the problem may be transient and will get corrected on its own as the child grows. Even though mothers' education, long distance to a health facility and poor income have been mentioned as independent predictors for delays in presentation to hospital for cataract in children [115] the role that each play in influencing a particular health behaviour is complex and an attempt to explain is illustrated in Figure 38.

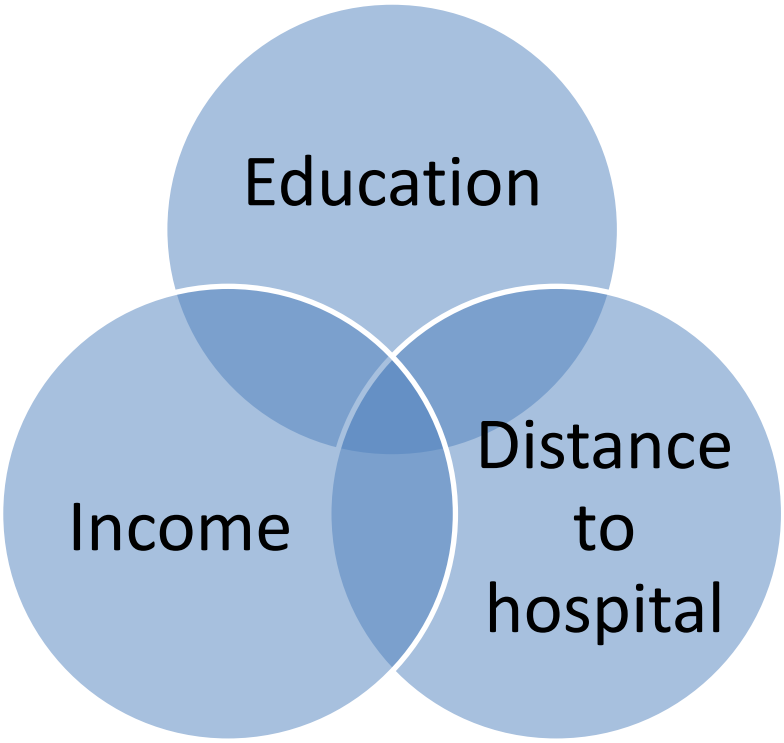


Figure 38: Role of education, income and distance to hospital in influencing health seeking behaviour

The mothers' educational status may influence health seeking behaviour in several possible positive ways, which are likely to be beneficial for the child. An educated mother is more likely to have a job and earn an

income, and also will better understand negative effects of the illness on the child and the importance of taking the child to hospital. A mother with an income and an education will not see distance as a barrier as she will be able to pay for costs to a health facility, or justify why she has to walk there. An educated mother with an income is likely to have access to media messages (newspaper, radio, phone or television), that emphasize the importance of taking the child early to the hospital when the child is sick, and will not consider distance as a barrier when the child is sick. Moreover, an educated mother is likely to live closer to where better education and health facilities are located, for the benefit of her children, in-order to have a quicker access. Finally, a better educated mother with an income may be able to positively influence the family decision making by giving a clear explanation of the child's illness or by offering to pay some of the transport costs to the hospital.
In this study, once a child was identified, parents were told to borrow money for transport and the transportations costs for the child and parents were reimbursed when they reached the health facility. A number of parents and children did not turn up.

In addition to factors that affect health seeking behaviour mentioned above, there are several other explanations for this: 1) the way the information was communicated to them, possibly they were not properly counselled about the importance of taking the child to the hospital and the consequences of not doing so, 2) they could not find someone to borrow the money from and 3) opportunity and other indirect costs associated with bringing the child to a health facility outweighed the transportation refund that were promised. In terms of indirect costs, bringing a child may mean postponing planned activities (such as small scale business) and losing an income which cannot be reimbursed through bringing a child to a hospital.

5.2.7 False positives by KIs and HSAs

Even though only 15.1% of all children examined were confirmed to be bilateral severely visually impaired or blind, it is important that a large proportion of children had unilateral severely visual impairing conditions or other eye conditions. Considering that during training KIs and HSAs were told to bring all blind/SVI and other children that they felt needed to be seen during the eye examination session, it would be inappropriate to say that the case detection success rate was only 15.1%. As can be seen from table 43, the actual false positive rates were lower. The similarities of percentages among the two groups suggest that regardless of the background educational qualification, both groups attained the same knowledge and skills. The low percentages of false positive from both groups suggests that if simple identification criteria (bilateral blind/not blind) are used for categorizing children, volunteers can be effectively be used for identifying such cases. It is therefore not surprising that even though HSAs had

mentioned during the initial FDG's that they were better placed to identify children than KIs as they already other skills, this was not supported by the number of false positives in each group.

The concept of "number needed to train per blind child" (Table 44), particularly looked at productivity of the groups trained and some cost implications can be deduced from this. The results suggest that it is more cost effective to train KIs than HSAs to identify a required number of children. However, for the long-term progress of in-country programs, apart from the cost, many issues would need to be considered (sustainability, continued motivation, supervision, policies in place etc.) before deciding which cadre to train. Other opportunities and challenges would need to be further explored, even though the study shows that active case identification may have merits for rare cases such as blindness in children.

Despite both KIs and HSAs being advised to tell the parents of all listed children to report with their children to the health centre, a large number of all children 78% seen at eye examination session had not attended the health (table 59). Poor utilization of medical care facilities of similar proportions has been reported in other studies of childhood morbidity in sub-Saharan Africa [281], with parents not taking up to 68% of children with serious conditions for a medical visit. Eye conditions are not a major source of morbidity and mortality in this population and are likely to be given less priority even when parents are aware that services are available. Reasons for non-attendance obtained from interviews of parents of blind children are indicated in table 62. Traditionally, reasons for non-attendance have been attributed to lack of awareness and long distance to hospital (resulting in problems with transport) and barriers resulting from poor communication from service providers have been overlooked .Some staff have solely focused their counselling skills on emergency and treatable eye conditions and have told parents who have children with irreversible causes of blindness (such as cornea blindness and retinal diseases) that nothing can be done, instead of counselling parents to access other interventions for educational and rehabilitation needs of the child, which are equally important and could benefit the child. It is a concern that some parents of children who were identified with cataract reported to have gone to the health centre, but were told to wait at home, yet information is available that cataract in children should be taken as an emergency, to prevent long standing delays that can have irreversible consequences on the visual recovery of the child [115, 117]. One explanation for this wrong advice is that health staff are used to dealing with adult with cataracts, who are told to wait in their communities until there is an eye camp, and then they are taken to a district hospital for surgery. In the midst of many other life threatening conditions seen at a health centre, even though some staff may be aware that cataract in a child is an emergency and requires immediate referral, this may-be still overlooked; in order to prioritise other life threatening conditions. One way to overcome this barrier would be to design brochures with pictures of children with cataract, including the management, and distribute them for displaying on notice boards in all health centres in Malawi, so that staff can be reminded to refer cases immediately.

Children identified by HSAs were more likely to attend a health facility before attending the eye examination session than those identified by KIs (Table 61), perhaps because HSAs official role gives them more authority. It is also possible that communities have less confidence in their health facilities as regards to eye service provision, and that when it is announced by HSAs that a team that do not usually work at the health facility is coming to examine eye patients, patients may turn up to seek alternative views. Unfortunately, KIs would not have this opportunity to announce at a health facility, and this may result to less of the identified numbers attending. Education of the mother has been linked to care seeking behaviour for illness in children [281-284]. Most studies have reported a positive relationship between education and care seeking behaviour but one study from India reported a possibility an inverse relationship between education and health seeking behaviour especially in the very highly educated mother [284]. The study looked at factors that affected decision to seek treatment in a rural area in Kerala, India and this included education of the mother. They noted that more maternal education was associated with initial less childhood medical care; educated mothers tended to neglect less serious childhood illnesses probably because the educated mother had adequate resources to obtain better care elsewhere if the condition worsened.

In this study, an inverse relationship was also noted between mothers' education and children attendance at a health centre, with the odds of uneducated mothers, for sending a child listed by an HSAS or KI, to a health facility, being 3.9 times to the odds of well-educated mothers (Table 61). As in the case with the India study [284], a possible explanation for such differences in decision making could be that better educated mothers may understand that their children's eye condition is not serious enough to warrant immediate reporting at the health centre, and also they may know that the health centres do not have on a regular basis specialized staff who attend to eye patients, and so they may decide to wait until when they hear someone else is coming or may want to get enough resources to go for treatment at a place which has a dedicated eye personnel. On the contrary, uneducated mothers may not understand the difference between a general health centre staff and a specialized eye staff and can be easily convinced by the KIs or HSAs to attend the health centre even when the child does not have a serious condition.

5.2.8 Prevalence and causes of blindness

5.2.8.1 Prevalence lower than expected

The study only identified a small proportion of all blind children (Table 45) expected in this region in accordance to an article by Chandna and Gilbert[28]. Several reasons can be given to explain the lower than expected prevalence, viz:

a) The numerator is lower than expected, due to the following:

i. Not all blind children were found in the study area.

Evidence to support that children could have been missed include the disparity in the numbers of children obtained by KIs and HSAs (more for KIs than HSAs), and information that some allocated villages were not visited. Indeed, it has been published that even though the key informant method is an effective way of finding children in the community a shortfall is that it usually underestimates the prevalence [13, 285]. However, with only less than half of all children identified by KIs using the door to door method, one may wonders how such a large number could have been missed. Possibilities of missing very young children are high, because the parents may not have realized there was a problem, or if they realized something was not right they may not have acknowledged it. Also, as it was noted during the qualitative studies during the pilot, when it comes to children disabilities, including blindness, many parents (especially fathers) experience a sense of shame about having a disabled child, and they keep the child hidden away. In some communities, children with disabilities are sent away to live with grandparents far away from their parents' original homes, and will not be counted as blind children from that area. Other children are sent (damped) to residential schools for the blind, and are not collected when the school term is over.

ii. The community may have misunderstood the term "blind", meaning totally blind i.e. unable to see even light in either eye. This would have resulted in children with vision of less than 3/60 but with light perception being missed, as they were not thought to be blind.

iii. There is a higher mortality rate among blind children than anticipated, especially among those with cortical blindness. This evidence is obtained by observations that there is a lot of cortical blindness in the very young ones, and the numbers reduce as the ages go up (Figure 31). Children with cortical blindness often have other disabilities, such as cerebral palsy, which will be associated with a very high mortality in rural Africa, and these children often die at a younger age. If studies are conducted much later after these children are dead, less numbers of cortical blindness will be reported.

iv. Blind children were not there on the day of the door to door visit as they were at school. However, this is unlikely to be case as most schools are within a short distance in the community and the children could have been followed up/called back by KIs/HSAs.

b) The denominator is higher than the actual number of children in the study areas

The study used an estimate of 42% for the proportion of the total population who are children in the study area. If in reality the proportion is lower, (say 35 %), then a higher prevalence will be obtained;

and if it is higher (say 50%) then a lower prevalence will be obtained; and both these will have a big impact on the prevalence estimate.

c) The prevalence estimate was an over estimate

There are a number of reports that state that many of the cause of blindness in children are being controlled in developing countries through vitamin A supplementation and measles immunization, with countries like Malawi reporting up to 90% coverage for both. This may be having a greater impact on lowering the incidence of cornea blindness in children in Malawi than anticipated. There have also been advances in paediatric eye care services in last few years, which may mean that some of the cataract blind children may have had their sight restored and do not come again for follow up or examinations in the community.

Interestingly the more people trained per head of child population leads to a higher prevalence as was noted for Zomba and Mangochi (Table 46). It is therefore possible that an even higher estimate would have been obtained if more health workers were trained, but this would have to be balanced with the increase in the overall cost of training them. Cost effectiveness was not looked at in this study, and is one of the limitations of the study.

One way of determining the true prevalence would be to conduct a population based survey in the same area and compare with KI findings; however, this would be an expensive exercise to undertake.

5.2.8.2 Causes of blindness and severe visual impairment (SVI**)**

Blind schools and annexes have predominantly been used to ascertain causes of blindness in children in Africa. Over the last few years there have been attempts to generate information from the community in some countries such as Ghana[53], Malawi[162] and Tanzania[286]. Information on the causes of blindness and visual impairment is useful for planning childhood blindness programs in rest of sub-Saharan Africa. The specific causes of blindness and severe visual impairment are discussed below. Cortical blindness and cataract were the two commonest causes of bilateral blindness and severe visual impairment followed up by optic nerve atrophy and cornea scarring.

i) Cortical blindness

The major causes of cortical blindness are: asphyxia, hypoxia or ischemia (due to problems occurring during the birth process or due to other settings); developmental brain defects; head injury; hydrocephalus and infections of the central nervous system, such as cerebral malaria[287], meningitis and encephalitis[288]. Lesions of the Central Nervous System (CNS) are the commonest causes of blindness and severe visual impaired (SVI) in the established market economies[13] where preterm birth is a major contributing factor. However, in sub-Saharan Africa (SSA) very premature babies rarely

survive. Infections and birth asphyxia are the commonest causes of cortical blindness in low income countries, and the diagnosis is often by exclusion of all other organic causes. The high proportion of cortical blindness in this population based study is in contradiction to data from school for the blind [13, 50], where children with additional disabilities are often not allowed access. Malawi has reported a marked decline in under-five mortality rates and it is possible that more children with cortical damage are surviving, being managed in district hospital neonatal units. If this indeed was the case, then more cases of cortical blindness will be evident in future. The result would not only lead to an increased prevalence of blindness and disability, but also to a change in the distribution of causes. Paradoxically, despite improvements in under-five mortality rates, by the time this study was done in 2010, Malawi had, according to the World Health Organisation, maintained very high maternal mortality ratios (MMR); being 1,800 deaths per 100,000 live births in 2003- the highest in the world [245]. This is however not supported by Colbourn et al. [289], who recently reviewed literature for population-based studies that provided estimates of the maternal mortality ratio (MMR) in Malawi, for a period of between 1997 and 2010. They concluded that MMR in Malawi must have increased from 317 maternal deaths/100,000 live-births in 1980 to 748 in 1990, before peaking at 971 in 1999, and finally falling to 846 in 2005, and 484 in 2010. The recent Demographic and Health survey (DHS 2013) estimates the MMR at 510 maternal deaths/100,000 live-births. Since MMR is a good indicator of levels of obstetric care, it may also indirectly reflect levels of care that babies receive on delivery. There may therefore be a positive relation between the number of children with cortical blindness and MMR, but this would need further exploration.

ii) Cataract

In this study cataract was the second commonest cause of blindness and visual impairment, contributing to 18.1% of all the causes. When combined with pseudophakia, the two contributed the same as cortical blindness (Figure 32). Some causes of cataract in children can be prevented (congenital rubella and other infections) and cataract is usually treatable (cataract surgery).

Blindness from cataract remains a problem in developing countries due to either parents not presenting with their children, or presenting very late with consequent amblyopia. The reported decrease in cornea blindness in developing countries [54, 102, 106, 161, 290, 291] has made cataract a relatively more important cause of blindness. Unless reasons why children with cataract do not come or come late at hospital are understood and addressed at the community level, paediatric eye units will continue handling only a few children with cataract. Community methods such as the KI method provide a good forum where eye health workers can directly link with the community members and understand reasons for such health seeking behaviours. For the children that attend the tertiary eye hospital, cataract surgery should result in restoration of vision in the child if the community is to understand the importance of surgery. In this study,

all children listed who had cataract surgery (N=12) had poor outcomes (3 were blind, 2 were SVI). Regardless of the cause of the poor outcome (selection, surgery or long term sequel), this has the potential to discourage other parents who have children with cataract bringing them to the hospital for surgery. It is possible that there were other children who had cataract surgery in the same communities and had good visual outcomes; these could not have been listed. Children who have poor outcome after cataract surgery are likely to be found in communities, and they may be anticipating better help. A recent study from eastern Africa that included Malawi found that a large proportion of children with very poor vision in blind schools/annexes had had cataract surgery when they were young, suggesting that results of cataract surgery in those children were not desirable [156].However, we do not know how many children would have had good outcomes as these would not be registered at blind schools/annexes. The study was meant to compare changes in causes of blindness in children admitted at blind schools/annexes within a 16-year period, and found that cataract/pseudophakia were becoming relatively more common causes of admission in comparison to cornea scarring. Our study has highlighted the challenges of managing cataract in low income countries (especially in sub-Saharan Africa). Cases of children with cataract may be identified from the community early and even have excellent intraocular surgery, but unless there is proper post-operative management, children may develop long term complications such as posterior capsule opacification. It is therefore necessary that clear protocols of follow up are in place, and that parents of children who had cataract surgery are absolutely clear that their children need to come back for follow up for a number of years, and that mechanisms to assist with transport reimbursement are put in place. Children that do not turn up at an agreed date need to be reminded through a telephone, and may need to be actively followed up in the community [292]. The presence of a strong community component in any project focusing on cataract in children need to be emphasized and appropriate resources need to be allocated not only for the surgery/optical services but for the community work. Mechanisms also need to be put in place at the hospital to monitor reasons for the poor visual outcomes in children (selection of cases, surgical reasons, or long term sequel) so that appropriate measures can be taken.

iii) Cornea blindness

In this study, bilateral cornea blindness (8.4%) was much less than cataract (18.1%) (Figure 32). This finding is supported by recent studies that suggest that cornea blindness is still a frequent cause of blindness in Africa but is on the decline in relation to cataract [13, 156, 162, 290, 291]. Cataract is becoming a relatively more important avoidable cause of blindness in children. If these findings are compared with an earlier study of xerophthalmia in Malawi over 20 years ago, the changes are remarkable. The earlier population based survey conducted in a different area of the southern region of Malawi found that cornea opacity secondary to Vitamin A deficiency was the only cause of blindness in all cases[47] and that the rate of xerophthalmia cornea scarring was 10 times higher than the WHO criteria for a disease to be of public health importance[293]. However, it should be noted that the study focused in areas where

xerophthalmia was thought to be a problem (Lower Shire valley), and that the teams only examined children for evidence of xerophthalmia/cornea scarring, such that children with cataract may well have been missed. Nevertheless, the result was that a series of public health interventions that included Vitamin A supplementation and measles immunization were then initiated and implemented over a number of years. It is possible that some of these efforts (especially the vaccines) contributed, not only to the falling under-five mortality rates at that time as was reported [63, 64], but also to reduction in blindness from xerophthalmia [102]. Recently, Kanyuka et.al [249], using representative household surveys, estimated child and neonatal mortality for the years 2000–2014, and quantified the number of children that were saved (280 000 children's lives saved between 2000 and 2013), attributable to various child health interventions, which included treatment for diarrhoea, pneumonia, and malaria (23%), insecticide-treated bed nets (20%), vaccines (17%) , reductions in wasting (11%) and stunting (9%), facility birth care (7%), and prevention and treatment of HIV (7%).

There is need to continue measures to control blindness from cornea diseases which is entirely preventable so that in the near future no children should be blind from cornea scarring. Successes that are apparent in the reduction of bilateral blindness from cornea opacity may not be replicated when it comes to unilateral causes of blindness and visual impairment, as the most common cause is injury. The study shows that cornea opacity was not only the commonest cause (53.3%) of unilateral blindness, but also that the prevalence was much more than that of unilateral cataract (Table 54). In terms of aetiology causes of unilateral blindness, childhood related factors (trauma being the most likely cause) were the commonest cause and contributed to 48.1%.

More than 200 children examined who were normal according to the WHO category had a significant visual impairing pathology in one eye (Table 53). In terms of using the study information for planning cataract services, if only the number of bilateral blind children is used for calculating the needs, resources may not be adequate to cover children with unilateral cataract who may also benefit from surgery despite having amblyopia. As illustrated in Table 55, cortical blindness and cataract are shown as the two most importance causes of blindness and visual impairment in children that may need priority. On the other hand, preventing cornea opacity through public health programs (such as community awareness) that addresses dangers of trauma (the commonest cause) should be a priority because the number of single eyes affected is large.

iv) Refractive errors

In this study, refractive errors were not a common cause of blindness and severe visual impairment, contributing to only 7.2% of the causes (Figure32). This is not surprising as refractive errors mainly cause visual impairment, evidenced in this study by the fact that the commonest cause of visual impairment was refractive error (Table 49). It may not be easy for KIs and HSAs to identify children with refractive errors without testing them or relying on parents'/teachers reports, and so the numbers

obtained are reasonable. However, it should be noted that school screenings are not cost effective especially in black African schools in sub-Saharan Africa where the prevalence of refractive errors in all ages among the school going pupils is approximately 1% [191, 294].

v) Other causes

Although optic nerve atrophy and retinal conditions are a common cause of blindness and visual impairment, these conditions are usually not avoidable. In contrast, conditions such as phthisis and disorganized eyes may either be avoidable (from infections or trauma) or unavoidable (congenital causes, such as microphthalmia).

vi) Etiological causes

In regard to etiological causes (which is a more useful category for planning) in the majority of cases of BL/SVI (43.4%) the time when the child was affected was unknown; this was seconded by BL/SVI which occurred in childhood (28.9%). This finding is similar to what has been reported in most studies of blind children in developing countries[23]. The results suggest that with strengthening of primary eye care and health systems potentially up to half of causes of blindness (those occurring in prenatal and childhood) in the developing world could be avoided.

5.2.9 Blindness and school attendance

There are several reasons why blind children were more likely never to have been to school or to drop out of school than their sighted peers (Table 64). Blind children in these communities face many challenges that may hinder them from attending school, some of which were highlighted in the pre-pilot phase of this study. Blind children have difficulties in conducting activities of daily living that require vision (bathing, eating, walking, etc.) and there are a lot of myths about blindness in the community so that blind children are often stigmatized. These factors make blind children not want to start school or to drop out of school. In-terms of opportunities to progress with education, currently less than half of children in primary school are selected to attend secondary school on first attempt of examinations, and this number is even less for blind/visually impaired children [248].

Hence even if some children may be keen to progress with their education, the quota system of secondary intake limits their chances. In addition, for the sake of their safety, parents may be overprotective and undermine the children's self-esteem and make the children lose confidence. Blind children reported that they were sometimes locked up by their parents preventing them from hurting themselves, particularly in the farming season when the whole family is away most of the day. Children had no food until the parents came back from the farm. Reports from children that were in school and staying on full board indicate that the school was often taken as a "safety net" where children could express their freedom and be allowed to develop relationships with peer blind and normal sighted

children. The result from the pre-pilot qualitative studies showed that blind children who were attending school had the same ambitions and expectations as sighted children, and were happier and had positive attitudes to life than those not attending school. These findings have highlighted the importance of properly counselling parents with blind or severely visually impaired children, of the need and value of their child to attend an appropriate school. The findings may be used to influence in country policies that are needed in relation to the adequate provision of schools that have an inclusive approach to disability, and which are adequately resourced. The United Nations Educational and Scientific Cultural Organization(UNESCO) reports that more than 90% of children with disabilities in developing countries do not attend school[295]. If the UN Millennium Development Goal(MDG) number 2 that aimed to achieve universal primary education by 2015 through ensuring that children everywhere, boys and girls alike, were able to complete a full course of primary schooling, was to be achieved, then current education provisions for disabled children needed to be increased.

5.3 Strengths and limitations of the study

The following strengths and limitations need to be taken into consideration in interpreting the results of the study.

Strengths

1.Good planning

The earlier, “one-year pilot study” ensured that methodological and logistical problems were addressed and changes implemented in the main study. Adapting the methodology (standard methodology that has been tested in several countries) for use by both KIs and HSAs meant that the same comparable procedures and steps were undertaken throughout the study.

2.Multiple means of data collection

The mixed methodology type of collecting data (quantitative and qualitative) meant that data collected from one method could be easily validated by another method.

3.Absence of community program involving both KIs and HSAs

The absence of another community program in the study area that neither involved HSAs nor KIs in identifying blind children during the study period and the testing of the KIs/HSAs knowledge before and after training meant that differences between the two groups could be attributed to the study and not to other factors (such as pre-existing knowledge).

4.Randomisation

Randomisation of the clusters to either the HSAs or KIs ensured that potential confounders between the two groups were evenly distributed. Also, the availability of the updated census data at the start of the study ensured that accurate cluster populations and population per village were obtained.

5.Designed manuals

The absence of training manuals in blindness in children for primary health care (PHC) and midlevel eye health workers at the start of the project resulted in the manuals designed for this study being used as official manual for PHC and midlevel eye health workers, a direct policy change.

6.Presence of a full-time childhood blindness coordinator

The availability of a full-time childhood blindness coordinator during the study period ensured that fieldwork and progress by KIs and HSAs was effectively coordinated and monitored.

Of course others may argue that introducing research staff that are external to the community, such as **"the coordinator"**, may lead to the Hawthorne effect [296], a term that refers to *"a change in behaviour among certain individuals involved in research, primarily due to attention being received from researchers, and not due to the manipulation of other independent variables".* The result is that some individuals or groups work harder and perform better when they are being observed, but do not do the same when they work in a natural setting. In this study, both KIs and HSAs were being monitored by the childhood blindness coordinator, so the Hawthorne effect would be expected to play the same role in both groups.

Limitations

1. Only one third of the HSAs working in the selected clusters were trained.

The fact that only a third of all the HSAs and an equivalent number of KIs were trained is a limitation in this study as results of findings from the selected groups are being extrapolated to the rest of the workers in the catchment population. The decision to only train a few was based on both financial and logistical implications, as it would have been very costly and very time consuming to train all the HSAs and an equivalent number of KIs. Moreover, it was assumed (based on findings from the pilot study) that those selected would be willing to cover other neighbouring villages. Due to the large number of HSAs available, different training and identification strategies may need to be adapted if at all HSAs were to be involved, but the use of HSAs is not recommended.

2. Comparison between KIs and HSAs based only on part primary eye care(PEC)

This study only compared successes of identifying blind and visually impaired children among KIs and HSAs. Identifying children with visual problems only forms a limited part of primary eye care and is relatively easy , however the scope of primary eye care is vast and includes adults and all elements of primary health care[220], such as health education to prevent local endemic diseases such as trachoma and detect treatable diseases such as cataract, provision of essential drugs for treating simple eye diseases such as conjunctivitis, and providing counselling on more difficulty non reversible conditions such as glaucoma. It may be that when given a specific PEC task such as identifying visually impaired children KIs may be better at case identification than HSAs, but when given multiple complex PEC tasks, the opposite may be true and HSAs may outperform KIs. Also, rolling out the full PEC strategy in the communities would involve much longer periods of training and more skills and knowledge transfer (in comparison to 1 day as was in this study), and HSAs maybe better at retaining the multiple skills and using them in the community, but there is no evidence to support that this would be the case. Also, even if HSAs retained more skills, there is no guarantee that these would translate to them being more productive, as other factors like overall daily workload are equally important and do affect the HSAs performance.

3. Contribution of roles of HSAs supervisors and Medical assistants in charge of Health centre not determined

During the study period, HSAs still needed to still report to their supervisors at Health centres for other duties such conducting immunizations and health promotion activities. In addition, they also needed to report to the childhood blindness coordinator about their progress in case identification of blind and visually impaired children. On the other hand, KIs did not have an obligation to report to the health centre. The study was not able to determine to what extent the supervisory role and the reporting mechanism affected the productivity of KIs versus HSAs. It is possible that HSAs could have been deterred from going to identify more children in their villages due to some unexpected roles given by the supervisor/medical assistant.

4. Evaluation of complex interventions is challenging

Even though the study compared the effectiveness of HSAs versus KIs in the present setting, it should have been more beneficial in evaluating how the whole process of integrating primary eye care would be rolled out in the general health care and what would be the contribution of KIs and HSAs. Though useful, evaluating complex interventions can be challenging: very expensive, time involving and need health

expertise with different backgrounds such as health economists, social scientists, clinical epidemiologists and clinical specialists.

5. Limited number of clusters to balance out all confounders and limited analysis

The number of selected clusters, 12 in total; 6 in each district, and 3 for each arm of the study in each district, many not have been enough to balance out all the measured and unmeasured potential confounders, which could have influenced the study results. The multivariate regression model was built by including only those univariate odds ratios that were significant at 95% level ($p<0.05$), based on statistical advice at that time, which is no longer recommended, and this may have affected the analysis.

With these limitations in mind, if the study was to be redone either in Malawi or elsewhere, a much larger number of clusters in each arm (at least 15), but with smaller populations would be proposed, and a robust statistical analysis that would involve adding all variables in building the multivariate model, regardless of whether these were significant or not on univariate model, would be done.

5.4 Implications for scaling up primary eye care

The findings of the study suggest that KIs are better case finders for cases of blindness and visual impairment in children. To scale up the method of using key informants in the rest of the country, thousands of key informants would need to be trained on how to identify children. Since it is not clear how the key informants would perform in other areas of PEC which do not involve case identification, it would not be advisable at this moment to extend all services of PEC to KIs. On the other hand, HSAs are being used in maternal and child health and will continue doing so as there is no evidence that replacing them with KIs would be more cost effective. Health surveillance assistants have other skills in primary health care which benefit the community. Training KIs in all aspects of primary health care or even only primary eye care would be very expensive. It is also obvious that in the long term, the high attrition rates among the KIs would remain a challenge. As a compromise, we agree with recommendations of the report on systematic review of community health workers[269] that they should be recognized as a formal group that can be used to improved health of communities. We suggest that for Malawi, key informants be trained and used to complement HSAs in situation where specific health interventions need to provide results in the short term and where delays have irreversible long consequences (such as blindness in children resulting from cataract).

Health surveillance assistants should continue to implement routine activities that have long term benefits in improving health of communities until more information on the cost -effectiveness of using KIs in those areas is available.

It is of concern that some children who were correctly identified with cataract and went to a health facility were not referred to an eye hospital but sent back home by health centre with no adequate explanation given to parents. This has implications for scaling up primary eye care in Malawi. It means for PEC to effectively scaled up, both identifiers from the communities and key staff from health centres need to be oriented about this programme, so that once identified in the community, children are not sent back from the health centres. This would however be very costly to implement.

5.5 Future research

This study has raised several important questions regarding blindness in children in developing countries and some of these can be addressed through the following research topics.

1. Studies on the roles and productivity of the entire health work force at the community level (medical assistants, nurses, HSAs) in primary eye care and how these relate to improvements in eye care at secondary and tertiary level.
2. Studies on cost effectiveness of eye care programs that use Health Surveillance Assistants versus Key informants.
3. Studies are needed to evaluate quality of eye care provided by key informants as compared to heath surveillance assistants in management specific eye condition at primary level.
4. Studies are needed to assess how effective key informants would be when using different models of remuneration (salaried/non-salaried).
5. Studies on the effectiveness of Key informants when given many tasks in their community.
6. Studies on how to identify innovative mechanisms of maintaining the sustainability of programs that use key informants.
7. Studies to determine to what extent does participation of Key informants versus Health surveillance assistants in eye health programs address the issues of equity and access, which are some of the key principles for Primary Health care.
8. Studies are needed to demonstrate how Key informants should be linked to the wider health system in terms of referrals and supervision.
9. Studies to determine to what extent does integrating of primary eye care into PHC result in improvement in eye-care in low income countries where main focus of primary health care is prevention and treatment of life threatening illness in children and adults (childhood infections, HIV/AIDS, Malaria).
10. Studies to determine the long term visual outcomes of cataract surgery in low income countries and how these impact of the child's education.
11. Studies on the social cultural and socio economic changes that occur in the family once the child has had successful sight restoration surgery.

5.6 Conclusions and Recommendations

5.6.1 Conclusions

This study compared the effectiveness of using trained key informants versus health surveillance assistants in identifying blind and visually impaired children in Malawi. The conclusion is that Key informants (KIs) were more effective than Health Surveillance assistants (HSAs) in identifying blind and visually impaired children. This was partly because KIs had fewer tasks and spent more time in villages than HSAs, who often had many tasks to accomplish. Both groups demonstrated more success in identifying children where the door to door method was used in comparison to other methods. Overall, the number of children identified by both group were less than what would be expected using the available estimates. Cultural factors, traditional beliefs, misinformation from health workers and other factors prevented parents and children from accessing eye health services. In addition, accessibility of eye services to children is dependent upon the education status of the mothers. Blind and visually impaired children were less likely to be in school in comparison to sighted children. Even though sight restoration surgery, optical correction and /or rehabilitation was done, in children whose parents accepted the intervention, no long term follow up was done in regard to their social economic and family dynamics.

5.6.2 Recommendations

1. Avoidable (preventable or treatable) causes of blindness and visual impairment in children contribute a large number of cases in Malawi, and the focus of paediatric eye care programs should be to address these.
2. Programs that address the education of the girl child need to be scaled up, as these are likely, in the long term, to contribute to access and improvement of child eye health services.
3. Blindness and visual impairment in children interfere with the children's education, and need to be controlled, for children to get equal opportunities for education
4. Mixed methods of data collection (population based surveys, key informants, blind schools, hospital records) need to be under-taken to confirm prevalence and causes obtained in this study.
5. The long-term productivity for health workers (KIs and HSAs) and sustainability of health services when financial incentives are provided/not provided need to be further explored.
6. The process of integrating primary eye care in the primary health care and the benefits in regard to childhood blindness programs need to be further explored.
7. Attempts should be made to document social cultural and socio economic changes that occur in the family once a child has had successful sight restoration surgery.

5.6.3 Update on care of children with cataracts and global health estimates on child mortality

The past 6 years since most of this work was completed has seen improvements both in eye-care and global health, with some more community tools developed, and better health systems research being undertaken.

In terms of eye-care, almost all children with congenital and developmental cataracts are getting intraocular lenses (IOL) rather than contact lenses, as IOL's have become more accessible. Also, tools for empowering community health workers to help detect avoidable blindness early, have been developed, and these include the multifunctional, smartphone based Portable Eye Examination Kit (Peek), a low-cost device for managing and monitoring the treatment of patients, even in the remotest of settings (http://www.peekvision.org/).Peek Retina slips neatly over the in-built camera on a smart phone, and when used with the Peek app, while holding the phone close to someone's eye, it will auto-focus to show the retina on screen, and the image can be taken and sent to a doctor or nurse who can assist with diagnosis. Cataracts can be viewed clearly enough for treatment classification, and signs of glaucoma, and optic nerve disease can be identified.

For global health, several institutions, including the London School of Hygiene and Tropical Medicine, have over the last 6 years been conducting good quality health systems research, which has been published in high impact journals such as the Lancet, under "Every New-born Lancet series" (http://www.thelancet.com/series/everynewborn). The Centre for Maternal, Adolescent, Reproductive, and Child Health (MARCH), is a hub for women's and children's health at the LSHTM, and comprises of academicians working in 100 countries (http://march.lshtm.ac.uk/).These provide expertise for better global and national estimates for new-born (impact indicators, quality of care improvement approaches, definition and tool development), signal functions for health facilities, health systems research, health policy evaluation, and evaluation of complex interventions. There are now more accurate data for under five mortality rates, including those from Malawi[249].

As a researcher, after completing this study, I have continued with other research projects on blindness in children, attracting several funding sources, and building a strong team in Malawi. In addition, on global health, I am involved in a multi-country clinical trial on child mortality, known as "mortality reduction after oral Azithromycin therapy" (MORDOR), as a local principal investigator in Malawi.

5.7 Publications resulting from this study

Publications that I have contributed as an author that are related to this study are listed below. These include papers that were directly published as a result of this study, and those that were published due to other work related to this topic. In all this, I contributed to the writing of the initial draft, and was responsible for editing and submitting the articles.

Publications arising from this study

Khumbo Kalua, Ruby Tionenji Ng'ongola, Frank Mbewe, Clare Gilbert (2012). Using primary health care (PHC) workers and key informants for community based detection of blindness in children in Southern Malawi, Human Resource Health 10:37. 2012 doi: 10.1186/1478-4491-10-37

Kalua K, Shija F Shirima S, Lewallen M, Courtright P (2010) Using Key Informants to identify and refer children who need eye care services. A manual for Africa. Kilimanjaro Centre for Community Ophthalmology, Tumaini University,Moshi Tanzania: 1-20. Supported by USAID.

Publications from further studies which addressed issues raised by this study

Kalua K, Gichangi M, Barassa E, Eliah E, Lewallen S, Courtright P. A randomised controlled trial to investigate effects of enhanced supervision on primary eye care services at health centres in Kenya, Malawi and Tanzania. BMC Health Serv Res. 2014; 14 Suppl 1: S6. doi: 10.1186/1472-6963-14-S1-S6. Epub 2014 May 12.

Schulze Schwering M, Finger RP, Barrows J, Nyrenda M, **Kalua K.** Barriers to uptake of free pediatric cataract surgery in Malawi. Ophthalmic Epidemiol. 2014 Jun; 21(3):138-43. doi: 10.3109/09286586.2014.892139. Epub 2014 Mar.

Kalua K, Gichangi M, Barassa E, Eliah E, Lewallen S, Courtright P. Skills of general health workers in primary eye care in Kenya, Malawi and Tanzania. Human Resources for Health [2014, 12(Suppl 1): Published online 2014 May 12. doi: 10.1186/1478-4491-12-S1-S2

Andriamanjato HH, Mathenge W, **Kalua K**, Courtright P, Lewallen S. Task shifting in primary eye care: how sensitive and specific are common signs and symptoms to predict conditions requiring referral to specialist eye personnel? Human Resources for Health [2014, 12(suppl 1):s3-s3]

Schulze Schwering M, Msukwa G, Spitzer MS**, Kalua K**. Pediatric cataract surgery in Malawi].Ophthalmologe [2014, 111(4):348-353]

Kaphle D, Marasini S, **Kalua K**, Reading A, Naidoo KS. Visual profile of students in integrated schools in Malawi. Clin Exp Optom. 2015 Jul; 98(4):370-4. doi: 10.1111/cxo.12269. Epub 2015 May 5

Schulze Schwering M, Gandiwa M, Msukwa G, Spitzer M, **Kalua K**, Molyneux EM. Ophthalmologe. Retinoblastoma in Malawi: why are admissions too late?2014 Dec; 111(12):1189-93. doi: 10.1007/s00347-014-3117-x.

Kalua. K, Masiye, F. Jumbe, V. Barrows. J, and Sheffield. V, (2013). Finding community solutions to improve access and acceptance of cataract surgery, optical correction and follow up in children in Malawi. Health, 5, 1533-1540. doi: 10.4236/health.2013.510208.

Khumbo Kalua, Misheck Nyirenda, Susan Lewallen, Paul Courtright (2013). Three-year follow up of primary health care workers trained in identification of blind and visual impaired children in Malawi. DOI: 10.4236/health.2013.511241

M Schulze Schwering, M Nyrenda, M S Spitzer, **K Kalua** (2013) Visual impairment and blindness in children in a Malawian school for the blind. Klinische Monatsblätter für Augenheilkunde 08/2013; 230(8):820-4. ·

Gogate P, **Kalua K**, Courtright P (2009) Blindness in childhood in developing countries: time for a reassessment? PLoS Med 6: e1000177.

Earlier but related publications:

Kalua K, Patel D, Muhit M, Courtright P (2008) Productivity of key informants for identifying blind children: evidence from a pilot study in Malawi. Eye (Lond) 23: 7-9.

Kalua K, Patel D, Muhit M, Courtright P (2008) Causes of blindness among children identified through village key informants in Malawi. Can J Ophthalmol 43: 425-427.

Kalua K (2007) Use of key informants in determining the magnitude and causes of childhood blindness in Chikwawa district, southern Malawi. Community Eye Health 20: 8.

References

1. *International Statistical Classification of Diseases and Related Health Problems,10th Revision. WHO,Geneva* 1992: p. 456-457.
2. Johnson G and A. Foster, *Prevalence,incidence and distribution of visual impairment.*, in *The Epidemiology of Eye Disease*, G. Johnson, et al., Editors. 2003, Arnold: London. p. 3-30.
3. Foster, A., *VISION 2020:from epidemiology to program*, in *The Epidemiology of Eye Disease*, G. Johnson, et al., Editors. 2003, Arnold: London. p. 373-384.
4. Resnikoff, S., et al., *Global data on visual impairment in the year 2002.* Bull World Health Organ, 2004. **82**(11): p. 844-51.
5. Resnikoff, S., et al., *Global magnitude of visual impairment caused by uncorrected refractive errors in 2004.* Bull World Health Organ, 2008. **86**(1): p. 63-70.
6. Dandona, L. and R. Dandona, *Revision of visual impairment definitions in the International Statistical Classification of Diseases.* BMC Med, 2006. **4**: p. 7.
7. *WHO.Change the definition of blindness.http://www.who.int/blindness/en/.* 2009.
8. Day, S., *Normal and abnormal visual development*, in *Paediatric Ophthalmology*, D. Taylor Editor. 1997, Blackwell science: London. p. 13-28.
9. Salamanca, M. and D. Kline. *Visual development.http://psych.ucalgary.ca/PACE/VA-Lab/Marcela/Pages/page35a.html*. 2011 [cited 2011 23/06/2011]; Available from: http://psych.ucalgary.ca/PACE/VA-Lab/Marcela/Pages/page35a.html.
10. Baiyeroju, A.M., et al., *Managing eye health in young children.* Community Eye Health J, 2010. **23**(72): p. 4-11.
11. Balyeroju, A., et al., *Managing eye health in young children* Comm Eye Health J, 2010. **23**(1): p. 4-11.
12. Helveston, E., *Understanding, detecting and managing strabismus.* Community Eye Health, 2010. **23**(72): p. 12-14.
13. Gilbert, C. and J. Rahi, *Visual impairment and blindness in children*, in *Epidemiology of Eye Diseaase*, G. Johnson, A. Foster, and C. Gilbert, Editors. 2010, Imperical College Press: London.
14. Day SH;DA, S., *Chapter 9. History, examination and further investigation. Taylor D., Hoyt CS., editors. London: Elsevier Saunders; .* 2005.
15. Leat, S.J., et al., *Development of Visual Acuity and Contrast sensitivity in Children.* Journal of Optometry, 2009. **2**: p. 19-26.
16. Rosser, D.A., D.A. Laidlaw, and I.E. Murdoch, *The development of a "reduced LogMAR" visual acuity chart for use in routine clinical practice.* Br J Ophthalmol, 2001. **85**(4): p. 432-6.
17. Birch, E.E., J. Gwiazda, and R. Held, *Stereoacuity development for crossed and uncrossed disparities in human infants.* Vision Res, 1982. **22**: p. 507.
18. Moller, H.U., *Milestones and Normative data*, in *Paediatric Ophthalmology*, D. Taylor Editor. 1997, Blackwell Scientific: London. p. 42-56.
19. Von Noorden, G.K. and A.E. Maumenee, *Clinical observations on stimulus-deprivation amblyopia (amblyopia ex anopsia).* Trans Am Ophthalmol Soc, 1967. **65**: p. 244-55.
20. Taylor, D., et al., *Amblyopia in bilateral infantile and juvenile cataract. Relationship to timing of treatment.* Trans Ophthalmol Soc U K, 1979. **99**(1): p. 170-5.
21. Tyler, C.W. and A.B. Scott, *Binocular Single Vision* in *Duanes Clinical Ophthalmology.Foundation Volume 2.Chapter 24*.
22. vonNoorden, G.K., *Binocular Vision and Ocular Motility.* 1980, CV Mosby: St. Louis.
23. Gilbert, C. and A. Foster, *Childhood blindness in the context of VISION 2020--the right to sight.* Bull World Health Organ, 2001. **79**(3): p. 227-32.
24. Ackland, P., *Contributing to achieve the goal of VISION 2020.* Community Eye Health, 2009. **22**(69): p. 1-3.
25. Foster, A., Gilbert C,Gordon,J, *Changing patterns in global blindness: 1988–2008.* Community Eye Health J 2008. **21**(67): p. 37-39.
26. Foster, A. and S. Resnikoff, *The impact of Vision 2020 on global blindness.* Eye, 2005. **19**(10): p. 1133-5.

27. Dandona, L. and R. Dandona, *What is the global burden of visual impairment?* BMC Med, 2006. **4**: p. 6.
28. Chandna, A. and C. Gilbert, *When your eye patient is a child.* Community Eye Health, 2010. **23**(72): p. 1-3.
29. Gilbert, C., J. Rahi, and E. Quinn, *Visual impairment and blindness in children* in.*Epidemiology of Eye Disease*, G. Johnson, et al., Editors. 2003, Arnold: London. p. 260-285.
30. Reynell, J., *Developmental patterns of visually handicapped children.* Child Care Health Dev, 1978. **4**(5): p. 291-303.
31. Dale, N. and P. Sonksen, *Developmental outcome, including setback, in young children with severe visual impairment.* Dev Med Child Neurol, 2002. **44**(9): p. 613-22.
32. Dale, N. and A. Salt, *Social identity, autism and visual impairment (VI) in the early years.* British Journal of Visual Impairment, 2008. **26**(2): p. 135-46.
33. Dale, N. and A. Salt, *Early support developmental journal for children with visual impairment: the case for a new developmental framework for early intervention.* Child Care Health Dev, 2007. **33**(6): p. 684-90.
34. Reichman, N.E., H. Corman, and K. Noonan, *Impact of child disability on the family.* Maternal Child Health, 2008 Nov. **12**(6): p. 679-83.
35. Jan, J., *The Visual impaired child and family* D. Taylor and C. Hoyt, Editors. 2005, Elsevier Saunders: London.
36. Rahi, J.S. and N. Cable, *Severe visual impairment and blindness in children in the UK.* Lancet, 2003. **362**(9393): p. 1359-65.
37. Dorairaj, S.K., et al., *Childhood blindness in a rural population of southern India: prevalence and etiology.* Ophthalmic Epidemiol, 2008. **15**(3): p. 176-82.
38. Lu, Q., et al., *A population-based study of visual impairment among pre-school children in Beijing: the Beijing study of visual impairment in children.* Am J Ophthalmol, 2009. **147**(6): p. 1075-81.
39. Berhane Y., W.A., A. B., *National survey of blindness, low vision and trachoma in Ethiopia. Addis Ababa, Ethiopia.* Ethiopian Public Health Association, 2006.
40. Fu, P., et al., *[A national survey on low vision and blindness of 0 - 6 years old children in China].* Zhonghua Yi Xue Za Zhi, 2004. **84**(18): p. 1545-8.
41. Nirmalan, P.K., et al., *The Kariapatti pediatric eye evaluation project: baseline ophthalmic data of children aged 15 years or younger in Southern India.* Am J Ophthalmol, 2003. **136**(4): p. 703-9.
42. Khandekar, R., et al., *The prevalence and causes of blindness in the Sultanate of Oman: the Oman Eye Study (OES).* Br J Ophthalmol, 2002. **86**(9): p. 957-62.
43. Dandona, L., et al., *Blindness in the Indian state of Andhra Pradesh.* Invest Ophthalmol Vis Sci, 2001. **42**(5): p. 908-16.
44. Thulasiraj, R.D., et al., *Blindness and vision impairment in a rural south Indian population: the Aravind Comprehensive Eye Survey.* Ophthalmology, 2003. **110**(8): p. 1491-8.
45. Zainal, M., et al., *Prevalence of blindness and low vision in Malaysian population: results from the National Eye Survey 1996.* Br J Ophthalmol, 2002. **86**(9): p. 951-6.
46. Dandona, R. and L. Dandona, *Childhood blindness in India: a population based perspective.* Br J Ophthalmol, 2003. **87**(3): p. 263-5.
47. Chirambo, M.C., et al., *Blindness and visual impairment in southern Malawi.* Bull World Health Organ, 1986. **64**(4): p. 567-72.
48. Zeidan, Z., et al., *Prevalence and causes of childhood blindness in camps for displaced persons in Khartoum: results of a household survey.* East Mediterr Health J, 2007. **13**(3): p. 580-5.
49. Naidoo, K., *Poverty and blindness in Africa.* Clin Exp Optom, 2007. **90**(6): p. 415-21.
50. Muhit, M.A., et al., *The key informant method: a novel means of ascertaining blind children in Bangladesh.* Br J Ophthalmol, 2007. **91**(8): p. 995-9.
51. Kalua, K., et al., *Productivity of key informants for identifying blind children: evidence from a pilot study in Malawi.* Eye (Lond), 2009. **23**(1): p. 7-9.

52. Razavi, H., et al., *Prevalence and causes of severe visual impairment and blindness among children in the lorestan province of iran, using the key informant method.* Ophthalmic Epidemiol, 2010. **17**(2): p. 95-102.
53. Boye, J., *Validating key informant method in detecting blind children in Ghana.* J Comm Eye Health, 2005. **18**(56): p. 131.
54. Muhit, M.A., et al., *Causes of severe visual impairment and blindness in Bangladesh: a study of 1935 children.* Br J Ophthalmol, 2007. **91**(8): p. 1000-4.
55. Morrissey, J.P., et al., *Assessments of community mental health support systems: a key informant approach.* Community Ment Health J, 1994. **30**(6): p. 565-79.
56. McDonald, J.R. and T. Natarajan, *Community care needs of people with AIDS--the key informant study: a research method for policy development, service planning, and achieving consensus.* J Palliat Care, 1989. **5**(2): p. 16-9.
57. Pal, D.K., T. Das, and S. Sengupta, *Comparison of key informant and survey methods for ascertainment of childhood epilepsy in West Bengal, India.* Int J Epidemiol, 1998. **27**(4): p. 672-6.
58. Muhit, M., *Finding children who are blind.* Community Eye Health, 2007. **20**(62): p. 30-1.
59. Courtright, P., M. Chirambo, and S. Kanjaloti, *Collaboration with african traditional healers for the prevention of blindness.* World Scientific Publishing Co. Pte. Ltd,Singapore, 2000.
60. Limburg, H., et al., *Prevalence and causes of blindness in children in Vietnam.* Ophthalmology, 2012. **119**(2): p. 355-61.
61. Cama, A.T., B.T. Sikivou, and J.E. Keeffe, *Childhood visual impairment in Fiji.* Arch Ophthalmol, 2010. **128**(5): p. 608-12.
62. Sommer, A. and F.R. Davidson, *Assessment and control of vitamin A deficiency: the Annecy Accords.* J Nutr, 2002. **132**(9 Suppl): p. 2845S-2850S.
63. Unicef. *The State of the World's Children reports.www.unicef.org*. 2010 .
64. Rajaratnam, J.K., et al., *Neonatal,postnatal,childhood, and under-5 mortality for 187 countries, 1970-2010:a systematic analysis of progress towards Millennium Developmnet Goal 4. The Lancet.2010 Jun 5; 375 (9730):1988-2008.doi: 10.1016/S0140-6736(10)60703-9. Epub2010 May 27.*
65. Gilbert, C.E., et al., *Prevalence of visual impairment in children: a review of available data.* Ophthalmic Epidemiol, 1999. **6**(1): p. 73-82.
66. Sommer, A., et al., *Incidence, prevalence, and scale of blinding malnutrition.* Lancet, 1981. **1**(8235): p. 1407-8.
67. West, K.P. and D. McLaren, *The epidemiology of vitamin A deficiency disorders (VADD)*, in *The Epidemiology of Eye Diseases*, G. Johnson, et al., Editors. 2003, Arnold: London.
68. Herrera, M.G., et al., *Vitamin A supplementation and child survival.* Lancet, 1992. **340**(8814): p. 267-71.
69. Sommer, A., *Vitamin A, infectious disease, and childhood mortality: a 2 solution?* J Infect Dis, 1993. **167**(5): p. 1003-7.
70. Sommer, A., et al., *Impact of vitamin A supplementation on childhood mortality. A randomised controlled community trial.* Lancet, 1986. **1**(8491): p. 1169-73.
71. Rahmathullah, L., et al., *Reduced mortality among children in southern India receiving a small weekly dose of vitamin A.* N Engl J Med, 1990. **323**(14): p. 929-35.
72. Vijayaraghavan, K., et al., *Effect of massive dose vitamin A on morbidity and mortality in Indian children.* Lancet, 1990. **336**(8727): p. 1342-5.
73. West, K.P., Jr., et al., *Efficacy of vitamin A in reducing preschool child mortality in Nepal.* Lancet, 1991. **338**(8759): p. 67-71.
74. Daulaire, N.M., *Childhood mortality after high dose vitamin A.* BMJ, 1992. **304**(6838): p. 1381.
75. Ross, D.A., *Vitamin A and childhood mortality. Ghana Vitamin A Supplementation Trials Study Team.* Lancet, 1993. **342**(8875): p. 861.
76. Stansfield, S.K., et al., *Vitamin A supplementation and increased prevalence of childhood diarrhoea and acute respiratory infections.* Lancet, 1993. **342**(8871): p. 578-82.
77. Pant, C.R., et al., *Impact of nutrition education and mega-dose vitamin A supplementation on the health of children in Nepal.* Bull World Health Organ, 1996. **74**(5): p. 533-45.

78. Barreto, M.L., et al., *Effect of vitamin A supplementation on diarrhoea and acute lower-respiratory-tract infections in young children in Brazil.* Lancet, 1994. **344**(8917): p. 228-31.
79. Venkatarao, T., et al., *Effect of vitamin A supplementation to mother and infant on morbidity in infancy.* Indian Pediatr, 1996. **33**(4): p. 279-86.
80. Donnen, P., et al., *Randomized placebo-controlled clinical trial of the effect of a single high dose or daily low doses of vitamin A on the morbidity of hospitalized, malnourished children.* Am J Clin Nutr, 1998. **68**(6): p. 1254-60.
81. Chowdhury, S., et al., *Effect of vitamin A supplementation on childhood morbidity and mortality.* Indian J Med Sci, 2002. **56**(6): p. 259-64.
82. Fawzi, W.W., et al., *Vitamin A supplementation and child mortality. A meta-analysis.* JAMA, 1993. **269**(7): p. 898-903.
83. Glasziou, P.P. and D.E. Mackerras, *Vitamin A supplementation in infectious diseases: a meta-analysis.* BMJ, 1993. **306**(6874): p. 366-70.
84. Gogia, S. and H.S. Sachdev, *Neonatal vitamin A supplementation for prevention of mortality and morbidity in infancy: systematic review of randomised controlled trials.* BMJ, 2009. **338**: p. b919.
85. Imdad, A., et al., *Vitamin A supplementation for preventing morbidity and mortality in children from 6 months to 5 years of age.* Cochrane Database Syst Rev, 2010. **12**: p. CD008524.
86. Farber, M.D., *National Registry for the Blind in Israel: estimation of prevalence and incidence rates and causes of blindness.* Ophthalmic Epidemiol, 2003. **10**(4): p. 267-77.
87. Al-Merjan, J.I., et al., *Registered blindness and low vision in Kuwait.* Ophthalmic Epidemiol, 2005. **12**(4): p. 251-7.
88. Norn, M., *Prevalence of congenital colour blindness among Inuit in East Greenland.* Acta Ophthalmol Scand, 1997. **75**(2): p. 206-9.
89. Bodeau-Livinec, F., et al., *Recent trends in visual impairment and blindness in the UK.* Arch Dis Child, 2007. **92**(12): p. 1099-104.
90. WHO, *Preventing blindenss in children.A report of the WHO scientific meeting,Hyderabad, India 13-17 April,1999*, WHO/PBL/0077, Editor. 2000.
91. Goh, P.P., et al., *Refractive error and visual impairment in school-age children in Gombak District, Malaysia.* Ophthalmology, 2005. **112**(4): p. 678-85.
92. Ahmad, F., et al., *Popular health promotion strategies among Chinese and East Indian immigrant women.* Women Health, 2004. **40**(1): p. 21-40.
93. Naidoo, K.S., et al., *Refractive error and visual impairment in African children in South Africa.* Invest Ophthalmol Vis Sci, 2003. **44**(9): p. 3764-70.
94. Dandona, R., et al., *Refractive error in children in a rural population in India.* Invest Ophthalmol Vis Sci, 2002. **43**(3): p. 615-22.
95. Murthy, G.V., et al., *Refractive error in children in an urban population in New Delhi.* Invest Ophthalmol Vis Sci, 2002. **43**(3): p. 623-31.
96. Pokharel, G.P., et al., *Refractive Error Study in Children: results from Mechi Zone, Nepal.* Am J Ophthalmol, 2000. **129**(4): p. 436-44.
97. Maul, E., et al., *Refractive Error Study in Children: results from La Florida, Chile.* Am J Ophthalmol, 2000. **129**(4): p. 445-54.
98. Zhao, J., et al., *Refractive Error Study in Children: results from Shunyi District, China.* Am J Ophthalmol, 2000. **129**(4): p. 427-35.
99. Kalua, K., *Use of key informants in determining the magnitude and causes of childhood blindness in Chikwawa district, southern Malawi.* Community Eye Health, 2007. **20**(61): p. 8.
100. Gilbert, C., et al., *Childhood blindness: a new form for recording causes of visual loss in children.* Bull World Health Organ, 1993. **71**(5): p. 485-9.
101. Foster, A., C. Gilbert, and G. Johnson, *Changing patterns in global blindness: 1988-2008.* Community Eye Health, 2008. **21**(67): p. 37-9.
102. Gilbert, C. and M. Muhit, *Twenty years of childhood blindness: what have we learnt?* Community Eye Health, 2008. **21**(67): p. 46-7.
103. ICEH, *WHO childhood blindness software.* http://www.cehjournal.org/files/s0801.html.

104. Rahi, J.S. and C. Dezateux, *Congenital and infantile cataract in the United Kingdom: underlying or associated factors. British Congenital Cataract Interest Group.* Invest Ophthalmol Vis Sci, 2000. **41**(8): p. 2108-14.
105. Gogate, P. and M. Muhit, *Blindness and cataract in children in developing countries 8th Annual Bethune Round Table Conference on International Surgery: May 9–10, 2008, Vancouver, BC.* Community Eye Health, 2009. **22**(69): p. 4-5.
106. Gogate, P., et al., *Changing pattern of childhood blindness in Maharashtra, India.* Br J Ophthalmol, 2007. **91**(1): p. 8-12.
107. Bowman, R.J., *How should blindness in children be managed?* Eye (Lond), 2005. **19**(10): p. 1037-43.
108. Taylor, D., *Congenital cataract, a cause of preventable child blindness.* Archives of Disease in Childhood, 1982. **57**: p. 165-165.
109. Shiels, A. and J.F. Hejtmancik, *Molecular Genetics of Cataract.* Prog Mol Biol Transl Sci. **134**: p. 203-18.
110. Shiels, A., T.M. Bennett, and J.F. Hejtmancik, *Cat-Map: putting cataract on the map.* Mol Vis. **16**: p. 2007-15.
111. Shiels, A. and J.F. Hejtmancik, *Genetic origins of cataract.* Arch Ophthalmol, 2007. **125**(2): p. 165-73.
112. Gilbert, C., et al., *Hereditary disease as a cause of childhood blindness: regional variation. Results of blind school studies undertaken in countries of Latin America, Asia and Africa.* Ophthalmic Genet, 1995. **16**(1): p. 1-10.
113. Chak, M., A. Wade, and J.S. Rahi, *Long-term visual acuity and its predictors after surgery for congenital cataract: findings of the British congenital cataract study.* Invest Ophthalmol Vis Sci, 2006. **47**(10): p. 4262-9.
114. Bronsard, A., et al., *Why are children brought late for cataract surgery? Qualitative findings from Tanzania.* Ophthalmic Epidemiol, 2008. **15**(6): p. 383-8.
115. Mwende, J., et al., *Delay in presentation to hospital for surgery for congenital and developmental cataract in Tanzania.* Br J Ophthalmol, 2005. **89**(11): p. 1478-82.
116. Mahalakshmi, B., et al., *Infectious aetiology of congenital cataract based on TORCHES screening in a tertiary eye hospital in Chennai, Tamil Nadu, India.* Indian J Med Res, 2010. **131**: p. 559-64.
117. Taylor , D., *Paediatric ophthalmology.second edition ,blackwell science.* 1997.
118. Lahbil, D., et al., *[Manifestation of congenital rubella syndrome: clinical and epidemiologic aspects].* Bull Soc Belge Ophtalmol, 2007(303): p. 13-20.
119. Kirwan, C., B. Lanigan, and M. O'Keefe, *Glaucoma in aphakic and pseudophakic eyes following surgery for congenital cataract in the first year of life.* Acta Ophthalmol, 2010. **88**(1): p. 53-9.
120. Wang, V.M., et al., *Diagnosing glaucoma in pediatric aphakia.* Optometry, 2002. **73**(11): p. 704-10.
121. Yorston, D., *Surgery for Congenital Cataract.* Community Eye Health, 2004. **17**(50): p. 23-5.
122. Vishwanath, M., et al., *Is early surgery for congenital cataract a risk factor for glaucoma?* Br J Ophthalmol, 2004. **88**(7): p. 905-10.
123. Zetterstrom, C. and M. Kugelberg, *Paediatric cataract surgery.* Acta Ophthalmol Scand, 2007. **85**(7): p. 698-710.
124. Lagreze, W.A., *[The management of cataract in childhood].* Klin Monatsbl Augenheilkd, 2009. **226**(1): p. 15-21.
125. Lin, A.A. and E.G. Buckley, *Update on pediatric cataract surgery and intraocular lens implantation.* Curr Opin Ophthalmol, 2010. **21**(1): p. 55-9.
126. Rastogi, A., et al., *Comparison of epilenticular IOL implantation vs technique of anterior and primary posterior capsulorhexis with anterior vitrectomy in paediatric cataract surgery.* Eye (Lond), 2007. **21**(11): p. 1367-74.
127. Vasavada, A.R. and B.R. Nihalani, *Pediatric cataract surgery.* Curr Opin Ophthalmol, 2006. **17**(1): p. 54-61.

128. Forbes, B.J. and S. Guo, *Update on the surgical management of pediatric cataracts.* J Pediatr Ophthalmol Strabismus, 2006. **43**(3): p. 143-51; quiz 165-6.
129. Petric, I. and V. Lacmanovic Loncar, *Surgical technique and postoperative complications in pediatric cataract surgery: retrospective analysis of 21 cases.* Croat Med J, 2004. **45**(3): p. 287-91.
130. Lloyd, I.C., et al., *Neonatal cataract: aetiology, pathogenesis and management.* Eye (Lond), 1992. **6 (Pt 2)**: p. 184-96.
131. Astle, W.F., et al., *Surgical outcomes of primary foldable intraocular lens implantation in children: understanding posterior opacification and the absence of glaucoma.* J Cataract Refract Surg, 2009. **35**(7): p. 1216-22.
132. Ahmadieh, H., et al., *Primary capsulectomy, anterior vitrectomy, lensectomy, and posterior chamber lens implantation in children: limbal versus pars plana.* J Cataract Refract Surg, 1999. **25**(6): p. 768-75.
133. Kim, K.H., et al., *Clinical Outcomes of Surgical Techniques in Congenital Cataracts.* Korean J Ophthalmol, 2008. **22**(2): p. 87-91.
134. Long, V., S. Chen, and S. Hatt, *Surgical interventions for bilateral congenital cataract.* Cochrane Database Syst Rev, 2006. **3**: p. CD003171.
135. Malukiewicz-Wisniewska, G., et al., *Intraocular lens implantation in children and youth.* J Pediatr Ophthalmol Strabismus, 1999. **36**(3): p. 129-33.
136. Wright, K.W., *Pediatric cataracts.* Curr Opin Ophthalmol, 1997. **8**(1): p. 50-5.
137. Morgan, K.S., *Pediatric cataract and lens implantation.* Curr Opin Ophthalmol, 1995. **6**(1): p. 9-13.
138. Young, T.L., et al., *The IOLAB, Inc pediatric intraocular lens study. AAPOS Reasearch Committee. American Association for Pediatric Ophthalmology and Strabismus.* J AAPOS, 1999. **3**(5): p. 295-302.
139. Cassidy, L., et al., *Outcome of lens aspiration and intraocular lens implantation in children aged 5 years and under.* Br J Ophthalmol, 2001. **85**(5): p. 540-2.
140. Shapiro, A. and E.J. Duval, *Visual functions following bilateral surgery of congenital cataracts in children.* J Pediatr Ophthalmol Strabismus, 1979. **16**(3): p. 176-9.
141. Koch, D.D. and T. Kohnen, *A retrospective comparison of techniques to prevent secondary cataract formation following posterior chamber intraocular lens implantation in infants and children.* Trans Am Ophthalmol Soc, 1997. **95**: p. 351-65.
142. Wilson, M.E., S.K. Pandey, and J. Thakur, *Paediatric cataract blindness in the developing world: surgical techniques and intraocular lenses in the new millennium.* Br J Ophthalmol, 2003. **87**(1): p. 14-9.
143. Ram, J., et al., *Role of posterior capsulotomy with vitrectomy and intraocular lens design and material in reducing posterior capsule opacification after pediatric cataract surgery.* J Cataract Refract Surg, 2003. **29**(8): p. 1579-84.
144. Knight-Nanan, D., M. O'Keefe, and R. Bowell, *Outcome and complications of intraocular lenses in children with cataract.* J Cataract Refract Surg, 1996. **22**(6): p. 730-6.
145. Dave, H., et al., *Simultaneous vs Sequential Bilateral Cataract Surgery for Infants With Congenital Cataracts: Visual Outcomes, Adverse Events, and Economic Costs.* Arch Ophthalmol, 2010. **128**(8): p. 1050-4.
146. Guo, S., R.S. Wagner, and A. Caputo, *Management of the anterior and posterior lens capsules and vitreous in pediatric cataract surgery.* J Pediatr Ophthalmol Strabismus, 2004. **41**(6): p. 330-7; quiz 356-7.
147. Basti, S., U. Ravishankar, and S. Gupta, *Results of a prospective evaluation of three methods of management of pediatric cataracts.* Ophthalmology, 1996. **103**(5): p. 713-20.
148. Wormald, R., *Evidence for effectiveness of interventions for congenital,infantile and childhood cataract.* Community Eye Health, 2004. **17**(50): p. 25-26.
149. Lloyd, I.C., et al., *Advances in the management of congenital and infantile cataract.* Eye (Lond), 2007. **21**(10): p. 1301-9.

150. Lambert, S.R., et al., *A comparison of grating visual acuity, strabismus, and reoperation outcomes among children with aphakia and pseudophakia after unilateral cataract surgery during the first six months of life.* J AAPOS, 2001. **5**(2): p. 70-5.
151. Hatt, S., et al., *Interventions for stimulus deprivation amblyopia.* Cochrane Database Syst Rev, 2006. **3**: p. CD005136.
152. Lloyd, I.C., et al., *Modulation of amblyopia therapy following early surgery for unilateral congenital cataracts.* Br J Ophthalmol, 1995. **79**(9): p. 802-6.
153. Davies, P.D. and D.T. Tarbuck, *Management of cataracts in infancy and childhood.* Trans Ophthalmol Soc U K, 1977. **97**(1): p. 148-52.
154. Moore, B.D., *Optometric management of congenital cataracts.* J Am Optom Assoc, 1994. **65**(10): p. 719-24.
155. Allen, R.J., L. Speedwell, and I. Russell-Eggitt, *Long-term visual outcome after extraction of unilateral congenital cataracts.* Eye (Lond), 2010. **24**(7): p. 1263-7.
156. Msukwa, G., et al., *Cataract in children attending schools for the blind and resource centers in eastern Africa.* Ophthalmology, 2009. **116**(5): p. 1009-12.
157. Birch, E.E., et al., *The critical period for surgical treatment of dense congenital bilateral cataracts.* J AAPOS, 2009. **13**(1): p. 67-71.
158. Ye, H.H., et al., *Long-term visual outcome of dense bilateral congenital cataract.* Chin Med J (Engl), 2007. **120**(17): p. 1494-7.
159. Muhit, M.A., *Childhood Cataract: Home to Hospital.* Community Eye Health, 2004. **17**(50): p. 19-22.
160. Courtright, P., *Meeting the needs of children with congenital and developmental cataract in Africa.* Community Eye Health, 2008. **21**(65): p. 18-9.
161. Gogate, P., K. Kalua, and P. Courtright, *Blindness in childhood in developing countries: time for a reassessment?* PLoS Med, 2009. **6**(12): p. e1000177.
162. Kalua, K., et al., *Causes of blindness among children identified through village key informants in Malawi.* Can J Ophthalmol, 2008. **43**(4): p. 425-7.
163. Waddell, K.M., *Childhood blindness and low vision in Uganda.* Eye (Lond), 1998. **12 (Pt 2)**: p. 184-92.
164. Gogate, P., et al., *The pattern of childhood blindness in Karnataka, South India.* Ophthalmic Epidemiol, 2009. **16**(4): p. 212-7.
165. Gogate, P. and C.E. Gilbert *Blindness in children: a wordwide perspective.* Comm Eye Health J 2007. **20**(62): p. 32–33.
166. Rajaratnam, J.K., et al., *Neonatal, postneonatal, childhood, and under-5 mortality for 187 countries, 1970-2010: a systematic analysis of progress towards Millennium Development Goal 4.* Lancet, 2010. **375**(9730): p. 1988-2008.
167. Burton, M.J., *Cornea blindness:Prevention, treatment and rehabilitation.* Community Eye Health, 2009. **22**(71): p. 33-5.
168. Holden, B., *Uncorrected refractive error: the major and most easily avoidable cause of vision loss.* Community Eye Health, 2007. **20**(63): p. 37-39.
169. Negrel, A.D., et al., *Refractive Error Study in Children: sampling and measurement methods for a multi-country survey.* Am J Ophthalmol, 2000. **129**(4): p. 421-6.
170. Muhit, M. and C. Gilbert, *A review of the epidemiology and control of childhood blindness.* Trop Doct, 2003. **33**(4): p. 197-201.
171. Dandona, L., et al., *Survival analysis and visual outcome in a large series of corneal transplants in India.* Br J Ophthalmol, 1997. **81**(9): p. 726-31.
172. Garg, P., et al., *The value of corneal transplantation in reducing blindness.* Eye (Lond), 2005. **19**(10): p. 1106-14.
173. Suttle, C.M., *Active treatments for amblyopia: a review of the methods and evidence base.* Clin Exp Optom, 2010.
174. De Weger, C., H.J. Van Den Brom, and R. Lindeboom, *Termination of Amblyopia Treatment: When to Stop Follow-Up Visits and Risk Factors for Recurrence.* J Pediatr Ophthalmol Strabismus, 2010: p. 1-9.

175. Schmucker, C., et al., *Effectiveness of early in comparison to late(r) treatment in children with amblyopia or its risk factors: a systematic review.* Ophthalmic Epidemiol, 2010. **17**(1): p. 7-17.
176. Schmucker, C., et al., *Effectiveness of screening preschool children for amblyopia: a systematic review.* BMC Ophthalmol, 2009. **9**: p. 3.
177. Powell, C. and S.R. Hatt, *Vision screening for amblyopia in childhood.* Cochrane Database Syst Rev, 2009(3): p. CD005020.
178. Li, T. and K. Shotton, *Conventional occlusion versus pharmacologic penalization for amblyopia.* Cochrane Database Syst Rev, 2009(4): p. CD006460.
179. Moseley, M.J., A.R. Fielder, and C.E. Stewart, *The optical treatment of amblyopia.* Optom Vis Sci, 2009. **86**(6): p. 629-33.
180. Lin, X.M., et al., *Long-term efficacy of excimer laser in situ keratomileusis in the management of children with high anisometropic amblyopia.* Chin Med J (Engl), 2009. **122**(7): p. 813-7.
181. Hess, R.F., B. Mansouri, and B. Thompson, *A Binocular Approach to Treating Amblyopia: Antisuppression Therapy.* Optom Vis Sci, 2010.
182. Awan, M., et al., *An audit of the outcome of amblyopia treatment: a retrospective analysis of 322 children.* Br J Ophthalmol, 2010.
183. Arnold, R.W. and S.J. Lichtenstein, *Treatment options for dense amblyopia in uncooperative children.* J Pediatr Ophthalmol Strabismus, 2010. **47**(3): p. 134-8.
184. Drummond, G.T. and B.J. Hinz, *Management of monocular cataract with long-term dilation in children.* Can J Ophthalmol, 1994. **29**(5): p. 227-30.
185. de Zárate, B.R. and J. Tejedor, *Current concepts in the management of amblyopia.* Clin Ophthalmol, 2007. **1**(4): p. 403-14.
186. Leone, J., Z. Georgievski, and K. Koklanis, *Atropine Treatment of Amblyopia: Is a Swap in Fixation Necessary?* J Pediatr Ophthalmol Strabismus, 2009: p. 1-7.
187. Repka, M.X., et al., *Treatment of severe amblyopia with weekend atropine: results from 2 randomized clinical trials.* J AAPOS, 2009. **13**(3): p. 258-63.
188. Krumholtz, I. and D. FitzGerald, *Efficacy of treatment modalities in refractive amblyopia.* J Am Optom Assoc, 1999. **70**(6): p. 399-404.
189. Tan, J.H.Y., J.R. Thompson, and I. Gottlob, *Differences in the management of amblyopia between European countries.* Br J Ophthalmol, 2003. **87**(3): p. 291-6.
190. Kulp, M.T., *Findings from the Vision in Preschoolers (VIP) Study.* Optom Vis Sci, 2009. **86**(6): p. 619-23.
191. Powell, C., S. Wedner, and S. Richardson, *Screening for correctable visual acuity deficits in school-age children and adolescents.* Cochrane Database Syst Rev, 2005(1): p. CD005023.
192. Wedner, S., et al., *Two strategies for correcting refractive errors in school students in Tanzania: randomised comparison, with implications for screening programmes.* Br J Ophthalmol, 2008. **92**(1): p. 19-24.
193. Odedra, N., et al., *Barriers to spectacle use in Tanzanian secondary school students.* Ophthalmic Epidemiol, 2008. **15**(6): p. 410-7.
194. Zeng, Y., et al., *A randomized, clinical trial evaluating ready-made and custom spectacles delivered via a school-based screening program in China.* Ophthalmology, 2009. **116**(10): p. 1839-45.
195. Agarwal, P.K., R. Bowman, and P. Courtright, *Child eye health tertiary facilities in Africa.* J AAPOS, 2010. **14**(3): p. 263-266.
196. WHO, *Strengthening health systems to improve health outcomes: WHO's framework for action Geneva. .* 2007.
197. Drager, S., G. Gedik, and M.R. Dal Poz, *Health workforce issues and the Global Fund to fight AIDS, Tuberculosis and Malaria: an analytical review.* Hum Resour Health, 2006. **4**: p. 23.
198. WHO, *Alliance for Health Policy and Systems Research . Strengthening health systems: the role and promise of policy and systems research Global Forum for Health Geneva.* 2004.
199. WHO, *Shaping the future. World Health Report 2003. Geneva,World Health Organization, 2003.*
200. WHO, *Improving health outcomes of the poor. Report of Working Group 5 of the Commission on Macroeconomics and Health. Geneva, World Health Organization, 2002.*

201. WHO, *Everybody's business: health systems strengthening to improve health outcomes. WHO's framework for action. Geneva, World Health Organization.* 2007.
202. Kirigia, J.M. and S.P. Barry, *Health challenges in Africa and the way forward.* Int Arch Med, 2008. **1**(1): p. 27.
203. WHO, *Task shifting: Global recommendations and guidelines.* 2008.
204. Sadana, R. and T. Pang, *Health research systems: a framework for the future* Bulletin of the WHO, 2003. **81**(3): p. 159.
205. Baris, E., *Defining and delimiting the boundaries of the Alliance for Health Systems and Policy Research. Geneva,Background document,.* Alliance for Health Policy and Systems Research, 1998.
206. Theobald, S., et al., *Towards building equitable health systems in Sub-Saharan Africa: lessons from case studies on operational research.* Health Res Policy Syst, 2009. **7**: p. 26.
207. English, M., et al., *Health systems research in a low-income country: easier said than done.* Arch Dis Child, 2008. **93**(6): p. 540-4.
208. *The 10/90 report on health research. Geneva, Global Forum for Health Research, 1999.*
209. Giusti, D., B. Criel, and X. De Bethune, *Viewpoint: public versus private health care delivery: beyond the slogans.* Health Policy Plan, 1997. **12**(3): p. 192-8.
210. Conner, M. and P. Norman, *Predicting Health Behaviours: research and practice with social cognition models Open University Press, Buckingham.* 1996.
211. Kroeger, A., *Anthropological and Socio-medical health care research in developing countries* Soc Sci Med 1983. **17**(3): p. 147-161.
212. Emerson, P.M., et al., *The SAFE strategy for trachoma control: Using operational research for policy, planning and implementation.* Bull World Health Organ, 2006. **84**(8): p. 613-9.
213. el Hassan, L.A., E.A. Khalil, and A.M. el-Hassan, *Socio-cultural aspects of leprosy among the Masalit and Hawsa tribes in the Sudan.* Lepr Rev, 2002. **73**(1): p. 20-8.
214. Molyneux, S.C., et al., *Intra-household relations and treatment decision-making for childhood illness: A Kenyan case study* Journal of Biosocial Science, 2002. **34**: p. 109-131.
215. Geneau, R., et al., *Using qualitative methods to understand the determinants of patients' willingness to pay for cataract surgery: a study in Tanzania.* Soc Sci Med, 2008. **66**(3): p. 558-68.
216. Hennink, M.M., *International Focus Group Reseach .A Handbook for the Health and Social Sciences; Kindle, editor: Cambridge University Press.* 2007.
217. Chambers , R., *Participatory Rural Appraisal (PRA).Challenges.Potentials and Paradigms* World developmnent, 1994. **22**(10): p. 1437-1454.
218. Gona, J.K., S. Hartley, and C.R. Newton, *Using participatory rural appraisal (PRA) in the identification of children with disabilities in rural Kilifi, Kenya.* Rural Remote Health, 2006. **6**(3): p. 553.
219. Hixon, A.L. and G.G. Maskarinec, *The Declaration of Alma Ata on its 30th anniversary: relevance for family medicine today.* Fam Med, 2008. **40**(8): p. 585-8.
220. WHO, *The Alma-Ata conference on primary health care.* WHO Chron, 1978. **32**(11): p. 409-30.
221. Passmore, R., *The declaration of Alma-Ata and the future of primary care.* Lancet, 1979. **2**(8150): p. 1005-8.
222. WHO, *Declaration of Alma-Ata.* Lancet, 1978. **2**(8100): p. 1144.
223. WHO, *Health for all by the year 2000.WHO declaration of Alma Ata .Internatational conference for Primary Health care.* 1978.
224. Twaha, A., et al., *Lessons for national health systems from small-scale projects: a case study from Tanzania.* J Trop Pediatr, 1989. **35**(1): p. 40-3.
225. Anyangwe, S.C. and C. Mtonga, *Inequities in the global health workforce: the greatest impediment to health in sub-Saharan Africa.* Int J Environ Res Public Health, 2007. **4**(2): p. 93-100.
226. WHO, *CSDH, Closing the gap in a generation:health equity through acion on the social determinatns of Health.Final report of the Commision on Social Determinats of Health.Geneva,World Health Organisation.* 2008.

227. Rohde, J., et al., *30 years after Alma-Ata: has primary health care worked in countries?* Lancet, 2008. **372**(9642): p. 950-61.
228. World Health Organisation (WHO): The equity action spectrum: taking a comprehensive approach. Guidance for addressing inequities in health. Geneva, World Health Organisation, 2014.
229. Solar, O. and A. Irwin, Social determinants, political contexts and civil society action: a historical perspective on the Commission on Social Determinants of Health. Health Promot J Austr, 2006. 17(3): p. 180-5.
230. Rifkin, S.B. and G. Walt, Why health improves: defining the issues concerning 'comprehensive primary health care' and 'selective primary health care'. Soc Sci Med, 1986. **23**(6): p. 559-66.
231. Walsh, J.A. and K.S. Warren, *Selective primary health care: an interim strategy for disease control in developing countries. .* New England Journal of Medicine, 1979. **30**: p. 967-74.
232. Wisner, B., *GOBI versus PHC? Some dangers of selective primary health care.* Soc Sci Med, 1988. **26**(9): p. 963-9.
233. Price, J.E., et al., *Integrating HIV clinical services into primary health care in Rwanda: a measure of quantitative effects.* AIDS Care, 2009. **21**(5): p. 608-14.
234. Macinko, J., B. Starfield, and T. Erinosho, *The impact of primary healthcare on population health in low- and middle-income countries.* J Ambul Care Manage, 2009. **32**(2): p. 150-71.
235. Baker, M.C., et al., *The impact of integrating the elimination programme for lymphatic filariasis into primary health care in the Dominican Republic.* Int J Health Plann Manage, 2007. **22**(4): p. 337-52.
236. Harris, J.B., et al., *Early lessons from the integration of tuberculosis and HIV services in primary care centers in Lusaka, Zambia.* Int J Tuberc Lung Dis, 2008. **12**(7): p. 773-9.
237. Topp, S.M., et al., *Strengthening health systems at facility-level: feasibility of integrating antiretroviral therapy into primary health care services in lusaka, zambia.* PLoS One, 2010. **5**(7): p. e11522.
238. Pfeiffer, J., et al., *Integration of HIV/AIDS services into African primary health care: lessons learned for health system strengthening in Mozambique - a case study.* J Int AIDS Soc, 2010. **13**: p. 3.
239. Lush, L., et al., *Integrating reproductive health: myth and ideology.* Bull World Health Organ, 1999. **77**(9): p. 771-7.
240. Dixon, K., *The roles of the behavioral health professional in integrated systems.* Behav Healthc Tomorrow, 1998. **7**(6): p. 35-9.
241. Botha, J.L., et al., *The distribution of health needs and services in South Africa.* Soc Sci Med, 1988. **26**(8): p. 845-51.
242. NPCB, *The Malawi National Eye Care 5 years plan :2006-2011.Ministry of Health document ,Lilongwe, Malawi* 2005.
243. Murthy, G.V. and U. Raman, *Perspectives on primary eye care.* Community Eye Health, 2009. **22**(69): p. 10-11.
244. IAPB, *Primary Eye care course :8th General Assembly of IAPB:Argentina 25-28th August, 2008.*
245. WHO, *World Health Statistics www.who.int/countries/mw.* 2015.
246. UNDP, *GDP Fact sheet.* 2015.
247. CIA, *The World fact book.Population below poverty 2016*.
248. Makoko, A.J.L. and P. Chimutu, *Baseline report on the status of special needs edcuation in Malawi* 2007, Catholic University of Malawi: Blantyre. p. 1-32.
249. Kanyuka, Mercy, et al. *"Malawi and Millennium Development Goal 4: a Countdown to 2015 country case study." The Lancet Global Health 4.3 (2016): e201-e214.*
250. Malawi Health Sector Strategic Plan 2011–2016. Moving towards equity and quality. Ministry of Health, Lilongwe, Malawi
251. Kadzandira, J. and W. Chilowa, *The Role of Health Surveillance Assistants (HSAs) in the Delivery of Health Services and Immunization in Malawi.UNICEF Evaluation Report.downloaded July 2010.* 2001.

252. MOH, *Ministry of Health, Republic of Malawi. Human Resources in the Health Sector: Towards a Solution.* 2004.
253. MOH., *How many HSAs in South West Zone Malawi ? South West Zonal officer personal communication* 2008.
254. Kalua, K., *Finding from key informant and HSAs focus group discussions in Malawi .Unpublished data 2007.*
255. Raman, U., *Human Resource for eye care:changing the way we think.* Community Eye Health, 2009. **22**(69): p. 12-13.
256. Chankova, S., S. Muchiri, and G. Kombe, *Health workforce attrition in the public sector in Kenya: a look at the reasons.* Hum Resour Health, 2009. **7**: p. 58.
257. Khaliq, A.A., R.W. Broyles, and A.K. Mwachofi, *Global nurse migration: its impact on developing countries and prospects for the future.* World Health Popul, 2008. **10**(3): p. 55-73.
258. Hall, E.J., *Nursing attrition and the work environment in South African health facilities.* Curationis, 2004. **27**(4): p. 28-36.
259. Dovlo, D., *Using mid-level cadres as substitutes for internationally mobile health professionals in Africa. A desk review.* Hum Resour Health, 2004. **2**(1): p. 7.
260. NPBC., *National prevention of blindness committee, Malawi, 2008*
261. *Ministry of Education Headquarters Special needs Education (SNE) Section* 2007: Lilongwe Malawi
262. Mturi, A.J. and M.M. Hennink, *Perceptions of sex education for young people in Lesotho.* Cult Health Sex, 2005. **7**(2): p. 129-43.
263. Green, J. and N. Thorogod, *Qualitative methods for Health Research .Second edition, London.Sage publications* 2004.
264. *Malawi Housing and Population 2008 census .National Statistical office,Zomba Malawi.* 2008.
265. Kirkwood, B. and J.A.C. Sterne, *Essential Medical statistics ,Second edition.Blackwell science.* 2003.
266. Bowling, A., *Research methods in Health:Investigating Health and Health Services.Open University Press.* 1997.
267. Chambers , R., *Participatory Rural Appraisal (PRA).Challenges,Potentials an Paradigm.* World development, 1994. **22**(10): p. 1437-54.
268. WHO, *WHO Guidelines:Incentives for Heath Proffesssionals.Global Health Workforce alliance*, in *WHO: Global Health Workforce alliance*. 2008, International Council of Nurses, International Hospital;Federation, International Pharmaceutical Federation, World Confederation for;Physical Therapy, World Dental Federation, World Medical Association: www.who.int/workforcealliance/.../Incentives_Guidelines%20EN.pdf. p. 1-44.
269. Global Health Workforce Alliance & WHO, *Global Experience of Community Health Workers for Delivery of Health Related Millennium Development Goals: A Systematic Review, Country Case Studies, and Recommendations for Integration into National Health Systems.* 2010: Geneva.
270. *Roberts, Bayard, et al.* "A new method to estimate mortality in crisis-affected and resource-poor settings: validation study." International journal of epidemiology 39.6 (2010): 1584-1596.
271. *Checchi, F. et.al.* Rates and causes of death in Chiradzulu District, Malawi, 2008: a key informant study. Tropical Medicine & International Health, 2011. 16: 375–378.
272. Bisika, T., *The Effectiveness Of The TBA Programme In Reducing Maternal Mortality And Morbidity In Malawi* East African Journal of Public Heath, Vol. 5, No. 2, August, 2008, pp. 103-110, 2008. **5**(2): p. 103-110.
273. Floyd, K., et al., *Cost and cost-effectiveness of increased community and primary care facility involvement in tuberculosis care in Lilongwe District, Malawi.* Int J Tuberc Lung Dis, 2003. **7**(9 Suppl 1): p. S29-37.
274. Zachariah, R., et al., *Community support is associated with better antiretroviral treatment outcomes in a resource-limited rural district in Malawi.* Trans R Soc Trop Med Hyg, 2007. **101**(1): p. 79-84.

275. Shija, F., et al., *Comparing key informants to health workers in identifying children in need of surgical eye care services.* International Health, 2011(doi:10.1016/j.inhe.2011.09.003): p. doi:10.1016/j.inhe.2011.09.003.
276. Rosenstock, I.M., V.J. Strecher, and M.H. Becker, *Social learning theory and the Health Belief Model.* Health Educ Q, 1988. **15**(2): p. 175-83.
277. Bronsard, A. and S. Shirima, *Cataract surgery:ensuring equal access for boys and girls.* Comm Eye Health J, 2009. **22**(20): p. 28-29.
278. Lewallen, S., et al., *Surgery for trachomatous trichiasis: findings from a survey of trichiasis surgeons in Tanzania.* Br J Ophthalmol, 2007. **91**(2): p. 143-5.
279. Courtright, P. and S. Lewallen, *Why are we addressing gender issues in vision loss?* Community Eye Health, 2009. **22**(70): p. 17-9.
280. Courtright, P. and S. Lewallen, *Improving gender equity in eye care: advocating for the needs of women.* Community Eye Health, 2007. **20**(64): p. 68-9.
281. Fosu, G.B., *Childhood morbidity and health services utilization: cross-national comparisons of user-related factors from DHS data.* Soc Sci Med, 1994. **38**(9): p. 1209-20.
282. Sreeramareddy, C.T., et al., *Care seeking behaviour for childhood illness--a questionnaire survey in western Nepal.* BMC Int Health Hum Rights, 2006. **6**: p. 7.
283. Kutty, V.R., *Women's education and its influence on attitudes to aspects of child-care in a village community in Kerala.* Soc Sci Med, 1989. **29**(11): p. 1299-303.
284. Pillai, R.K., et al., *Factors affecting decisions to seek treatment for sick children in Kerala, India.* Soc Sci Med, 2003. **57**(5): p. 783-90.
285. Gona, J.K., et al., *Identification of people with disabilities using participatory rural appraisal and key informants: a pragmatic approach with action potential promoting validity and low cost.* Disabil Rehabil, 2010. **32**(1): p. 79-85.
286. Shirima, S., et al., *Estimating numbers of blind children for planning services: findings in Kilimanjaro, Tanzania.* Br J Ophthalmol, 2009. **93**(12): p. 1560-2.
287. Brewster, D.R., D. Kwiatkowski, and N.J. White, *Neurological sequelae of cerebral malaria in children.* Lancet, 1990. **336**(8722): p. 1039-43.
288. Lambert, S.R., *Brain problems*, in *Paediatric Ophthalmology*, D. Taylor, Editor. 1997, Blackwell Science: London. p. 740-771.
289. Colbourn et al. Maternal mortality in Malawi, 1977–2012. BMJ open 2013; 3:e004150 doi: 10.1136/bmjopen-2013-004150.
290. Gogate, P. and M. Muhit, *Blindness and cataract in children in developing countries.* Community Eye Health, 2009. **22**(69): p. 4-5.
291. Njuguna, M., et al., *Causes of severe visual impairment and blindness in children in schools for the blind in eastern Africa: changes in the last 14 years.* Ophthalmic Epidemiol, 2009. **16**(3): p. 151-5.
292. Kishiki, E., et al., *Improving postoperative follow-up of children receiving surgery for congenital or developmental cataracts in Africa.* J AAPOS, 2009. **13**(3): p. 280-2.
293. Tielsch, J.M., et al., *Prevalence and severity of xerophthalmia in southern Malawi.* Am J Epidemiol, 1986. **124**(4): p. 561-8.
294. Wedner, S.H., et al., *Prevalence of eye diseases in primary school children in a rural area of Tanzania.* Br J Ophthalmol, 2000. **84**(11): p. 1291-7.
295. *UNESCO*. 2012 [cited; Available from: http://portal.unesco.org/education/en/ev.php-URL_ID=32969&URL_DO=DO_TOPIC&URL_SECTION=201.html.
296. Franke, R.H. and J.D. Kaul, *The Hawthorne experiments: First statistical interpretation.* Am Sociol Rev, 1978. **43**: p. 62-6433.

Appendices

Materials that were developed and used as part of the fieldwork are outlined in appendices 1 to 34.

Appendix 1: Topic guide for Focus Group Discussions (FGD's) with HSAs
Appendix 2: Topic guide for FGD's with potential KIs
Appendix 3: Topic guide for FGD's with parents of blind children
Appendix 4: Topic guide for FGD's with blind children
Appendix 5: Topic guide for FGD's with normal children
Appendix 6: Coding Framework
Appendix 7: KI AND HSA training manual
Appendix 8: Brochure for KI AND HSA training
Appendix 9: How to measure visual acuity (VA) in children >6 years
Appendix 10: Standardized history for blind children <6 years
Appendix 11: Unique ID number linking child to training session, KI and HSA
Appendix 12: Form 1: List of Key informants trained
Appendix 13: Form 2: KI village allocation list
Appendix 14: Form 3: KI lists of children identified
Appendix 15: Form 4: KI referral form
Appendix 16: Form 5: KI master list
Appendix 17: Form 6: List of HSAs trained
Appendix 18: Form 7: List of HSA allocated villages
Appendix 19: Form 8: List of children identified by HSAs
Appendix 20: Form 9: HSA referral form
Appendix 21: Form 10: HSA master list
Appendix 22: Form 11: Eye clinical examination form
Appendix 23: Form 12: Eye examination clinic summary
Appendix 24: Form 13: Registers kept by KIs and HSAs
Appendix 25: Form 14: Clinical officer referral form
Appendix 26: Form 15: KIs & HSAs interviews after identification
Appendix 27: Topic guide for children
Appendix 28: Form 16: Topic guide for parents
Appendix 29: Form 17: Interviews with EHOs, DEHOs, and Medical assistant
Appendix 30: Cycles of KI & HSA training and screening sessions
Appendix 31: Training timetable
Appendix 32: Consent form for parents
Appendix 33: Trainers Manual for KIs and HSAs
Appendix 34: Published Key informants' articles

Appendix 1: Topic guide for Focus Group Discussions (FGD's) with HSAs

Qulitative questions (semi structured interview through focus group discussions)

HSA's

Introductions (participants and facilitators)
Introduction of Research Topic
Purpose of the Research
Name of Research insitution
Name of funding body
Ethical issues and consent

Introductory Questions 30 minutes

1 Tell us the name of your health centre and what you like about your work
(probe:distance)
2 Share with us experiences of immunising children in the community ?how?who?
(Probe age of children;time spent on immunisations; no.not immunised;barriers)
3 Are HSA involved in the village health ?where?how
(Pobe existence of village health commitees VHC's & functions)

Main topic of discussion 1 hour

4 Are there eye care services for children in the community
(Probe: Preventive,treatment)
5 How are the existing health services/system used to promote eye care.How?
(Probe :Eye health promotion)
6 Tell us about any blind children in your area?What happens to them? Where,how ?
7 How can the blind children from your catchment area be identified?
(probe;numbers)
8 Share with us knowledge /experience of how blindess in children be prevented? How?
9 What could be the causes of blindness in children?
Probe(witchcaft,Vitamin A deficiency,Cataract)
10 What problems can arise as result of delay in sending a blind child to hospital?
Probe(reasons)
11 How can HSA's be involved in identifying blind children from their communities?
(Probe:time availabilty,willingness)
12 How much knowledge and skills do HSA's have in eye care?where from,how?
(probe:sources of knowledge;eye examinations)
13 How Can a programme of immunisation in children be linked to identifying blind children?
(Probe:workload,coverage)

Concluding/Closing Questions 30 minutes

14 So what have we agreed to be the role of HSA's in identifying blind children?
15 What areas should primary eye care training focus on.where should the training be done?
16 Can we summarise what the key issues discussed?
(Probe:consensus ;burning issues)

Thank you very much .We have now reached the end of our discussions.

Appendix 2: Topic guide for FGD's with potential KIs

Qulitative questions (semi structured interview through focus group discussions)

Prospective Key informants

Introductions (participants and facilitators)
Introduction of Research Topic
Purpose of the Research
Name of Research insitution
Name of funding body
Ethical issues and consent

Introductory Questions 30 minutes

1 Tell us the name of your village and chief and how far is your house from here ?
2 Tell us experiences you have in the community which involve working with children?
(Probe:disabled children,blind children)
3 Are all the children in your village immunised?how?who does the immunisations?
(Probe:HSA,health centre,barriers,successes)

Main topic of discussion 1 hour

4 Can villagers be used to promote childrens eye health.how
(Probe:village networks)
5 Do village health committee exists? Could they have a role in finding blind children?how?
(functions,leadership,existence,efficiency,effectiveness,benefits/enumeration)
6 Are there any blind children in your area?
(Probe:magnitude,services,what,where)
7 How can the blind children from your catchment area be identified?Are they there?
(Probe:role of villagers,challenges,which KI to use-church elders,traditonal healers,
womes groups,selection criteria for KI)
8 What can be done about blindness in children?
(Probe:prevention,tretament,rehabilitation,tradtional medicine)
9 What causes of blindness in children?
(Probe:cataract,pregnacy related ,traditional medicine,witchcraft)
10 Can problems arise as result of delay in sending a blind child to hospital?
(probe;awareness of services)
12 Where do people go when they have eye problems
(Probe :sources;role of traditional healers,HSA)
13 Can villagers be trained to identfy blind children?
(Probe:willingness,expectations,volunteering,enumeration,motivation factors)

Concluding/Closing Questions 30 minutes

15 So what have we agreed to be the role of villagers in childhood blindness?
Probe:expectations,enumeration)
16 What should the eye training on villagers focus on.?
(Probe:place of training,time,length)
17 Now that we have discussed in detail can we summarisewe think
should be done about blind children?
(Probe:consensus;burning issues)

Thank you very much .We have now reached the end of our discussions.

Appendix 3: Topic guide for FGD's with parents of blind children

Qulitative questions (semi structured interview through focus group discussions)

Parents of blind children

Introductions (participants and facilitators)
Introduction of Research Topic
Purpose of the Research
Name of Research insitution
Name of funding body
Ethical issues and consent

Introductory Questions 30 minutes

1 Tell us the name of your village and how many people live in your house ?
2 What help does your child need on a day to day basis
(Probe:Medical.Social;Education)
3 Can we share experiences and challenges we have in taking care of blind children ?
(probe:hospital challenges,barriers)
4 Can blind children be detected/recognised early in the communities?
(Probe:benefits,importance,role of parents,health staff)

Main topic of discussion 1 hour

5 How do parents/guardians know/discover that their child is blind?
(Probe: knowledge,family networks,no.of children)
6 Have you held about HSAs?what do they do? Have they ever given advice for your child
(Probe: availablity,access)
7 What role do traditional healers play in the community in blind children?
(Probe:availablity,accessibility)
8 Tell us experiences of parents of blind children visiting traditional healers.where ;how?
(Probe:management ,treatment methods,payment)
9 What is the role of traditional healers be trained in identifying blind children?
(Probe:key informant,training)
11 How does the community view blind children?
(Probe: Appropriate key informants,community assistance)
12 What happens if a child goes to hospital and comes back home blind?
(Probe: Rehabilitation,social services,education)
12 How can parents/guardians of blind children be involved in a community
programme to identify other blind children in the villages
(Probe;willingness,networking)

Concluding/Closing Questions 30 minutes

13 Decision making for blind child going to hospital(who is more involved?father /mother/othe
(delay reasons,effect of Sex of child)
14 Which other groups in the community that can be involved with
identification of blind children?
(Probe:disability community services,education sector,itinerant teachers)
15 Summary of discussion
(Probe:consensus;burning issues)

Thank you very much .We have now reached the end of our discussions.

Appendix 4: Topic guide for FGD's with blind children

Qualitative questions (semi structured interview through focus group discussions)

Blind children

- Introductions (participants and facilitators)
- Introduction of Research Topic
- Purpose of the Research
- Name of Research institution
- Name of funding body
- Ethical issues and consent

Introductory Questions 30 minutes
1 Tell us the name of your village and how many people live in your house ?
2 What help is needed for your daily living? why?
(Probe: Medical.Social; Education)
3 Can we share experiences and challenges we have had as blind children ?
(probe: hospital challenges, barriers)
4 Do you have friend in the community?
(Probe: benefits, importance, role of parents, friends)

Main topic of discussion 1 hour
5 How do did you end up at this school?
(Probe: knowledge, family networks, no.of children ,social structures)
6 Are there any things that you would like to share about this place?
(Probe: likes. dislikes, accessibility)
7 how do you feel when its time to go home for holiday?
(Probe: fears, challenges)
8 Tell us what you would like to do in future?
(Probe: expectations)
9 Any things that you would like people to know about children like you?
(Probe: stigmatisation, training)
10 How does the community view you as blind children?
(Probe: fiends, social inclusion, community assistance)

Concluding/Closing Questions 30 minutes
11 So where are you happier, here at school or at home
(Probe reasons, relationship with siblings)
11 Summary of discussion
(Probe: consensus; burning issues)
Thank you very much .We have now reached the end of our discussions

Appendix 5: Topic guide for FGD's with normal children

Qulitative questions (semi structured interview through focus group discussions)

Normal sighted children children at an integrated school

Introductions (participants and facilitators)
Introduction of Research Topic
Purpose of the Research
Name of Research insitution
Name of funding body
Ethical issues and consent

	Introductory Questions	30 minutes
1	Tell us the name and your most favourite spot ?	
2	What help is needed for your daily living?why? (Probe:Social;Education)	
3	Do blind children do the same things as you? (probe:challenges,barriers)	
4	Do you have blind children as friends? (Probe:benefits,importance,attitudes)	
	Main topic of discussion	1 hour
5	Are there any children who are special at this school (Probe: knowledge,family networks,no.of children,social structures)	
6	Are there any things that you would like to share about blind children? (Probe:relationships with blind children	
9	Any things that you would like people to know about blind children ? (Probe:stigmatisation,training)	
10	How does the community view blind children? (Probe: fiends,soci inclusion,community assistance)	
	Concluding/Closing Questions	30 minutes
11	Sodo you u help blind children ? In what ways (probe reasons)	
12	Summary of discussion (Probe:consensus;burning issues)	

Thank you very much .We have now reached the end of our discussions.

Appendix 6: Coding framework

Question	Theme	Subtheme	Examples
Topic: blindness Cataract in children	Terminology & Knowledge	Naming	*It's called "mwana m'maso" (FGD 2, key informants, P3)* *We call it Ng'ala* (FGD 1, key informants, P2)
What causes cataract in children?	Causes and symptoms	Trauma	*It might be that a person had an accident of the eye and that wound grows and it becomes a cataract in the eye* (FGD 2, Key informant, P15)
		Congenital	*I can explain that this disease comes because you can be born with week veins in your eyes so diseases finds advantage on that* (FGD 3, HSA, P15)
		Exposure	*Sometimes the things that children play with like "tidzitsotso" may enter in the eyes or any other objects they use when playing in their groups or even hurting each other in the eyes so if that child doesn't get treatment fast, then the eye can develop a cataract as you know that sand or any "tidzitsotso" can destroy the eyes of the children.* (FGD5, KI, P5).
		Infection	*The illness may start due to eye infections* (FGD 3, HSA, P11)
		Harmful traditional medicines	*It happens that you have an eye disease you end up going to a traditional doctor to be treated not knowing that you will destroy your eyes, due to the trees they will use you will have problems with your eyes, instead of going to hospital* (FGD2, KI, P20)
			This disease can come if you are not clean with your eyes, germs can enter your eyes (FGD4, HSA, P15)
		Unhygienic practice Pregnancy related	*Cataract can be passed on and when a woman is pregnant and has got sexually transmitted disease like syphilis and that disease it's easy for a child to get and when the child is born you find out that he/she has eye problem* (FGD 3, HSA, P23)
How does a cataract a child present?	Signs and symptoms	Symptom Sign	*Like there is fog in the eyes, and one cannot see (FGD 3, HSA, P16)* *"Ana" (referring to whitish spots in the eye) hides the thing which makes you to see with that you cannot see (FGD 2, KI, P17)*
	Cultural beliefs	Sexual exposure in pregnancy	*There are some beliefs that make a child to have cataract for example when a mother is pregnant and the days are due and she has slept with the husband that can also cause the child to have cataract. (FGD 4, HSA, P24)*
	blindness	Linkages with cataract	*It's true because cataract when has covered on the thing which helps you to see you end up being blind (FGD 2, KI, P15)*
	Parent view of blind chldren	hopelessness	*"It's true that if we ignore the child so the condition turns into blindness and his/her future is finished right there."* (FGD 6, HSA, P10).
	Treatment of cataract	referrals	*A cataract can be treated if the people have seen that condition and have rushed to the hospital. It's possible to treat a cataract because the medical staff has skills they use when treating a cataract with the education they acquired."* (FGD 5, parents, P3).

	Perceived consequences of cataract	Loss of sight No work opportunities No future Risk of abuse/can get diseases	*If the child didn't receive treatment will never see again and will suffer the rest of her life (FGD 5, KI, P20)* *If the child has a cataract or blindness condition, if she is grown up girl, can meet some fathers who can't control their libido, they can just rape her and transmit today's virus because she has no sight." (FGD 5, KI, P5).*
	Hospital /health systems	Satisfaction Benefits Fear Distance	*….the family is happy...they didn't believe that the child can regain his sight, they were helped and now they are happy that the child is able to see (FGD3, KI, P15)* *It is important because if you will not take the child to hospital the disease will grow but if you go to hospital will be treated and you will be doing your job as parent (FGD5, parent, P19)*
	Health seeking behavior	Roles of family Motivators demotivators	*The way I see it it's the mother who is responsible because while the father is often away, the mother is always at home, so the one who sees the problem it's the mother (FGD1, KI, P15)* *My younger sister stays the other side; she was blind and was using glasses but she went to hospital and the problem is no longer there. She has a good job and the blouse I am wearing is hers. Others can get encouragement from this*. (FGD 5, HSA, P29). *Those who do this mostly are men, they can go and drink beer forgetting that the child is sick (FGD2, KI, P20)*
	Future of a blind child	challenges	*Blindness is good as being dead, even if you can have a good thing if you cannot see, there is no life and future.* (FGD 7, normal, P21).
		Myths	*The future of a child with cataract and blindness is difficult because he/she cannot go to school and can't see properly, can't read and has to be helped as he/she grows.* (FGD 2, KI, P31).
		hope	*We just hear through the radio that there are some blind people who are doing well. They are in offices and even doing business through what they have been trained." I want to be like one of them (FGD 8, blind child, P23).*

Appendix 7: KI AND HSA selection criteria and training manual

Job description of key informants (KIs) and Health Surveillance Assistants (HSAs)

- To identify blind children in the community

Tasks

- Communicate with families and community about visual impairment in children
- Find the children with visual impairment
- Motivate parents and community to bring the identified children for assessment

Sub tasks

- Meet various village leaders
- Explain the purpose of their visit/ what she/he is looking for
- Ask leaders if they know or have heard of children who do not see well
- Go & talk to identified families and convince them to go to report to an agreed location on a particular day
- List all the identified children

Who should be chosen ad Key informants for the study?

Selection criteria of key informant

- Must live in the village/community
- Must be selected by the community leaders in that village
- Must be able to work as a volunteer
- Must be willing and have time and capability to do the job
- Able to read and write
- Able to travel/walk long distances from home
- Able to influence or convince people in the community
- Empathetic and understanding about disability
- Energetic/active

SUBTASK	KNOWLEDGE	SKILLS	ATTITUDE
Meet Village leaders	Community +++	Speak local language, convince +++	Respect ++
Explain purpose	Blindness +	Communication +++	Patience/positive +++
Ask about blind children	Blindness +	Communication +++	Sensitive +++
Talk, convince, refer	Local culture, calendar of activities transport +++	Communication +++	Positive/ +++ sensitive
List identified children	Making a list ++	Reading and writing ++	Positive ++

Who should be chosen as Health surveillance assistants for the study?

Must be an HSA working in a Health Centre situated within the chosen cluster and must be selected by in-charge of the health centre (Medical assistant).

Objectives of the KI and HSA training:

By end of a one day training session, the participants must be able to:

- Recognize /identify blind children in the allocated villages
- Communicate with the families of children with visual impairment
- Mobilize parents to send the identified children to the district hospital
- Submit a prepared list of all children identified.

Teaching methods:

- Didactic lectures
- Group discussions
- Demonstrations
- Role play

Assessment at end of training: formative

KI AND HSA training manual

Outline of training manual for Key Informants and Health Surveillance Assistants

i. Background

- Childhood blindness is one of the priorities of VISION 2020
- Prevalence and magnitude of blindness in Malawi
- Some information about blindness in children

ii. Why Childhood Blindness Project?

iii. Aims of the Research and training

iv. Structure and functions of parts of the healthy eye

v. Impact of blindness on the child, their family and the community

vi. How might we know if a child cannot see properly?

vii. Main causes of blindness in children in Malawi

viii. How to list identified children?

ix. Where and When to refer?

Take Home Messages

- ALL children who are blind can be helped in some way, either by medical treatment or by support for them to go to school or for rehabilitation so they can learn to live independent lives
- ALL blind children should be referred to the Health Centre for assessment by the Ophthalmic Clinical Officer. He will decide if the child needs to be referred to Blantyre
- Cataract in children can be treated and sight restored if children are brought in earlier. Children should be screened at birth for a “white pupil” and again at immunization.
- Cataract in children does not need to “mature” so children should be brought in the hospital as soon as the diagnosis has been made. This does not need a torch!
- If you are in doubt whether a child is blind or not, it is better to refer than not to refer.
- You can use the skills and knowledge you have acquired to identify and refer adults to hospital; but do not use forms given for adults

Appendix 8: Brochure for KI AND HSA training

Brochure for KI /HSA training
Children to refer –all blind / visually impaired or suspected blind children must be brought

Cataract: The pupils look white

Corneal scarring: the front part of the eye is damaged

1. **Eyes look normal** from the outside but the inside is damaged and child is blind
2. **Normal looking child and normal eyes –do not list**

1

2

How to find children who are blind:

1. Put up posters in public places
2. Talk to villages leaders
3. Talk to teachers
4. Go from house to house asking if there is a child "with problems with their vision" living there
5. Speak to people attending men and women's groups
6. Make announcements in public places e.g. church, funerals, markets

If in doubt contact Project Co-ordinator, Queen Elizabeth Hospital, Blantyre.
Cell phone number: 09241019

Appendix 9: How to measure visual acuity (VA) in children >6 years

How to measure vision in children

1. Explain to the child and the parent that you would like to measure the child's vision as they may have "some problem with their vision". Explain that this is not painful and will only take a few minutes
2. Measure out 6 meters by taking the number of paces you need to take for 6 meters (women = usually 8 paces, men= 7). Mark the beginning and the end of the 6 meters
3. Hold the E about 30cm away from their eyes make sure the child understands that you want them to show the direction the "arms" of the E are pointing in. Rotate the E chart several times until you are sure they understand.
4. Once you are sure the child understands what they should do, ask the child to go to the 6 meter mark and face you.
5. Show the E chart 4 times. Change direction of the E each time. Give the child one chance to show the direction of the E.
6. Count how many times the child correctly shows the direction of the arms of the E.
7. Refer all children who get the direction of the arms of the E wrong one or more times.

What to tell the parents:

Do NOT tell them their child is blind – this will worry them and you may be wrong

DO tell them that their child needs to be examined in a clinic which will be set up in the community shortly

What I should do now:

Complete the details of the child on the form I have been given

Motivate the parents to take the child to the clinic.
Accompany the child and their guardian to the clinic

Childhood Blindness Project

BICO

Blantyre Institute for Community Ophthalmology
Excellence in Community Eye Health

Queen Elizabeth Central Hospital, Blantyre

Project Co-ordinator, Blantyre Institute for Community Ophthalmology (BICO)
Cell phone number: 09241019/08302232

Appendix 10: Standardised history for blind children <6 years

Standardized history for blind children <6 years

1. How might we know if a child cannot see properly?

Adults complain if they lose vision, but children do not usually complain. We have to ask some questions first and go by what the parents, teachers or others have observed, or noticed. The following are some important indications that a child cannot see properly:

Babies:0-6 months

- The mother notices that the child does not look at her face, does not smile when she smiles at her baby, and the baby does not watch her as she moves around
- The mother may also have noticed a "white spot" in her babies eyes, or some other abnormality
- The baby's eyes may "wobble" from side to side and they cannot hold them still

Toddlers and young children:6months-4 years

- The child is reluctant to walk around, particularly in the evenings when the light is not good
- The child bumps into things or falls over objects on the floor

Older children:4 -5 years and above

- They stop doing what they used to do
- They start holding the things they want to look at very close

Important message: If the mother, father or other family member thinks the child cannot see properly they are nearly always right, even if they are not well educated. They know their child very well!

2. How to measure vision in children:

In children aged 0-5 years:

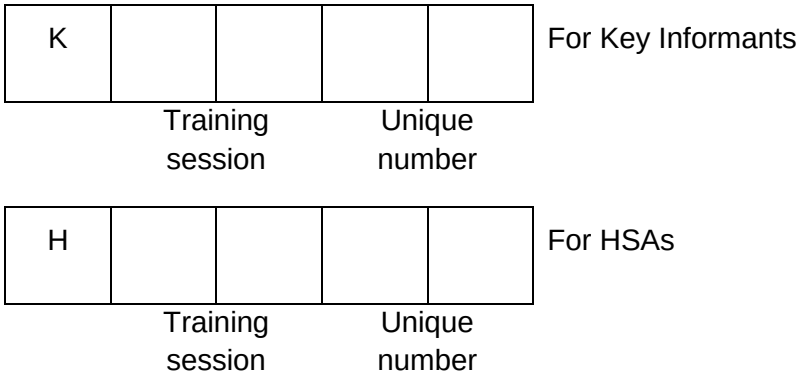
This can be difficult!

We can assess whether the child:

- Looks at your face and smiles when you smile
- Looks at a brightly coloured object held about 20 cms in front of them, and whether they follow the object with their eyes when you move the object slowly from side to side. They may want to grab it, which means they have seen it!
- Reaches for a small object held on the palm of your hand when you put your hand out flat in front of them

Note: Refer all children that you suspect may be blind, or the ones that you are in doubt

Appendix 11: Unique ID number linking child to training session, KI and HSA



Appendix 12: Form 1 List of Key informants trained

Childhood Blindness Project, Blantyre
List of Key Informants trained

Form 1: Key Informants trained

KI training session number: ** Put this number in the first column in the table below

Date of training: Day / Month / Year (2 0 __ __)

Location of training:
1 Mulanje
2 Zomba
3 Mangochi

Health Centres KIs recruited from:
1 _____ 3 _____
2 _____ 4 _____

Catchmnet population

KI unique code

Session No	KI No	Name	Age Yrs	Sex 1=M; 2=F	Health Centre	Role in community#	Code	Phone number	Edu code
K	01								
K	02								
K	03								
K	04								
K	05								
K	06								
K	07								
K	08								
K	09								
K	10								
K	11								
K	12								
K	13								
K	14								
K	15								
K	16								
K	17								
K	18								
K	19								
K	20								
K	21								
K	22								
K	23								
K	24								

** Co-ordinator responsibility

Codes for role in comm
VDC member
Religious leader
Health volunteer
Ordinary local farmer
Traditional healer/attendar
Community CBO
Orphan carer
Human rights
Other

*Codes for Education(E
Standard 1-4
Standard 5-8
Form 1-2
Form 3-4
Post secondary course
None or informal

Appendix 13: Form 2 KI village allocation list

Childhood Blindness Project, Blantyre
Allocation of villages to Key Informants **Form 2: KI village allocation**

District 1 Mulanje 2 Zomba 3 Mangochi Health Centres _____

Training session K☐☐ Total number trained ☐☐

Date of training ☐☐ Day ☐☐ Month 2 0 ☐☐ Year

	First name	Surname	Home village	Other villages allocated	Estimated total population	Health centre	K
1							K
2							K
3							K
4							K
5							K
6							K
7							K
8							K
9							K
10							K
11							K
12							K
13							K
14							K
15							K

Appendix 14: Form 3 KI lists of children identified

Childhood Blindness Project, Blantyre
Children listed by Key Informants

KI code: [ ][ ][ ][ ] (Training session / KI number)

Form 3: Key Informant's list

Name of volunteer _____

District of volunteer _____

Phone number of volunteer _____

1	Mulanje
2	Zomba
3	Mangochi

Health Centre :

Name of child identified	Age (years)	Sex M or F	Name of guardian	Village	Tick ONE of these boxes: Child blind in both eyes	Child is blind one eye	Can see but has other eye problems
1							
2							
3							
4							
5							
6							
7							
8							
9							
10							
11							
12							
13							
14							
15							

Important note: Only list children aged under 16 who were born in Malawi or who have lived in Malawi for the past year.

Comments: _____

Appendix 15: Form 4 KI referral form

Childhood Blindness Project, Blantyre **Form 4: KI referral form**

Form for listing individual children
and referring child to Ophthalmic Clinical Officer in the District Hospital

Referred to Ophthalmic Clinical Officer in [1] *Mulanje* [2] *Zomba* [3] *Mangochi* *District Hospital*

Refered through which Health centre _____

Date child identified [ ][ ] Day [ ][ ] Month [2][0][ ][ ] Year

Name of child _____

Name of guardian _____

Age of child [ ][ ] years

Sex of child (tick one)
[1] Male
[2] Female

District child lives in _____

Village child lives in _____

Health Centre nearest child _____

Vision of child
[1] Child is blind/SVI in both eyes
[2] Child is blind/SVI in one eye only
[3] Child is not blind but has other eye problems

How did you find this child? _____
(describe the method used)

Have you advised the parent of the child to go the district hospital with the child
[1] Yes
[2] No, if no why_____

_____

Volunteer who identified child _____

Volunteer code [K][ ][ ][ ][ ][ ]
Training session KI number

Thank you for seeing this child

Appendix 16: Form 5 KI master list

Childhood Blindness Project, Blantyre

Key Informant Master List Eye Exam Session EES | K | I | | | Session

Data entered | | (Tick when entered)

Form 5: KI Master list

Date of eye exam: _____ Day / month / Year **Health Centre:** _____ **District** _____

Cum no	KI No	Child No	Childs name	Guardians name	Village	Age (yrs)	Sex	Child listed as blind	Already been to district	Examined at 6 wks	Case: <6/60 both eyes	Action
						NK = not known	1=M; 2=F	1=Yes; 2=No	1=yes, 2=No	1=Yes; 2=No	1=Yes; 2=No	0=None; 1=ref OCO; 2=ref OEH; 3=Other
1	K											
2	K											
3	K											
4	K											
5	K											
6	K											
7	K											
8	K											
9	K											
10	K											
11	K											
12	K											
13	K											
14	K											
15	K											
16	K											
17	K											
18	K											
19	K											
20	K											
	TOTAL:											Codes 0, 1,2,3

Appendix 17: Form 6 List of HSAs trained

Childhood Blindness Project, Blantyre
List of HSAs trained

Data entered ☐ **Form 6: HSAs trained**
(Tick when entered)

HSA training session number: ☐☐ ** Put this number in the first column in the table below

Date of training ☐☐ *Day* ☐☐ *Month* 2 0 ☐☐ *Year*

Location of training:
1 Mulanje
2 Zomba
3 Mangochi

Health Centres KIs recruited from:
1 3
2 4

HSA unique code

Session No	HSA No.	Name	Age Yrs	Sex 1=M; 2=F	Health Centre	Phone number
HS	1					
HS	2					
HS	3					
HS	4					
HS	5					
HS	6					
HS	7					
HS	8					
HS	9					
HS	10					
HS	11					
HS	12					
HS	13					
HS	14					
HS	15					
HS	16					
HS	17					
HS	18					
HS	19					
HS	20					
HS	21					
HS	22					
HS	23					
HS	24					
HS	25					

** Co-ordinator

Appendix 18: Form 7 List of HSA allocated villages

Childhood Blindness Project, Blantyre
Allocation of villages to HSAs

Form 7: HSA village allocation

District: 1 Mulanje, 2 Zomba, 3 Mangochi Health Centre _____

Training session HS☐☐

Date of training ☐☐ (Day) ☐☐ (Month) 20☐☐ (Year)

	First name	Surname	Home village	Other villages allocated	Health Centre	HSA Number
1						HS
2						HS
3						HS
4						HS
5						HS
6						HS
7						HS
8						HS
9						HS
10						HS
11						HS
12						HS
13						HS
14						HS
15						HS
16						HS
17						HS
18						HS
19						HS
20						HS
21						HS
22						HS
23						HS
24						HS
25						HS

Appendix 19: Form 8 List of children identified by HSAs

Childhood Blindness Project, Blantyre

Blind children listed by HSAs

HSA code: H S [ ] [ ] Training session

Form 8: HSAs list

1 Mulanje
2 Zomba
3 Mangochi

Name of HSA: _____

District of HSA: _____ [ ]

Phone number of HSA: _____

Name of child identified	Age (years)	Sex M or F	Name of guardian	Village	Nationality	Tick ONE of these boxes: Child blind in both eyes	Tick ONE of these boxes: Has other eye problems
1							
2							
3							
4							
5							
6							
7							
8							
9							
10							
11							
12							

Important note: Only list children aged under 16 who were born in Malawi or who have lived in Malawi for the past year.

Comments: _____

Appendix 20: Form 9 HSA referral form

Childhood Blindness Project, Blantyre **Form 9: Health SA referral form**

Form for referring child to Ophthalmic Clinical Officer in the District Hospital

Referred to Ophthalmic Clinical Officer in_____ District Hospital

Date child identified ☐☐ Day ☐☐ Month 2 0 ☐☐ Year

Name of child _____

Age ☐☐ years

Sex _____

District child lives in _____

Village child lives in _____

Health Centre nearest child _____

Name of guardian _____

Vision of child
1 Child is blind (presenting vision of <6/60 in better eye)
2 Not certain if child is blind
3 Child is blind in one eye only
4 Child is not blind but has other eye problems

HSA who identified child _____

HSA code HS ☐☐ Training session ☐☐ HS number

Thank you for seeing this child

Appendix 21: Form 10 HSA master list

Childhood Blindness Project

HSA Master List Eye Exam Session EES H S ___ ___ Session Data entered ___ *(Tick when entered)* **Form 10: HSA Master list**

Date of eye exam: ___ Day / month / Year **Health Centre:** ___ **District** ___ ___

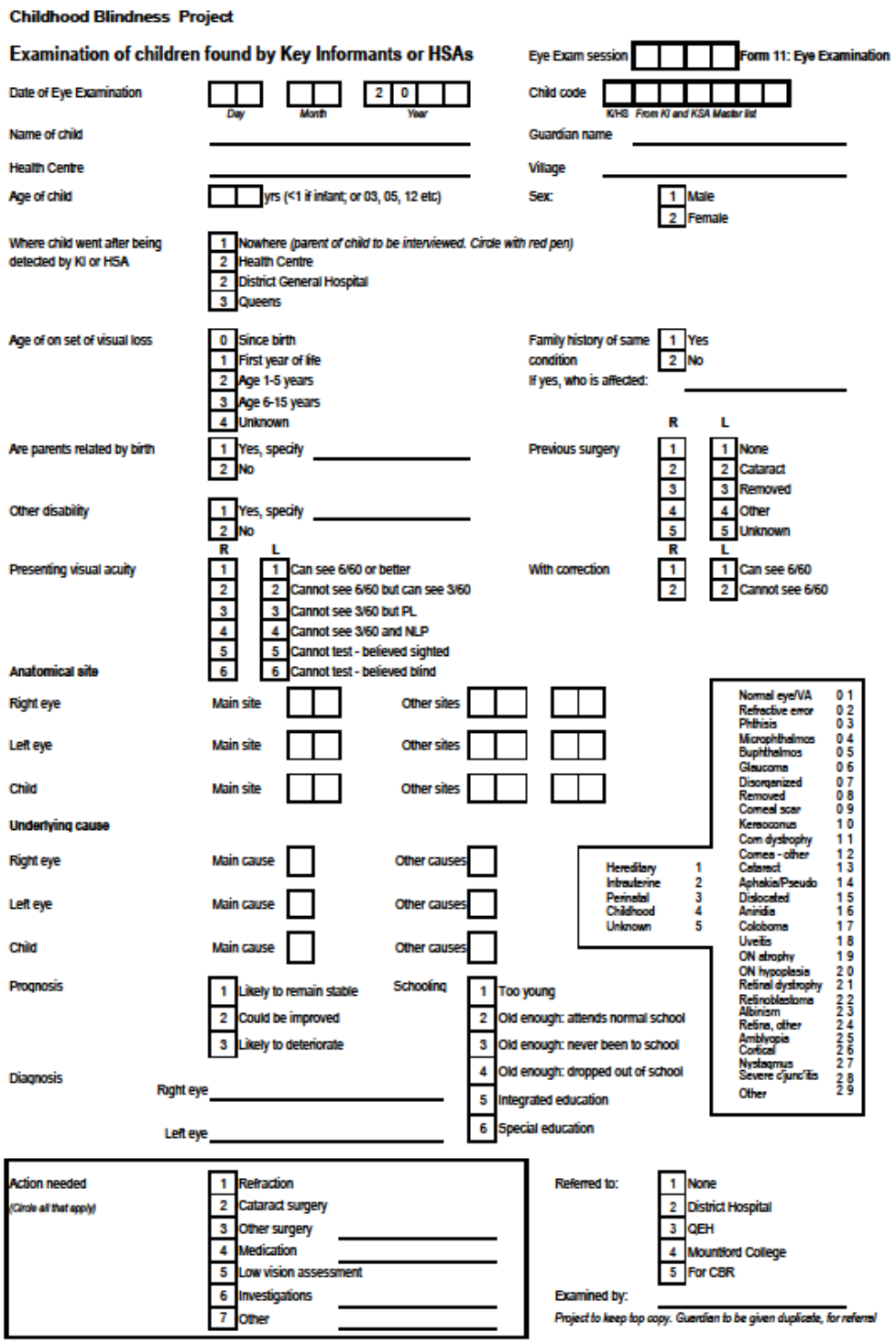
Cum no	H.S.A No	Child No	Childs name	Guardians name	Village	Age (yrs) NK = not known	Sex 1=M; 2=F	Child listed as blind 1=Yes; 2=No 3=not known	Already been to DGH 1=yes, 2=No	Examined at 6 wks 1=Yes; 2=No	Case: <6/60 both eyes 1=Yes; 2=No	Action 0=None; 1=ref OCO; 2=ref QEH; 3=Other
1	HS0101											
2	HS											
3	HS											
4	HS											
5	HS											
6	HS											
7	HS											
8	HS											
9	HS											
10	HS											
11	HS											
12	HS											
13	HS											
14	HS											
15	HS											
	TOTAL:											Codes 1,2,3

1. Only list children aged under 16 who were born in Malawi or who have lived in Malaw 2. Check names are not duplicated

Do not leave until completed!

Appendix 22: Form 11 Eye clinical examination form*

*(Modified WHO standard form for causes of blindness in children)



Childhood Blindness Project

Examination of children found by Key Informants or HSAs

Eye Exam session ____ Form 11: Eye Examination

Date of Eye Examination: ____ (Day) ____ (Month) 2 0 ____ (Year)

Child code: ____ (K/HS From KI and KSA Master list)

Name of child: _____ Guardian name: _____

Health Centre: _____ Village: _____

Age of child: ____ yrs (<1 if infant; or 03, 05, 12 etc) Sex: 1 Male 2 Female

Where child went after being detected by KI or HSA:
1 Nowhere (parent of child to be interviewed. Circle with red pen)
2 Health Centre
2 District General Hospital
3 Queens

Age of on set of visual loss:
0 Since birth
1 First year of life
2 Age 1-5 years
3 Age 6-15 years
4 Unknown

Family history of same condition: 1 Yes 2 No
If yes, who is affected: _____

Are parents related by birth: 1 Yes, specify _____ 2 No

Previous surgery:

	R	L
None	1	1
Cataract	2	2
Removed	3	3
Other	4	4
Unknown	5	5

Other disability: 1 Yes, specify _____ 2 No

Presenting visual acuity / With correction:

	R	L	With correction R	With correction L
Can see 6/60 or better	1	1	1	1
Cannot see 6/60 but can see 3/60	2	2	2	2
Cannot see 3/60 but PL	3	3		
Cannot see 3/60 and NLP	4	4		
Cannot test - believed sighted	5	5		
Cannot test - believed blind	6	6		

Anatomical site

	Main site	Other sites	
Right eye	____	____	____
Left eye	____	____	____
Child	____	____	____

Normal eye/VA	0 1
Refractive error	0 2
Phthisis	0 3
Microphthalmos	0 4
Buphthalmos	0 5
Glaucoma	0 6
Disorganized	0 7
Removed	0 8
Corneal scar	0 9
Keratoconus	1 0
Corn dystrophy	1 1
Cornea - other	1 2
Cataract	1 3
Aphakia/Pseudo	1 4
Dislocated	1 5
Aniridia	1 6
Coloboma	1 7
Uveitis	1 8
ON atrophy	1 9
ON hypoplasia	2 0
Retinal dystrophy	2 1
Retinoblastoma	2 2
Albinism	2 3
Retina, other	2 4
Amblyopia	2 5
Cortical	2 6
Nystagmus	2 7
Severe c'junc'itis	2 8
Other	2 9

Underlying cause

	Main cause	Other causes
Right eye	____	____
Left eye	____	____
Child	____	____

Hereditary	1
Intrauterine	2
Perinatal	3
Childhood	4
Unknown	5

Prognosis:
1 Likely to remain stable
2 Could be improved
3 Likely to deteriorate

Schooling:
1 Too young
2 Old enough: attends normal school
3 Old enough: never been to school
4 Old enough: dropped out of school
5 Integrated education
6 Special education

Diagnosis
Right eye _____
Left eye _____

Action needed (Circle all that apply):
1 Refraction
2 Cataract surgery
3 Other surgery _____
4 Medication _____
5 Low vision assessment
6 Investigations _____
7 Other _____

Referred to:
1 None
2 District Hospital
3 QEH
4 Mountford College
5 For CBR

Examined by: _____

Project to keep top copy. Guardian to be given duplicate, for referral

Appendix 23: Form 12 Eye examination clinic summary

Childhood Blindness Project
Eye Examination summary form

Form 12: Eye Exam summary

Follow up of trainees listed children
1 Key Informants
2 HSAs

Number trained

Eye Examination Session number EE$

Date (Day / Month / Year) 2 0

Place - District

Place - Health Centre 1

Place - Health Centre 2

Place - Health Centre 3

Total number of "blind" children listed *(From master lists)*

Number of child who had been to DGH or QEH *(From Eye Examination forms)*

Number of "blind" children examined *(From Eye Examination forms)*

Number confirmed as BL/SVI (<6/60 better eye) *(From Eye Examination forms)*

Number referred: *(From Eye Examination forms)*
Not needed
District Hospital
QEH
Montford
For CBR

Number involved in eye examination
Medical doctor
Ophthalmic Clinical Officers
Project Coordinator
Driver

Mileage
Starting at Blantyre
Back in Blantyre
Round trip

Overnight stay
1 Yes
2 No

Cost of accommodation + food while away

Appendix 24: Form 13 Registers kept by KIs and HSAs

Childhood Blindness Project

Information to be kept in registers

Form 14:Registers

For register at District Level and at QEH:

Suggest seperate pages for the following:

1. Referred by Key Informants

1 KI code number
2 Date seen
3 Date referred
4 Interval from KI referral to attending
5 Reason for delay if >8 days
6 Name of child
7 Age
8 Sex
9 Health Centre
10 Village
11 Guardians name
12 Presenting VA R
13 Presenting VA L
14 Corrected VA R
15 Corrected VA L
16 Diagnosis R
17 Diagnosis L
18 Action/management
19 Where referred

2. Referred by Health Surveillance Assistants

1 HS code number
2 Date seen
3 Date referred
4 Interval from HS referral to attending
5 Reason for delay if >8 days
6 Name of child
7 Age
8 Sex
9 Health Centre
10 Village
11 Guardians name
12 Presenting VA R
13 Presenting VA L
14 Corrected VA R
15 Corrected VA L
16 Diagnosis R
17 Diagnosis L
18 Action/management
19 Where referred

3. "Walk-in" children

1 Date seen
2 Name of child
3 Age
4 Sex
5 Health Centre
6 Village
7 Guardians name
8 Presenting VA R
9 Presenting VA L
10 Corrected VA R
11 Corrected VA L
12 Diagnosis R
13 Diagnosis L
14 Action/management
15 Where referred

Appendix 25: Form 14 Clinical officer referral form

Childhood Blindness Project

Form for referring child to Queen Elizabeth Hospital, Blantyre

Form 13: OCO referral form

District Hospital child referred from:
1 Mulanje
2 Zomba
3 Mangochi

Date child seen in District Hospital: ☐☐ Day ☐☐ Month 2 0 ☐☐ Year

Name of child _____

Age ☐☐ years (<1 for baby) Sex 1 Male 2 Female

District child lives in
1 Mulanje
2 Zomba
3 Mangochi

Village child lives in _____

Health Centre _____

Name of guardian _____

Who identified child
1 Key Informant after training *Add KI code below*
2 Health Surveillance Assistant *Add HSA code below*
3 "Walk-in"
4 Outreach
5 Other

KI or HSA code number ☐☐☐☐☐☐
KI/KS

Vision of child:
1 Child is blind (presenting vision of <6/60 in better eye)
2 Not certain if child is blind
3 Child is blind in one eye only
4 Child is not blind but has other eye problems

Cause of visual loss:
(Only complete if <6/60 in one or both eyes)
1 Cataract
2 Corneal scar/staphyloma
3 Refractive error
4 Other. Specifiy _____

Reasons for referral:
1 Refraction
2 Cataract surgery
3 Other surgery
4 Medication
5 Low vision assessment
6 Investigations
7 Other,specify

Referred by (position) : ☐

Thank you for seeing this child

Appendix 26: Form 15: KIs & HSAs interviews after identification

CHILDHOOD BLINDNESS RESEARCH PROJECT BLANTYRE

Semi structured interview topic guide

HSAs & KIs post identification of children

Introductions (participants and facilitators)
Purpose of the Research
Ethical issues and consent

60 minutes

1 Tell us how the identifcation of children went on after training ?
Probe coverage,obstacles
2 What help can be given to make the process easier?
(Probe:incentives)
3 Do you believe there are still blind children in the villages you were allocated ?
(probe:willingness to go back)
4 Can we discuss what we agreed during trianing?
(Probe:knowledge,recall of facts,skills)
5 Check notebooks and forms that were given
(probe :why blank?)

Thank the partcipants for their involvement

Appendix 27: Topic guide for children

Qualitative questions (semi structured interview through focus group discussions)

- Introductions (participants and facilitators)
- Introduction of Research Topic
- Purpose of the Research
- Name of Research institution
- Name of funding body
- Ethical issues and consent

Introductory Questions 30 minutes

1 Tell us the name of your village and how many people live in your house?
2 What help is needed for your daily living? why?
(Probe: Medical, Social; Education)
3 Can we share experiences and challenges we have had as blind children?
(probe: hospital challenges, barriers)
4 Do you have friend in the community?
(Probe: benefits, importance, role of parents, friends)

Main topic of discussion 1 hour

5 How do did you end up at this school?
(Probe: knowledge, family networks, number of children, social structures)
6 Are there any things that you would like to share about this place?
(Probe: likes. dislikes, accessibility)
7 how do you feel when it is time to go home for holiday?
(Probe: fears, challenges)
8 Tell us what you would like to do in future?
(Probe: expectations)
9 Any things that you would like people to know about children like you?
(Probe: stigmatisation, training)
10 How does the community view you as blind children?
(Probe: fiends, social inclusion, community assistance)

Concluding/Closing Questions 30 minutes

11 So where are you happier, here at school or at home
(Probe reasons, relationship with siblings)
11 Summary of discussion
(Probe: consensus; burning issues)
Thank you very much. We have now reached the end of our discussions

Appendix 28: Form 16: Topic guide for parents

Form for parents of blind children post identification period

District where child from:

1	Mulanje
2	Zomba
3	Mangochi

Date child seen ☐☐ ☐☐ 20☐☐

Day *Month* *Year*

Where child seen

1	At 6 weeks mop up visit in the community
2	District hospital
3	Central hospital
4	Other, where

Name of child _____

Age ☐☐ years *(<1 for baby)* Sex 1 Male 2 Female

Village child lives in _____

Health Centre _____

Name of guardian _____

Who identified child(tick)

1	HSA	Tick	HSA ☐☐☐☐☐☐☐
2	KI		KI

Reasons for interviewing parents/guardians

1	Child did not attend Health centre
2	Child did not go to District hospital
3	Child did not go to central hospital
4	Child did not attend follow up visits

Vision of child:

1	Child is blind both eyes
3	Child is blind in one eye only
4	Child is not blind but has other eye problems

Why did the parents/guardians not bring the child

1	Not told to do so by the person who identified child
2	Told but did not have transport to go
3	Went to health centre but sent back
4	Did not believe condition was serious
5	Have previously been told nothing can be done
6	Went to a traditional healer
7	Waiting for Drs to visit them at home
8	Awaiting for decision from one parent who is away
9	Other _____

Appendix 29: Form 17: Interviews with EHOs, DEHOs, and Medical assistant

Childhood Blindness Project

Form for medical assistants and environmental health officers

Form 17: Medical assistant and EHO form

District where child from:

1	Mulanje
2	Zomba
3	Mangochi

Date interview

				2	0		
Day		*Month*		*Year*			

Who allocates duties to HSAs

1	In charge of health centre
2	Environmental health officer for the area
3	District environmental health officer
4	Other _____

How often are duties allocated

1	Daily
2	weekly
3	Every 2 weeks
4	Every month
5	1-3 months
6	3-6 months
7	6-12 months
8	other _____

Who supervises HSAs

1	In charge of health centre
2	Environmental health officer for the area
3	District environmental health officer
4	Other _____

How often are HSAs supervised

1	Daily
2	weekly
3	Every 2 weeks
4	Every month
5	1-3 months
6	3-6 months
7	6-12 months
8	other _____

How busy are HSAs?

1	Not busy, can be trained and have time to identify blind children
2	Busy, but time can be allocated for identifying blind children
3	Can normally identify blind children within their working schedule
4	Extremely busy, do not have time to identify blind children

If HSAs were trained in identifying blind children in their villages, how would they be supervised (tick yes or no)

In charge of health centre (HC) can know that they are doing the work	1	Yes	2	No
In charge of health centre would not be involved	1	Yes	2	No
District environmental health officer would know if they were doing eye work	1	Yes	2	No
HSAs would send a report to in charge of HC on what they were doing	1	Yes	2	No
Ideally the training team would be the one to provide supervision	1	Yes	2	No
It would be difficulty to monitor whether HSAs were doing the work or not	1	Yes	2	No
Other duties would prevent HSAs from identifying children	1	Yes	1	No

Appendix 30: Cycles of KI & HSA training and screening sessions

			WEEK										
		1	2	3	4	5	6	7	8	9	10	11	12
Cluster 1	Plan HSA and KI training	1											
	Training HSAs and KIs			#									
	HSAs and KIs finding children												
	Reminder phone call one week after training												
	OCO examining referred children in DGH												
	Project Co-ordinator compiles lists and plans visit												
	Examining children in the community												
	In-depth interviews												
	Plan Focus Group Discussions												
	Focus Group discussions with HSAs and KIs												
Cluster 2	Plan HSA and KI training				2								
	Training HSAs and KIs						#						
	HSAs and KIs finding children												
	Reminder phone call one week after training												
	OCO examining referred children in DGH												
	Project Co-ordinator compiles lists and plans visit												
	Examining children in the community												
	In-depth interviews												
	Plan Focus Group Discussions												
	Focus Group discussions with HSAs and KIs												
Cluster 3	as above												

Appendix 31: Training timetable

Time	Session number	Activity/content	Facilitator
08.30-09.00	1	• Introductions • Background – VISION2020 • Childhood Blindness Research • Purpose of training	
09.00-10.00	2	• Structure and function of parts of the eye	
10.00-11.00	3	• Blindness • Number of children who are blind • Impact of blindness on children, their families and the community • Case study from Malawi	
11.00-11.15		Break	
11.15-13.00	4	• How do we know if a child cannot see? • Finding and referring blind children	
13.00-14.00		Lunch	
14.00-15.15	5	• How to measure vision in children? • Main causes of blindness in children in Malawi and how they are prevented or treated	
15.15-15.30	6	• Health promotion	
15.30-16.00	7	• How to feel forms for those children who might be blind	
16.00-16.30	8	• Which children to refer, where and how • Distribution of villages	
17.00		Formative assessments /feedback Closing remarks	

Appendix 32: Consent form for parents and children interviews

ENGLISH ENROLLMENT & CONSENT FORM/ (Translated into Chichewa/Yao during training)

INTRODUCTION
We kindly ask you to be enrolled and participate in the research mentioned above which is being conducted by College of medicine, Lions Sight First Eye Hospital in Blantyre and funded from British Council for Prevention of Blindness through London School of Hygiene and Tropical Medicine (LSHTM). This research is a follow up of the work that was done when KIs and HSA's visited you in your village and identified a blind /visual impaired child from this village. The aim is to interview parents of blind children, the children that were identified and the community members to find reasons why the children and parents did or did not report to the eye hospital in Blantyre. This information will help us possible find solutions to improve children's access and acceptance to surgery, optical corrections and follow up in Southern Malawi. We would like to ask you several questions.

You must know that:
- Enrollment into this research is voluntarily on your part
- You have the right not to be enrolled or to stop at any time even if you are already enrolled without losing your rights for treatment.

PROCEDURE
Once you have accepted to be enrolled into the research and signed a consent, we will conduct an indepth interview with you and a focus group discussion with memebrs of your community.
We like to hear your views about the child and the community ; howver if you are unable or reluctant we will stop interviwing you .

CONFIDENTIALITY
We ensure that all documents,tests and results related to you being involved in this reaserch are kept with strict confidentiality.We will give you a unique number and will use that number for discussing you results.We will not give results to a third party without your consent.

ENQUIRIES
Futher questions regarding this research may be adressed to the following:
- Dr Khumbo Kalua, Principal Investigator ,Senior Eye Specialist , Queen Elizabeth Central Hospital, Telephone number 01-873-214/0999958176

If you have further questions regarding your rights of freedom,please contact the following
- The Chairman of College of Medicine Research Ethics Committee, College of Medicine, telephone 01870911

Consent form form for (please circle one option applicable)
1. Child examination
2. Indepth interview
3. Focus Group discussion with community memebrs

If you have read this form,or the form has been read to you and you understand and have accepted your child to be involved in the Research,we ask you to sign the form below

_____	_____	
Name of participant /guardian	Signature	Date
_____	_____	
Name of worker getting consent	Signature	Date
_____	_____	
Name of Witness	Signature	Date

Appendix 33: Trainers manual for KIs and HSAs

Blantyre Institute for Community Ophthalmology

BICO
Lions Sight First Eye Hospital

Excellence in Community Eye Health

Childhood Blindness Project
Queen Elizabeth Central Hospital, Blantyre
Malawi

Research Trainers Manual for Key Informants (KIs) & Health Surveillance Assistants (HSA's)

Children in a school for the blind

Produced by:
Dr Khumbo Kalua & Prof Clare Gilbert
International Centre for Eye Health
London School of Hygiene & Tropical Medicine
2008

1. Background

VISION 2020

- A global initiative to eliminate avoidable blindness by the Year 2020.
- Coordinated jointly by the World Health Organization (WHO) and the International Agency for the Prevention of Blindness (IAPB) with an International membership of NGOs, professional associations, eye care institutions and corporations.
- VISION 2020 member organizations are working together to eliminate avoidable blindness, to give everyone in the world the Right to Sight.
- Malawi is a signatory to VISION 2020
- Focus is on disease control; making sure there are adequate staff in terms of numbers and skills as well as buildings and equipment
- Childhood blindness is one of the priorities of VISION 2020

Prevalence and magnitude of blindness in Malawi

- Adults: 1 per 100 total population is blind (approx 100,000 blind)
- Children: 1 per 2000 total population is blind (approx 5000 blind children)
  In a total population of 50,000 there will be 25 blind children

Some information about blindness in children

- In Malawi over half of all blind children need not be blind because the cause of their blindness could have been entirely prevented, or they need treatment so they can see again
- Only around 10% of blind children are in school in Malawi – the others just stay at home
- Many parents believe that if a child is born blind there is nothing that can be done and so they do not take their child for a medical assessment.
- Parents often use traditional medicines in their child's eyes which can make the condition worse

Why Childhood Blindness Project?

- Children are the future of tomorrow- blind children have many years of disability ahead of them compared with adults
- Common causes of childhood blindness are treatable / preventable if early intervention is done

2. Aims of the Research:

The overall aim of the research is to get better information on how many children are blind, why they are blind, what services they need and how these services change children's' lives. This information will be useful for planning services. The objectives are to:

- To compare two methods of identifying blind children in the community; using trained key informants versus trained HSAs in identifying children

This training manual is for Health surveillance assistants (HSA) and key informants. It is a one-day training programme and it is envisaged that training will take place within the district near a District Hospital or Health Centre.

3. One-day training:

The training aims to educate the HSA & KIs in Childhood Blindness so that they are able to identify and refer blind children from their communities to the eye unit in the district Hospital where a thorough examination can be done and appropriate measures taken.

What tasks should be expected to be performed after training?

- Those who have attended the one training course should in addition to performing other PHC related work be able to do the following:
    I. Take a history from a child or their parents who present with an eye problem
    II. Know signs of a healthy eye and an eye with visual problems
    III. Identify whether a child is blind or not e.g. by using a visual acuity chart to measure the vision in older children
    IV. Learn the skills to be able to assess vision in younger children
    V. Identify cases of cataract in children and refer them to the hospital immediately
    VI. Promote eye health at the Health Centre and in the community
    VII. Record and keep records of all eye patients seen and referred.

Who will teach this course?

- The Ophthalmic Clinical Officer will be able to conduct the training.

Teaching materials and methods

- Lectures, posters of eye conditions, using flip charts, demonstration and practical of visual acuity testing in children, discussion and group work.

Note: Trainees will be given a visual acuity chart, a notebook and referral forms at the end of the training.

4. Structure and functions of parts of the healthy eye:

Overview:

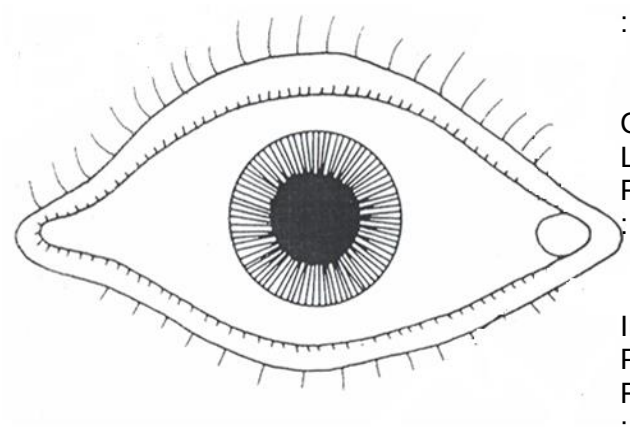
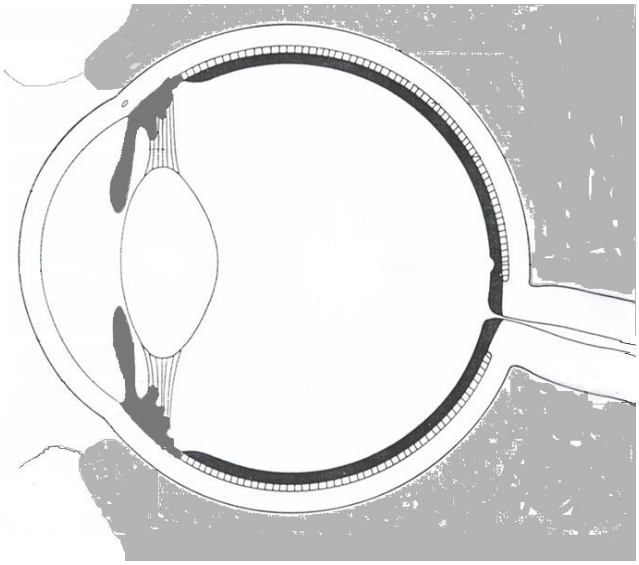
The eyelids and eye lashes are to protect the eye. The eyelids should open fully and close completely

The cornea is a transparent structure at the front of the eye.
The lens of the eye, which is also transparent, is located just behind the pupil of the eye.
The cornea and the lens focus light entering the eye.

The iris is the brown coloured structure at the front of the eye. It is behind the cornea.
The pupil is the round, black area at the centre of the iris. It should be round, and it gets bigger in the dark and smaller in the light.

The iris and pupil control the amount of light entering the eye

The retina lines the inside of the eye. It cannot be seen from the outside without special equipment. It converts light into images.
The optic nerve takes these images to the brain
The retina and optic nerve form the image of the world and transmit this to the brain.

Front view of the eye	Parts the eye and their functions	Cross section of the eye
	Eyelids Eyelashes Function: Cornea Lens Function: Iris Pupil Function: Retina Optic Nerve Function:	

5. Blindness:

"Blindness" is a word that means different things to different people.

What is blindness? How does the community define and perceive blindness? Discussion
WHO definition of blindness and severe visual impairment versus community definition?

WHO – presenting visual acuity less < 6/60 in the better eye

The World Health Organization defines blindness according to the ability of the person to be able to read letters on a “visual acuity” chart.

For this study we will are using the following way to describe a child who is blind:

Child = someone aged 0 – 15 years Blind = the child cannot see a letter in 4 directions in the visual acuity chart that will be given, or a child is thought to be blind from the history or other simple assessments of vision

6. Number of children who are blind:

In African countries blindness in children is more frequent than in other parts of the world, but it is still uncommon.

In Africa, about 1 child will be blind in every 2,000 population of all ages. For Malawi this is roughly 1 blind child per every 1-2 villages

The following is an example of how to calculate the number of children who are blind in the area served by your Health Centre:

Total population: 40,000

Number of blind children = $\frac{40{,}000}{2{,}000} = 20$

Calculate the number of children who are blind in the population covered by your Health Centre/village:

Total population:

Number of blind children = $\frac{\ldots\ldots.}{2{,}000} =$

7. Impact of blindness on the child, their family and the community:

What effect do you think blindness has on the child themselves, on other family members and on the wider community?

Impact on the child:

Impact on their family:

Impact on the community

We need to do all we can to prevent blindness in children or to make sure children who are blind receive the services they need. Even if a child has an incurable cause of blindness they still need support to go to school, and rehabilitation so they can learn to do what their sighted brothers, sisters and friends can do.

Actions that can help children who are blind:

How we can help families where there is a blind child:

How communities can help families where there is a blind child:

8. Case study from Mulanje

Childhood Blindness coordinator to fill in and conduct in this section

Picture of GM to be shown to the class

GM

Born normal and able to see everything until the age of 3; when the child started having difficulties with his eyes. By then he still used to see properly but with difficulties.
At age 10 (3 years ago), he was hit with a stick, on the right eye, by a friend. The eye was terribly damaged; hence it lost its vision. The boy was only left with one eye that could see.
Suddenly, this only left eye also started to have difficulties and he began losing vision with time. Eventually, he completely lost sight in both eyes. This was early this year and when he was in standard six at a normal school.
He has found it extremely difficult to cope in class.

When was he identified?
How was he identified?
What was the result?
Where is he now?

How many more of such children are out there?

9. How might we know if a child cannot see properly?

Adults complain if they lose vision, but children do not usually complain. We have to ask some questions first and go by what the parents, teachers or others have observed, or noticed. The following are some important indications that a child cannot see properly:
Clues to telling that a child is blind:

- Child not following light /objects
- Child not looking /smiling back as mother/other people smiles at the child
- Child bumping into objects
- Child not able to see objects across the room
- Child playing well during the day but refusing/all afraid at night
- Older child not able to read/see letter at a distance of 6 metres
- Mother convinced that child is not seeing
- Child with white pupil

Babies:0-6 months

- The mother notices that the child does not look at her face, does not smile when she smiles at her baby, and the baby does not watch her as she moves around
- The mother may also have noticed a "white spot" in her babies' eyes, or some other abnormality
- The baby's eyes may "wobble" from side to side and they cannot hold them still

Toddlers and young children:6months-4 years

- The child is reluctant to walk around, particularly in the evenings when the light is not good
- The child bumps into things or falls over objects on the floor

Older children:4 years and above

- They stop doing what they used to do
- They start holding the things they want to look at very close

Important message: If the mother, father or other family member thinks the child cannot see properly they are nearly always right, even if they are not well educated. They know their child very well!

10. How to measure vision in children?

Practical on how to screen blind children using visual acuity (in older children)
Single prototype E letter chart. see copy of how to take visual acuity in children <6 years and children >= 6 years

A. Standardized history for blind children <6 years

1. How might we know if a child cannot see properly?

Adults complain if they lose vision, but children do not usually complain. We have to ask some questions first and go by what the parents, teachers or others have observed, or noticed. The following are some important indications that a child cannot see properly:

In children aged 0-5 years:

This can be difficult!

We can assess whether the child:

- Looks at your face and smiles when you smile

- Looks at a brightly coloured object held about 20 cms in front of them, and whether they follow the object with their eyes when you move the object slowly from side to side. They may want to grab it, which means they have seen it!
- Reaches for a small object held on the palm of your hand when you put your hand out flat in front of them

Note: Refer all children that you suspect may be blind, or the ones that you are in doubt

Babies:0-6 months

- The mother notices that the child does not look at her face, does not smile when she smiles at her baby, and the baby does not watch her as she moves around
- The mother may also have noticed a “white spot” in her babies’ eyes, or some other abnormality
- The baby’s eyes may “wobble” from side to side and they cannot hold them still

Toddlers and young children:6months-4 years

- The child is reluctant to walk around, particularly in the evenings when the light is not good
- The child bumps into things or falls over objects on the floor

Older children:4 -5 years and above

- They stop doing what they used to do
- They start holding the things they want to look at very close

Important message: If the mother, father or other family member thinks the child cannot see properly they are nearly always right, even if they are not well educated. They know their child very well!

B. Standardized history for blind children >=6 years

How to measure vision in children

1. Explain to the child and the parent that you would like to measure the child’s vision as they may have “some problem with their vision”. Explain that this is not painful and will only take a few minutes
2. Measure out 6 meters by taking the number of paces you need to take for 6 meters (women = usually 8 paces, men= 7). Mark the beginning and the end of the 6 meters
3. Hold the E about 30cm away from their eyes make sure the child understands that you want them to show the direction the “arms” of the E are pointing in. Rotate the E chart several times until you are sure they understand.
4. Once you are sure the child understands what they should do, ask the child to go to the 6 meter mark and face you.
5. Show the E chart 4 times. Change direction of the E each time. Give the child one chance to show the direction of the E.
6. Count how many times the child correctly shows the direction of the arms of the E.
7. Refer all children who get the direction of the arms of the E wrong one or more times.

What to tell the parents:

Do NOT tell them their child is blind – this will worry them and you may be wrong

DO tell them that their child needs to be examined in a clinic which will be set up in the community shortly

What I should do now:

Complete the details of the child on the form I have been given

Motivate the parents to take the child to the clinic.
Accompany the child and their guardian to the clinic

Childhood Blindness Project

BICO

Blantyre Institute for Community Ophthalmology
Excellence in Community Eye Health

Queen Elizabeth Central Hospital, Blantyre

Project Co-ordinator, Blantyre Institute for Community Ophthalmology (BICO)
Cell phone number: 09241019/08302232

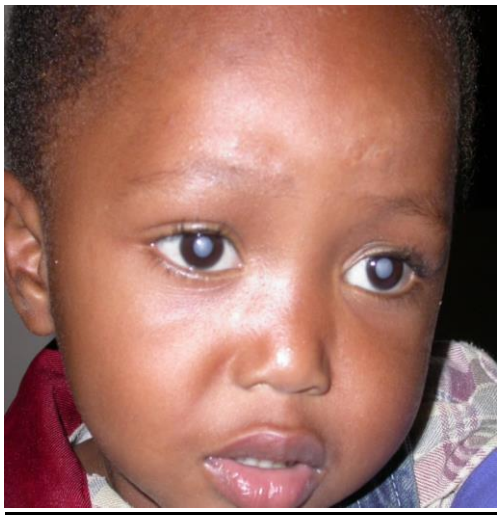
11. Main causes of blindness in children in Malawi

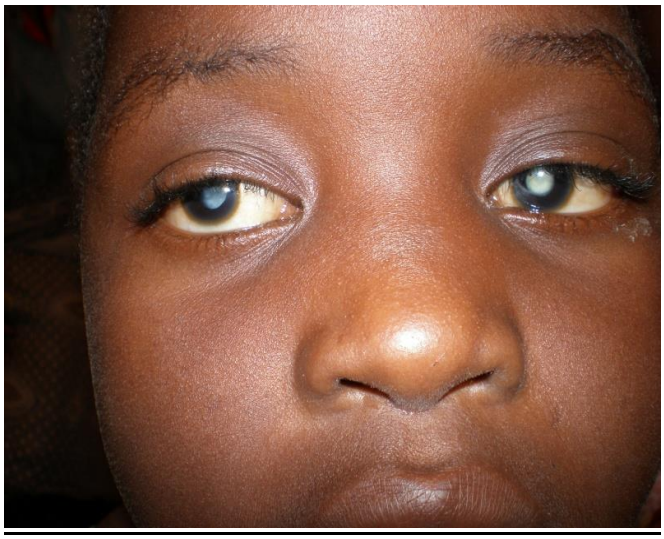
1. Congenital versus developmental cataract
2. Cornea blindness secondary to measles and Vitamin A deficiency
3. Other eye diseases
4. Use of Traditional herbal medicines
5. Refractive errors

A few notes about cataract in children:

A. Cataract:

- A cataract is when the lens of the eye is cloudy
- The pupil of the eye is whitish instead of black
- The pupil is still round and regular in shape





A child may be too young to complain about poor vision, but there are some signs you may notice if the child has cataract.

- Family members may notice that the child does not recognize the mother (normally babies recognize mother's face by 2 months of age).
- The cataract may make the black centre of the eye & look white or grey.
- Sometimes the eye with cataract may turn in or out.
- The eye with cataract may show a jiggling movement (nystagmus).
- Sometimes when it involves only one eye, it may be difficult to detect, as the child may be using the good eye too.
- A child may have poor vision due to reasons other than cataract. Only an eye doctor can determine this.

Children can be born with cataracts (congenital), or they can develop when a child is a few years old, having previously had normal eyes.

The underlying causes of cataract are:

- They can run in families, and one parent may also have had cataracts since childhood
- They may be due to infection in the mother during pregnancy (e.g. rubella)
- They may follow injury to the eye
- In many children, the cause is never discovered

The child may either be born with cataract or may develop cataract early in life. It may be caused by some disease in the mother during pregnancy or due to some problem with the child's general health. It may also be due to injury to the eye. Sometimes it may be passed to the child from a parent who has the same problem.
A child may have cataract in both eyes or in only one eye. It is possible for a baby or young child to have cataract because they can be born with it.
Cataract in children does not need to mature before child is brought to the hospital; child should be brought as soon as there is suspicion.
Cataract in children is treatable and services are free of charge at the hospital

Treatment:
Cataracts cannot be prevented but they can be treated. Treatment consists of an operation to "wash out" the cataract. Afterwards the child will be able to see better.

Children with cataracts need urgent referral as the sooner they have the operation the better chance they have of good vision after surgery.

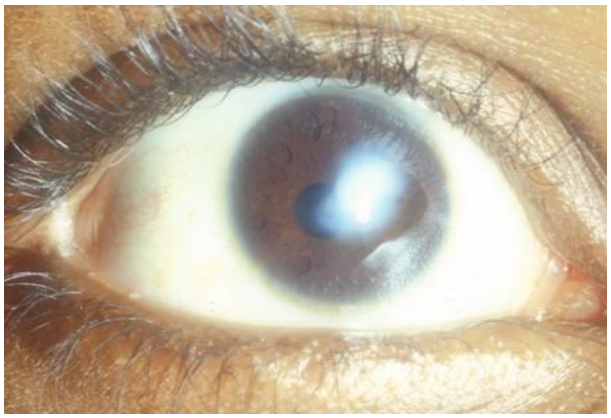
Will a blind child see properly after cataract surgery?

Many children with cataract in both eyes see better after surgery, but only if it is done very soon after the cataract develops and only if the child wears the proper glasses after surgery. It is important to come for regular eye checks after surgery.

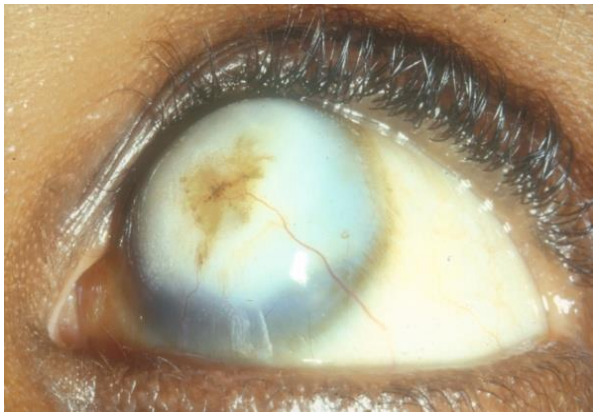
B. Corneal scarring:

- If the cornea has an ulcer, or is injured, it heals leaving behind a white scar
- The scar stops light entering the eye
- If the cornea is scarred, you cannot see the pupil

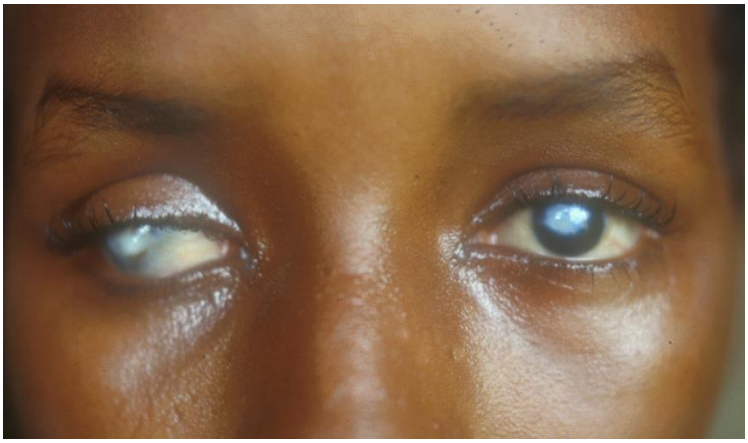
a.



b.



c.



a. Corneal scar which is not completely covering the pupil. This eye will have some vision
b. The scar is totally covering the pupil – this eye is blind
c. Child from corneal scarring as the scars in both eyes cover the pupils

Underlying causes of corneal scarring:

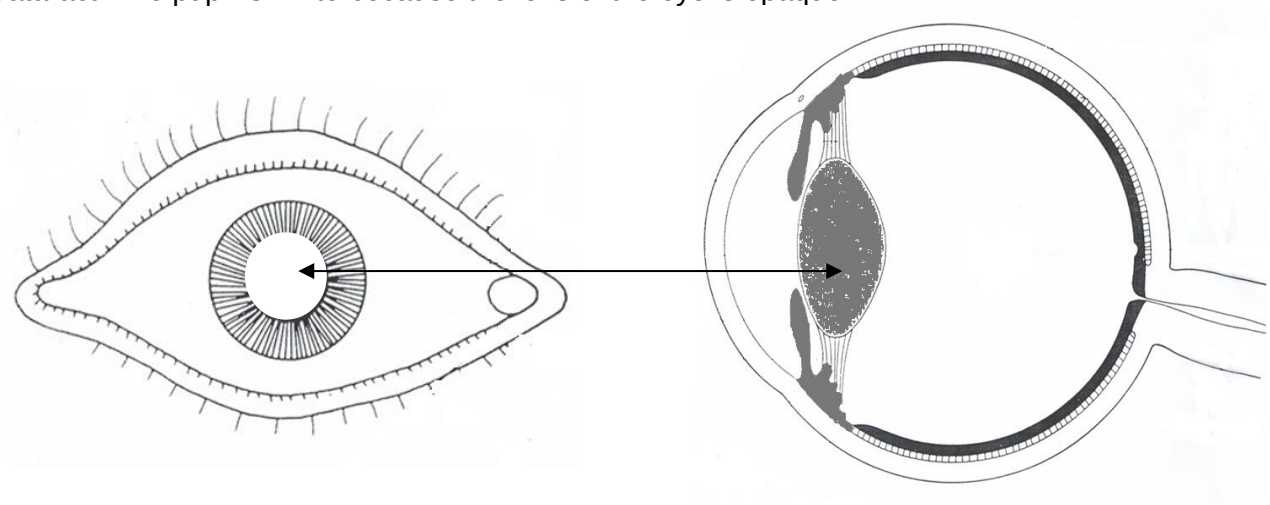
- Vitamin A deficiency
- Measles
- Use of harmful traditional eye medication or practices

Prevention and treatment:
Most of the causes of corneal scarring are preventable. Your work as HSAs is very important in preventing blindness from corneal scarring by measles immunization, vitamin A supplementation, health promotion about breast feeding etc.
Sometimes a child with corneal scarring can regain some vision with a small operation.

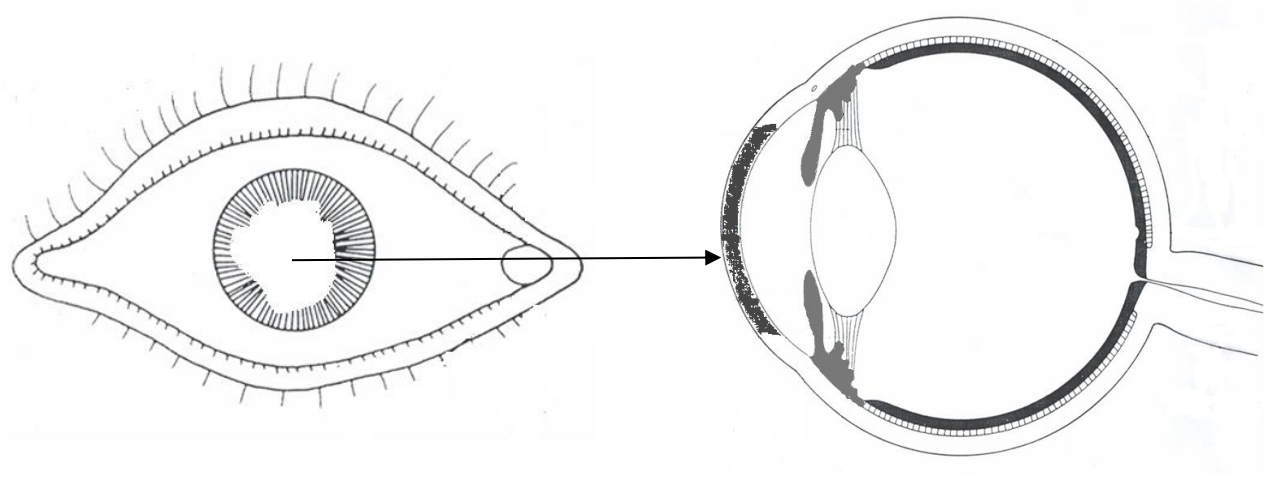
ALL children blind from corneal scarring should be referred: they need assessment for education and rehabilitation even if nothing can be done to help them to see better.

Difference between cataract and corneal scarring:

Cataract: The pupil is white because the lens of the eye is opaque



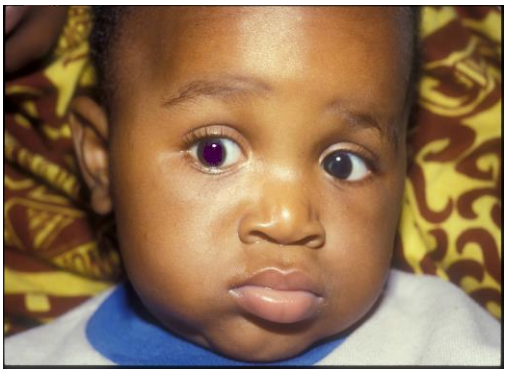
Corneal scarring: The cornea is white and the pupil cannot be seen



C. Other causes:

There are many other causes of blindness in children.

It is important to know that if the condition affects the retina or the optic nerve **the external appearance of the eyes can be entirely normal.** So, just because a child has eyes that look normal does NOT mean they should be able to see.



This child is blind because of a problem in the retina.

The front of his eyes look entirely normal

12. Health Promotion (Information, Education and Communication):

All the things listed below can help to prevent a child from becoming blind and are important messages for the community:

- All children should receive measles immunization and vitamin A supplementation
- All children should have their eyes checked at least once before 1 year of age by an HSA while giving immunisations
- Traditional medicines (e.g. pepper, tomato leaves, urine, sap or extracts from plants and many others) should not be put in the eyes as they make the condition worse
- Breast feeding from immediately after birth and until the age of 18 months is recommended, with nutritious complementary feeds from 6 months
- Any new-born baby with red, puffy eyes with discharge should be referred to the Health Centre immediately
- The only treatment for cataract is an eye operation where the cataract is washed out
- Even if a child is not blind but they complain of a persistent eye problem they should be referred to a health centre
- Allergic conjunctivitis is the commonest cause of itching, tearing and red eyes in children-but usually doesn't not cause blindness. Treatment for allergic conjunctivitis can be obtained from a health centre

13. How to identify children who might be blind?

The following are some ideas

- Door to door
- Snow balling techniques
- Participatory rural appraisal (PRA) techniques
- Church announcements
- Village meetings
- Orphan care and other community places
- Schools
- Social gatherings
- Market days
- Mothers discussion groups

Techniques that may help in getting more children listed.

Snowballing technique:
What is it?

Participatory rural appraisal (PRA):
What is it?

Participatory rural appraisal (PRA) has been defined as a:
'family of participatory approaches and methods which emphasize local knowledge and enable local people to do their own appraisal, analysis and planning. PRA uses group animation and exercises to facilitate information sharing, analysis and action among stakeholders

What is social mapping?
A tech of identifying a group of people who do and not do a particular thing (like going to school) - can also be used for identifying blind children.

14. **How to list identified children**: (spend time practising on the forms form 3 and 4 for KIs and 8, 9 for HSAs –each key informant/HSAs gets a form at this time).
Two forms to be used:
One master list for all children (must be in duplicate)
One refer form for each child (must be in duplicate)

15. What to list? Go through the form 3 & 4 with the KIs and 8,9 with HSAs
Child is blind in both eyes
Child is blind only in one eye
Child had other eye problems

16. Where do we send the children after listing?
All children should be sent to the health centre within 2 weeks of being listed where the medical assistant will organise transport for them to go to the hospital and be seen by the ophthalmic clinical officer. The OCO must record each child seen and keep the form (form 4,9) that the child has brought. Each child referred must have form 4 and KIs/HSAS must ensure that all children have been referred by the end of 2 weeks after training.

The project coordinator will communicate with the leaders of KIs/HSAs to get the master lists (form 3) at around week 4 after training

At week 5 after training project coordinators will communicate with KI /HSA team leaders that the research team will be coming at 6 weeks to see all the children in their villages

(Please do not disclose this information during the training period –not even to the medical assistant!!!!!)

Week 6 the research team visits the children in the villages and feels forms 11,12 ,13,14, 15 ,16 and 17. ***Do not leave these forms blank***

17. Which HSAs/ KI will cover which villages? Village allocation Discussions –feel form 2 & 7

18. Motivating parents
Motivating parents to come with children. Discussion
Transport reimbursements (for parent and child) for correctly identified children needing to go to the hospital in Blantyre

19. **Agreement and allocating deadlines for referring children for examination-** 2 weeks

20. Which children to refer, where they should be referred to, and how to refer them -revision

Which children NOT to refer using the project referral form:

Please do refer the following children so they can be assessed, but DO NOT complete a project referral form for them, as in the project we only want to collect data on children aged 0-15 years who were born in Malawi:

- Children aged 16 years and above
- Children born in Mozambique:

Which children to refer using project referral form:
ALL children born in Malawi who you think have a problem with the vision in both eyes, whether you can measure the vision using the chart or not. This will include children with

- white pupils
- corneal scars
- eyes that have other obvious abnormalities
- eyes that appear normal from the outside but can still see
- Children whose mothers believe are blind

Where the child should be referred?

- To the Ophthalmic Clinical Officer at the District Hospital through the health centre (keep duplicate forms)

How should the child be referred?
For each child you refer you need to

- Complete the form in duplicate
- Complete a referral form (see below). Give the top copy to the guardians and keep the duplicate. All duplicates should be kept properly. for HSAs keep one folder at health centre for duplicates
- Make sure your own identity number (HSA/KI) is added on the referral form. This will allow us to contact you again if we want to, for example if the child does not come back for follow up.

What to say to parents of children you want to refer:

- Do NOT tell them their child is blind – this may frighten them and make them reluctant to seek advice. Say something like " I think your child has a problem with their vision which needs to be confirmed by someone who has been trained in eye care"
- Do NOT tell the parents the child needs surgery, for the same reasons (and you may be wrong!)
- DO BE encouraging: say that even if there is no medicine that can help, there are other ways in which the child can be helped
- DO SAY that the child should be taken for assessment as soon as possible

Take Home Messages

- ALL children who are blind can be helped in some way, either by medical treatment or by support for them to go to school or for rehabilitation so they can learn to live independent lives
- ALL blind children should be referred to the Health Centre for assessment by the Ophthalmic Clinical Officer. He will decide if the child needs to be referred to Blantyre
- Cataract in children can be treated and sight restored if children are brought in earlier. Children should be screened at birth for a "white pupil" and again at immunization.
- Cataract in children does not need to "mature "so children should be brought in the hospital as soon as the diagnosis has been made. This does not need a torch!
- If you are in doubt whether a child is blind or not, it is better to refer than not to refer.
- You can use the skills and knowledge you have acquired to identify and refer adults to hospital; but do not use forms given for adults

CHILDHOOD BLINDNESS RESEARCH PROJECT

Selecting Key informants

Training of key informant is crucial and should be planned and implemented carefully. Training includes not only skill development to pick 'suspect blind' children but also developing motivation among the key informants as a group as well as individuals – the more motivated they are, the more likelihood of finding most of the blind children. Following is a summary of main components of the key informant training.

During one full day training of key informants the following will be covered:

1. The purpose of the workshop
2. What is blindness, and how to assess blindness in children
3. Causes of blindness in children, and how the eyes may appear
4. How to identify families with blind children?
5. How to assess visual acuity in younger and older children?
6. What to do with a child suspected blind
7. Referring blind children to the examination centre
8. How to motivate parents to bring their children for assessment?
9. Allocating dates for examination
10. Receiving feedback from the trained KI's

Who are the Key informants (KIs)?

These are people in the community who know their villages very well and can be used to identify blind children; most importantly there are willing to help identify these children in the community and have time to volunteer and spare time (about 3 weeks).
No one should be forced or encouraged to participate with the view that they will benefit financially. KI may be provided with some gifts as a token appreciation. Transport money will be reimbursed where justified.

How do we identify key informants?

The point of entry must always be through the village/community leaders where the KIs will be selected from. The chief should be contacted and discussions should take place as to who could be potential key informants.
Selection of KIs should only be done after you liaising with the Village /community leaders
Examples are given below.

1. Villagers who were working with a local charity in the area and now are doing nothing but stay/are in that village should be considered as KIs
2. Any villager who is active and keen to do volunteering work should be considered
3. Women leaders; or selected people from women groups taking care of disadvantaged groups
4. Traditional birth attendants and traditional healers
5. Religious or church leaders
6. Any other village resident that may do the job.

Who should be chosen?

Criteria for being chosen as a key Informant

1. Must live in the village/community

2. Must be selected by the community leaders in that village
3. Must be able to work as a volunteer
4. Must be willing and have time and capability to do the job
5. Must be able to read and write
6. Must be fit and able to travel/walk long distances from home
7. Able to influence or convince people in the community
8. Empathetic and understanding about disability
9. Energetic/active

How many will be selected per village
Usually one key informant will be required to cover 2 villages; the one they live in and the neighbouring one. Selection of which village the key informant will come from will be done before at the project offices in Blantyre and the chief will be communicated about who to select in consideration for other factors (age, sex).

What will happen to Key informants once identified?
The identified KIs will be communicated when and where to go for the training and they people should be told that the training will take place for a whole day usually within a centre not very far away from their villages

Training dates and venues are to be organized and confirmed in liaison with the KI's and the medical assistant from the health centre located in the catchments area where the KIs are coming from, who will also be required to attend the training

Transport reimbursements and refreshments /lunch will be provided during the training.

Key informant

Job description of a key informant

- To identify blind children in the community

Tasks

- Communicate with families and community about visual impairment in children
- Find the children with visual impairment
- Motivate parents and community to bring the identified children for assessment

Sub tasks

- Meet various village leaders
- Explain the purpose of their visit/ what she/he is looking for
- Ask leaders if they know or have heard of children who do not see well
- Go & talk to identified families and convince them to go to report to an agreed location on a particular day
- List all the identified children

Selection criteria of key informant

- Must live in the village/community
- Must be selected by the community leaders in that village
- Must be able to work as a volunteer
- Must be willing and have time and capability to do the job
- Able to read and write
- Able to travel/walk long distances from home
- Able to influence or convince people in the community
- Empathetic and understanding about disability
- Energetic/active

SUBTASK	KNOWLEDGE	SKILLS	ATTITUDE
Meet Village leaders	Community +++	Speak local language, convince +++	Respect ++
Explain purpose	Blindness +	Communication +++	Patience/positive +++
Ask about blind children	Blindness +	Communication +++	Sensitive +++
Talk, convince, refer	Local culture, calendar of activities transport +++	Communication +++	Positive/ +++ sensitive
List identified children	Making a list ++	Reading and writing ++	Positive ++

Where training will take place?

Any place that is easily by people within the community. It could be a Health Centre, a school or even a church?

CHILDHOOD BLINDNESS RESEARCH PROJECT

Selecting Health Surveillance assistants

Training of HSAs is crucial and should be planned and implemented carefully. Training includes not only skill development to pick 'suspect blind' children but also developing motivation among the HSAs as a group as well as individuals – the more motivated they are, the more likelihood of finding most of the blind children. Following is a summary of main components of the HSA training.

During one full day training of key informants the following will be covered:

1. The purpose of the workshop
2. What is blindness, and how to assess blindness in children
3. Causes of blindness in children, and how the eyes may appear
4. How to identify families with blind children?
5. How to assess visual acuity in younger and older children?
6. What to do with a child suspected blind
7. Referring blind children to the examination centre
8. How to motivate parents to bring their children for assessment?
9. Allocating dates for examination
10. Receiving feedback from the trained KI's

Who are the HSAs

HSAs are health personnel who are based at Health centre and do most of the health promotion and PHC activities in villages surrounding health centres

A selected group of HSAs from each health centre will be chosen to be trained in identifying blind children as part of their work. They will be encouraged to participate but they should not have a view that they will benefit financially. They may be provided with some gifts as a token appreciation. Transport money will be reimbursed where justified.

How do we identify HSAs?

The point of entry will be through the District environmental health officer (DEHO) and medical assistant from each health centre. The number per health centre will depend upon the catchment population for each centre and this number will be decided by the project in Blantyre and communicated to the medical assistant/DEHO.

What will happen to HSAs once identified?

The identified HSAs will be communicated when and where to go for the training and they people should be told that the training will take place for a whole day usually within a centre not very far away from their health centre

Training dates and venues are to be organized and confirmed in liaison with the HSAs and the medical assistant from the health centre located in the catchments area where the HSAs are coming from ,who will also be required to attend the training

Transport reimbursements and refreshments /lunch will be provided during the training.

TRAINING CURRICULLUM FOR THE KEY INFORMANTS

Task	Skills needed	How to teach specific skills	KIs should know:	How to teach
1. Identification of children with visual impairment	Key informants must be able to determine whether or not a child has visual impairment	Show pictures of children with cataract and other eye diseases.	- their role in the program and in the community - that blindness (especially due to cataract) can also occur in children and not only in elderly - a white pupil in children should be treated as an emergency case	Use short lectures on perceptions of cataract and the outcomes when children are left untreated
2. Proper recording of identified children with visual impairment	Key informants must be able to record background information of the children they find. This information includes name, age, sex, child's village, village leader, contact details.	Give an illustration on how to fill in the report forms	- such information will be used to relocate and keep track of the children identified.	Mention the use of each variable in the form and let them practice filling in a sample form on their own.
3a. Transport arrangement for the child and caretaker from the village to the screening site	KIs are responsible for referring a child identified as low vision for examination at a screening site, and for making sure the child gets there.	Instruct KIs to work closely with field assistants, DECs or RECs to organize a screening site and ensure maximum attendance.	- different basic strategies to counsel parents regarding the importance of surgery	Cover this information during the opening lecture about cataracts
3b. Transport of those with	KIs must be able to	Emphasize to KIs the	- importance of providing social	To be covered in the lecture

congenital or developmental cataract to tertiary facility	organize transport between their villages and nearest tertiary facility	importance of providing social support	support to children and families	
4. Promotion to parents and the community	Key informants should be able to interact with community groups and leaders to transmit important information	Ask KIs to target specific areas for promotion. Set a task to see their levels of interaction skills	- importance of spreading knowledge about pediatric eye disease	To be covered in the lecture
5. Convey proper information to parents whose child has visual impairment	KIs should be able to give important information about childhood cataract and the process after recognition to parents whose children are affected	Give the KIs important information about childhood cataract and the process of education and counseling	Basic information about pediatric cataract and possible treatment	To be covered during the lecture

TRAINING TIMETABLE FOR THE KEY INFORMANTS/COMMUNITY WORKERS

Time	Session number	Activity/content	Facilitator
08.30-09.00		• Introductions • Purpose of training • Background – VISION2020 • Childhood Blindness Research	
09.00-10.00		• Structure and function of parts of the eye	
10.00-11.00		• Blindness • Number of children who are blind • Impact of blindness on children, their families and the community • Case study from Malawi	
11.00-11.15		Break	
11.15-13.00		• How do we know if a child cannot see? • Finding and referring blind children	
13.00-14.00		Lunch	
14.00-15.15		• How to measure vision in children? • Main causes of blindness in children in Malawi and how they are prevented or treated	
15.15-15.30		• Health promotion	
15.30-16.00		• How to feel forms for those children who might be blind	
16.00-16.30		• Which children to refer, where and how • Distribution of villages	
17.00		Formative assessments /feedback Closing remarks	

Supplementary Literature

Kalua K. “Use of key informants in determining the magnitude and causes of childhood blindness in Chikwawa district, southern Malawi.” Community Eye Health. 2007;20(61):8.

Kalua K, Patel D, Muhit M, Courtright P. “Causes of blindness among children identified through village key informants in Malawi.” Can J Ophthalmol. 2008 Aug;43(4):425-7.

Kalua K, Patel D, Muhit M, Courtright P. “Productivity of Key Informants for Identifying Blind Children: Evidence from a Pilot Study in Malawi.” Eye (Lond). 2009 Jan;23(1):7-9. Epub 2008 Mar 14.

Muhit MA, Shah SP, Gilbert CE, Hartley SD, Foster A. “The Key Informant Method: A Novel Means of Ascertaining Blind Children in Bangladesh.” Br J Ophthalmol. 2007 Aug; 91(8):995-9. Epub 2007 Apr 12.

Appendix 34: Published Key informants' articles

Review

Eye (2009) **23,** 7–9; doi:10.1038/eye.2008.49; published online 14 March 2008

Productivity of key informants for identifying blind children: evidence from a pilot study in Malawi

K Kalua[1], D Patel[2], M Muhit[2] and P Courtright[3]

1. [1]Department of Ophthalmology, University of Malawi College of Medicine, Blantyre, Malawi
2. [2]Department of Infectious and Tropical Diseases, International Centre for Eye Health, London School of Hygiene and Tropical Medicine, London
3. [3]Department of Infectious and Tropical Diseases, Kilimanjaro Centre for Community Ophthalmology, Tumaini University, Moshi, Tanzania

Correspondence: K Kalua, Department of Ophthalmology, University of Malawi College of Medicine, P/Bag 360, Blantyre, Malawi. Tel: +265 8302232; Fax: +2651873103; E-mail: khumbokalua@yahoo.com

Received 12 November 2007; Accepted 29 January 2008; Published online 14 March 2008.

Abstract

Objectives

To determine the productivity of village-based 'key informants' (KIs) in identifying blind children.

Materials and methods

Ngabu subdistrict (population 101 000) of Chikwawa district was divided into KI catchment areas. KIs, selected by local village leaders, were trained to register children reported to be blind or with severe visual impairment. These children were clinically assessed at designated centres.

Results

In total, 44 KIs were selected and trained to cover 196 villages in Ngabu. They identified and referred 151 children, 37 of whom were blind (presenting vision <3/60 best eye). Overall, village leaders tended to choose female KIs (80%) compared to male KIs (20%); however, male KIs tended to be more productive, identifying 4.22 children each (compared to 3.23 for female KIs). Male KIs were 2.7 times more likely to identify blind children compared to female KIs. Only 25% of all identified blind children of school going age were in school.

Conclusions

KIs may be effective in identifying blind children in the community; however, additional work is needed to determine who will be the most effective KI in a community and whether gender roles will limit interpretation of findings from KIs activities.

Keywords:

Malawi, key informants, childhood blindness

Introduction

Childhood blindness is one of the five priority diseases that have been targeted by the VISION 2020 initiative.[1] WHO reports that there are 1.4 million blind children and about four times this number have low vision.[2] Previous research in Malawi demonstrated that many children, although recognized with surgically correctable blindness, have not accessed available services.[3] The use of community-based rehabilitation workers or school-based screening to identify children has not been generally productive.[4] Recent evidence from Bangladesh suggests that the trained key informants (KIs) are very effective in identifying children in an Asian setting.[5, 6] KIs are people living in their respective communities who are well-known and connected through their occupational and/or social roles. Through their unique positions in the communities KIs are likely to know about children with blindness or severe visual impairment or people who would notify if a child has such visual loss. In densely populated Bangladesh, it is relatively easy to organise communities to identify children with visual difficulties.[7] Africa is much more sparsely populated and has less well-organized community structures, posing challenges that may limit the application of a KI method. We sought to assess the productivity of KI to better understand the potential value of this methodology in an African setting.

Methods

Ethical approval to do the study was obtained from the Ethics Committee of the London School of Hygiene and Tropical Medicine and the district administrative authorities in Chikwawa district, Malawi.

The study area was Ngabu subdistrict (estimated population 101 000) of Chikwawa district.[8] There are 196 villages (population ranging from 300 to 1100 per village) and we estimated that 40 KIs were needed, with each KI covering at least five villages (about 2500 people). The estimate was based on the current practice of a community eye health worker covering five villages. There is one school for the blind in Ngabu. The study was carried out over a period of 6 weeks in mid-2006.

Selection of the KI was done by village leaders, the criteria for selection being that the person had lived in and knew that community well, was willing and had time to do voluntary work, and was able to read and write. The village leaders were approached a few weeks before the study to consult and decide who would be the appropriate KI in their villages. Assignment of villages for the KI was based on consultation with village leaders and on the proximity of the KI to villages. One ophthalmic clinical officer and one itinerant teacher working in the area were responsible for training the selected KI (two groups of approximately 20 each). The training was one half-day in duration and focused on how they would register blind children in the community as well as some practice. The approaches adopted by the KI included the following: announcing in local churches that the KI needed to see all children with visual impairment, encouraging village headman to call a village meeting to request that children be brought to the KI, and visit by the KI to orphan care settings in selected villages. Some KIs met women groups in communities and one KI used a political mass meeting as an opportunity to have children with vision problems brought forward. Only a few KIs reported to have visited house to house. All KIs were given at least 7 days (after training) to visit their allocated villages, identify the blind children, and inform parents of a date and place for examination. At predetermined sites, the examiner met the KI and identified children; all children were screened by the

principal investigator. After vision testing, children found to be blind were examined and information gathered using a modified WHO questionnaire for childhood blindness surveys.[9] All children who were in need of further treatment and follow-up were referred to the appropriate personnel. The area covered by the KI was verified using random village checks. Data were entered and analysed using Epi info 6.4 and Stata version 9.0.

Results

From the 196 villages originally planned for the study, 185 villages (94%, population about 91 500, about 43 000 of whom were children under 16 years of age) were included. Eleven villages were not included because they were situated across the river and the only means of accessing the villages was by canoe.

In total, 44 KIs were trained, 35 (80%) of whom were women and 9 (20%) were men. The KIs were relatively young (mean age 30.6 years), ranging from 20 to 60 years.

In total, 151 children were identified and referred to the agreed examination centres by the KI; each referring between 0 and 9 children (average=4). Six KIs reported not finding any blind children in their village. Nine male KIs referred 38 children (average=4.22 each), while 35 female KIs referred 113 children (average=3.23)

After vision testing and examination by the ophthalmologist, 37 of 151 children (24.5%) were confirmed to be bilaterally blind (presenting vision <3/60 in the better eye), giving a prevalence of 0.9 per 1000 children. The remaining children had either unilateral blindness or visual impairment; no child brought by KIs had normal visual acuity. Male KIs were just as likely to identify boys and girls with vision loss as female KIs. Nine male KIs brought 15 blind children (1.67 per KI), whereas 35 female KIs brought 22 blind children (0.63 per KI). Male KIs were 2.7 times (95% CI 1.21–6.00) more likely to identify blind children from among those brought for examination than female KIs.

Among 37 blind children, 28 (76%) were of school going age (6–15 years), only 7 (25%) of whom were in school. Among the seven-attending school (four boys, three girls) four were at an integrated school, two were at a normal school and one was at a school for the blind.

All children identified with operable conditions or who could be improved with correction were referred to the appropriate centres for treatment.

Discussion

Most of the 151 identified children had obvious severe unilateral eye problems, with one in four being unilateral blind by WHO criteria. It is possible that some blind children were not identified by KI; however, they are probably few in number since follow-up checks with village leaders revealed that all villagers had been visited by a KI and KIs were familiar with their work.

Village leaders were more likely to select women KIs. The selection of women as KI was anticipated since responsibilities regarding health of children primarily lies with women. Most men in this area work in sugar plantations and are not living at home. The women KIs reported that they felt that it was their duty as mothers to ensure that all the blind children were identified. In spite of these community preconceived parameters regarding roles and responsibilities, male KIs were more productive.

Reasons for lower female productivity could be due to literacy (educational attainment of women may have limited their understanding during training), inability to travel distant from their homes, less assertiveness in promotion of their activities, and other family responsibilities. It is also possible that parents, perceiving men as having greater authority when interacting with health care providers, were more likely to bring

children forward for treatment. The implication of this is that the KI method, although useful in identifying children who are blind or with severe visual impairment, may have an uneven coverage. Qualitative work is needed to further understand gender roles that empower or disempower men and women to identify blind children.

However, KIs identified 28 school age children who were blind, 75% of whom not going to school, in spite of the fact that there is both a school for the blind and an integrated school in the area. Further research is needed to determine whether KIs can be effective in assisting children in placement in an appropriate educational setting.

In summary, our findings suggest that a KI method may be an effective tool for identifying blind children in rural Africa. Referral networks also need to be created for children who could benefit from education and rehabilitation. It is unclear whether KI can become long-term advocates of childhood blindness, or whether they will only serve as a (one time only) 'burst' to identify children in the community. Understanding the potential roles and responsibilities of KI and comparison with other community health workers is needed.

References

1. World Health Organisation. *Prevention of Blindness and Deafness. Global Initiative for Elimination of Avoidable Blindness*. WHO: Geneva, 2000 WHO/PBL/9761 Rev2.
2. Gilbert C, Foster A. Childhood blindness in the context of VISION 2020—the right to sight. *Bull World Health Organ* 2001; **79**(3): 227–232. | PubMed | ISI | ChemPort |
3. Van Dijk K, Courtright P. Barriers to surgical intervention among blind and low vision children in Malawi. *Vis Impair Res* 2000; **2**(2): 75–79. | Article |
4. Muhit M, Gilbert CE, International Centre for Eye Health, London school of Hygiene and Tropical Medicine. Key informant method for identifying children with blindness and severe visual impairment in the Community. Reaching the unreached. Unpublished data, 2004.
5. Muhit MA. Finding blind children: key informant methodology. *J Comm Eye Health* 2007; **62**(20): 30–31.
6. Muhit MA, Shah SP, Gilbert CE, Hartley SD, Foster A. The key informant method: a novel means of ascertaining blind children in Bangladesh. *Br J Ophthalmol* 2007; **91**: 995–999. | Article | PubMed |
7. Muhit MA, Shah S, Gilbert CE. Causes of severe visual impairment and blindness in Bangladesh: a study of 1935 children. *Br J Ophthalmol* 2007;**91**(8): 1000–1004. | Article | PubMed | ChemPort |
8. National Statistical Office. *Malawi Housing and Population Census 1998*. Zomba, Malawi.
9. Gilbert CE. Childhood Blindness: a new form for recording causes of visual loss in children. *Bull World Health Organ* 1993; **71**: 485–489. | PubMed | ISI | ChemPort |

Acknowledgements

We thank Steve Kanjoloti, ophthalmic clinical officer from Chikwawa district, Malawi for helping in data collection, Adrienne Burrough, funding manager for ICEH and finally Task Force Sight and Life (TFSL) for agreeing to fund this research.

Community Eye Health. 2007 Mar; 20(61): 8.

PMCID: PMC1919440

Use of key informants in determining the magnitude and causes of childhood blindness in Chikwawa district, southern Malawi

Khumbo Kalua

Author information ► Copyright and License information ►

Background: Population-based studies to determine the magnitude and causes of childhood blindness require very large sample sizes and are very costly. Alternative methods such as the key informant method (which is cheap and easy to use) have been found to be as reliable as population-based studies in settings where the population is very dense.

Aims: To determine the magnitude and causes of childhood blindness in Chikwawa district, Malawi, using the key informant method; to see how this method can be used in a setting of low population density, where the population is widely dispersed.

Methods: Key informants are local people who know their community well. They were randomly selected by the communities themselves and trained for one day in techniques to identify children in the community who are blind. Each key informant covered on average 4–7 villages which were widely dispersed. Identified children were examined by the ophthalmologist to confirm the diagnosis.

Results: A group of 44 key informants was selected and trained. There were more female (80%) than male (20%) key informants. The key informants correctly identified 37 children who were blind in 196 villages (86% of the expected number from the area). The prevalence of childhood blindness was found to be 0.09%. Cataract was found to be the most common cause (35%) of childhood blindness, followed by corneal scarring (22%).

Conclusion: The key informant method was found to be cheap and useful in identifying children who are blind, even in areas where the population is widely dispersed. We recommend that this method be used to identify children who are blind in other districts of Malawi and where population-based surveys cannot be conducted.

Gogate P, Kalua K, Courtright P. Blindness in Childhood in Developing Countries: Time for a Reassessment?
PLoS Med 2009 6(12): e1000177. doi: 10.1371/journal.pmed.1000177

Published: December 8, 2009
http://dx.doi.org/10.1371/journal.pmed.1000177
http://journals.plos.org/plosmedicine/

Funding: No specific funding was received for this piece.
Competing interests: Paul Courtright is married to Susan Lewallen who is on the Editorial Board of *PLoS Medicine.* Susan Lewallen was not involved in the peer review of this paper.
Abbreviations: KI, key informants; NGO, nongovernmental organization; ROP, retinopathy of prematurity
Provenance: Commissioned; externally peer-reviewed.

Summary Points

- Childhood blindness is a priority area for VISION 2020, a global initiative to eliminate avoidable blindness, because blind and visually impaired children have a lifetime of blindness ahead of them.
- Globally, vitamin A deficiency– and measles-related blindness in children has declined substantially although it persists in some focal settings.
- With reductions in nutritional and infectious causes of blindness, intra-uterine and genetic causes of blindness (e.g., cataract and congenital anomalies) have assumed increased importance and need tertiary care–level interventions and long-term follow-up to achieve good visual rehabilitation.
- Further research is needed to identify the underlying causes of congenital and developmental cataract and to determine the best strategies for recognition, referral, treatment, and rehabilitation.
- Changing patterns of global childhood blindness suggest a reassessment of research, training, and programmatic needs.

Our Understanding of Childhood Blindness at the Adoption of VISION 2020 in 1999

Magnitude of Childhood Blindness

The global initiative—VISION 2020: The Right to Sight—launched in 1999, targeted blindness in children as one of the five priority areas of disease control [1]. Selecting childhood blindness was based on the fact that blindness in childhood can lead to decades of life spent blind and because the major interventions to control childhood blindness were public health in nature (vitamin A

supplementation and measles immunization) for the control of vitamin A-related corneal blindness. Childhood blindness causes significant economic burden on the family and community [2]. At the time, it was estimated that globally there were 1.4 million blind children, twice this number with low vision, and an estimated 500,000 children becoming blind each year [3]. It was anticipated that many of the incident blind would not survive because of vitamin A deficiency, so the annual cumulative annual incidence would be only about 200,000 per year [4].

Causes of Childhood Blindness

Blindness can occur through many different pathways and due to many different pathogens or insults. Classifying the causes of childhood blindness has always been quite complicated and WHO adopted both an anatomical and aetiological classification system in an attempt to focus attention on those conditions that can be prevented, those that can be treated, and those with no prevention or treatment strategies available that would need rehabilitation [5].
Corneal scarring and phthisis bulbi due to vitamin A deficiency, measles, and infection were the commonest causes of blindness in the early 1990s in much of Asia and Africa [6]–[8]. Thus corneal blindness was listed as the primary cause of blindness in children for planning for childhood blindness [8]. In Africa, in particular, it was anticipated that corneal conditions would be responsible for approximately one-third of all childhood blindness. The correlation between vitamin A-related corneal conditions and mortality has been well documented. At the time, there was evidence to suggest that there was a positive correlation between national rates of dying under the age of 5 years (under-5 mortality rates) and the prevalence of blindness in children [9], which led to the suggestion that national under-5 mortality rates could be used as a proxy indicator of a national childhood blindness-prevalence rate for the purpose of planning [8].

Generating Information on Childhood Blindness

Due to the rarity of blindness in children, population-based surveys to determine the prevalence of blindness require very large sample sizes and are very costly. Consequently, in the period 1980–2000, only a few population-based studies [10],[11] were carried out. A second source of information on childhood blindness are specially designed vitamin A studies in which blindness was also measured [12],[13]. Most data for making estimates of the prevalence and causes of childhood blindness, however, have come from surveys in schools for the blind or annexes [6],[7]. The limitations of using studies carried out in schools for the blind have been well recognized. Generally, children enrolled in these schools represent “past history”—that is, they developed blindness 5 or more years in the past and do not reflect current patterns of causes. Additionally, it is recognized that children enrolled in schools for the blind or annexes make up only a small proportion of the total blind in the community. Children with multiple disabilities are likely to be under-represented. Thus, generating reliable information on childhood blindness has been fraught with difficulties.

What Have We Learned about Childhood Blindness in the Last 10 Years?

Gradual Elimination of Vitamin A-Related Blindness

Even back in 2000 it was anticipated that “old enemies” like vitamin A-deficiency blindness would be eradicated [14]. Linking vitamin A deficiency to childhood mortality shifted vitamin A deficiency into a global public health issue rather than just a prevention of blindness issue. The number of agencies, governmental and nongovernmental, that included vitamin A supplementation and measles immunization as core programmes mushroomed. Consequently, as reported in annual UNICEF State of the World's Children reports, vitamin A-supplementation coverage has increased and blindness due to vitamin A deficiency has been virtually eliminated in many developing countries. Probably most telling was the recent report from the Lower Shire Valley of Malawi, once known as the Valley of Blindness because of the high prevalence of vitamin A-deficiency and related blindness. Compared to the previous (1983) survey [12] in which vitamin A-related corneal scars accounted for all of the children found blind, the 2007 survey [15], which used the key informant method, found that only 22% of the 37 children found blind were blind from corneal scars; 35% were blind from congenital cataract. It is possible, however, that variable study methods may account for some of the differences noted.

Regardless of the reductions in vitamin A-related corneal blindness, vitamin A deficiency still contributes to increased mortality in preschool children [16],[17]. Efforts to achieve high coverage of measles immunization and vitamin A-supplementation coverage remain just as important today as in 1999. There remain some focal areas, such as post conflict zones, refugee camps [18], and other areas [19] where vitamin A-related blindness may still occur and these areas need to be closely monitored.

General Economic Growth and Improvements in Eye Care Infrastructure

In most developing countries, general economic growth and improved health care planning have resulted in an increasing number of eye care providers, even including doctors doing private practice in rural areas. In the last 20 years Africa has seen a 4–5-fold increase in the number of ophthalmologists with increased distribution of services outside of capital cities. India has increased many fold its primary health care infrastructure in the past four decades and NGO hospitals providing high-quality low-cost eye care have been established across the country. Programmes have been put into place to reduce the use of harmful traditional eye medicines and practice, further decreasing the risk of corneal conditions [19]. There also has been easier and cheaper availability of antibiotics and better managed procurement and distribution systems. All of these health and economic infrastructural improvements have helped reduce the preventable causes of blindness. Refractive errors are a common cause of visual impairment [20], but uncorrected refractive errors rarely cause blindness unless it is high myopia. Owing to a variety of reasons, the incidence of myopia has risen dramatically in the past two decades in east and south-eastern Asia [21], however similar findings have not been detected in Africa.

Changes in Strategies to Measure Childhood Blindness

Surveys in schools for the blind and annexes have continued [22]–[24] with the recognition, however, that many children are placed there inappropriately [25]. The shift to integrated education in some countries has led to reduced numbers of children in schools for the blind and a focus on

multiple disabilities at these institutions. Thus, using surveys of schools for the blind to make estimates of causes of blindness has become less tenable.
The successful testing of "key informant" (KI) methods to find children who are blind [26] has led to the application of this method to make estimates of childhood blindness. KIs are local volunteers who live and/or work in their communities and through their vocation have a social role and are likely to know the local context, the people, and the conditions in their community. The method involves identifying and contacting the community and mapping of social networks. Local volunteers (KI) are then selected by the community and trained to find blind children in their community. An eye clinic is scheduled (2–3 weeks after training) and all of the children identified are brought to be examined by an ophthalmologist. As noted in Bangladesh, the KI method may not capture all blind children but it does provide a reasonable estimate and causes of blindness are similar to large, population-based surveys [27]. The work in Bangladesh was followed by similar activities in Ghana [28], Malawi [29], Iran [30], and Tanzania [31]. KI strategies, primarily in place to identify prevalent cases of blindness, are likely to continue to generate information in settings where there are no other practical strategies to assess childhood blindness.

Changes in Eye Care Services for Children

While vitamin A supplementation, immunization, and improved nutrition helped decrease corneal blindness; cataracts, glaucoma, penetrating trauma, and retinoblastoma needed tertiary-level paediatric eye centres for treatment. Surgical services are expensive in terms of equipment, instrumentation, and trained human resources. The WHO recommends that there be one paediatric eye centre per 10 million population [32]. In the intervening years, there have been major investments in many parts of Asia and Africa to establish these centres. In India, in the past 10 years at least 20 new paediatric eye centres have been established, in addition to the existing four; and there are 26 centres in ten countries of sub-Saharan Africa.
With the availability of good quality surgical services has come the recognition that congenital and developmental cataract are important causes of blindness in many developing countries [33]–[35]. Furthermore, it is recognized that these centres can only be effective if they have strong links with the community and health care providers [36]. As links have been established, finding children with surgical needs has led to steep increases in numbers of surgeries being done—a typical of case of "seek and ye shall find." At the same time, these centres have also recognized that they face significant challenges to ensure that they provide the best possible visual outcome. Delay in presentation for surgery [37] and inadequate follow-up [38],[39] remain daunting problems. The outcomes are not as spectacular as with adult cataract surgery, nonetheless the intervention substantially improves vision and a child's ability to negotiate in the world. It has been shown in developing countries that intra-ocular lenses may also be safely implanted in very young children [40],[41].
Recent studies from India put untreatable conditions such as anopthalmos and micropthalmos [22] and retinal dystrophies [42] as common causes of blindness in children, requiring strategies for rehabilitation. The etiology of congenital anomalies like anophthalmos and microphthalmos is multifactorial with a gene–environment interaction. Few studies have been able to pinpoint the exact cause [43],[44]. Even if a maternal nutritional deficiency (like folate) is implicated, interventions may be difficult to implement. Providing good quality counselling for

parents and children, a high quality optometric unit (for spectacles and amblyopia management), and a low vision unit (and a larger, more diverse team), while costly, are essential to ensuring good visual outcome and proper visual rehabilitation. Older blind children continue to require good quality low vision and appropriate education opportunities. Creating links to rehabilitation programmes and educational services also has required an investment in human resources. Retinopathy of prematurity (ROP) has been rapidly increasing in many middle-income countries, with reports from Brazil, South Africa, India, and China [45]–[48]. With better neonatal care and increased survival of more preterm babies, it seems likely that ROP blindness will become another avoidable cause unless screening programs for premature babies are implemented in the neonatology units. In order to prevent the "spread of the ROP epidemic" being experienced by Latin America and Eastern Europe, programs for prevention and treatment need to be put in place, as is occurring in many cities in India and China.

What Next?

In least developed countries, congenital and developmental cataract, retinal pathology, and congenital anomalies are gaining importance as causes of blindness in children. The relative decline in childhood factors and the corresponding increase in intra-uterine and genetic factors suggest a need for a reassessment of research, training, and programmatic priorities. Reasonable steps to be undertaken in the next 5 years include:

1. Recalculation of global estimates of prevalence, incidence, and cause of childhood blindness.
2. Investment in testing different strategies to recognize, refer, and follow up children needing surgical services.
3. Rational investment in tertiary paediatric eye care facilities along WHO recommended criteria. Coordination and collaboration between NGOs and hospitals is needed.
4. Research on the cause of congenital anomalies (e.g., anophthalmos, microphthalmos, congenital and developmental cataract, congenital glaucoma) in order to put preventive strategies in place—likely difficult and expensive steps, but nonetheless necessary to address.
5. Development of new training materials on childhood blindness, particularly for primary eye-care and secondary eye-care workers in the least developed countries.
6. Screening of premature and low birth weight babies at risk of ROP, requiring cooperation between neonatal nurses, neonatologists, paediatricians, paediatric ophthalmologists, retina specialists, and even immunization workers.

Author Contributions

ICMJE criteria for authorship read and met:
PG KK PC. Wrote the first draft of the paper: Contributed to the writing of the paper:

References

1.Pizzarello L, Abiose A, ffytche T, Duerksen R, Thulsiraj R, et al. (2004) VISION 2020: The Right to Sight. A global initiative to eliminate avoidable blindness. Arch Ophthalmol 122: 615–620.
2.Frick KD, Foster A (2003) The magnitude and cost of global blindness: an increasing problem that can be alleviated. Am J Ophthalmol 135: 471–476.
3.World Health Organization (1999) Global Initiative for the Elimination of Avoidable Blindness. WHO/PBL/97.61. Geneva: World Health Organization.
4.Sommer A (1993) Vitamin A, infectious disease, and childhood mortality: a 2 solution? J Infect Dis 167: 1003–1007.
5.Gilbert C, Foster A, Negrel AD, Thylefors B (1993) Childhood blindness: a new form for recording causes of visual loss in children. Bull World Health Organ 71: 485–48.
6.Rahi JS, Sripathi S, Gilbert CE, Foster A (1995) Childhood blindness in India: causes in 1318 blind school students in nine states. Eye 9: 545–550.
7.Gilbert CE, Wood M, Waddel K, Foster A (1995) Causes of childhood blindness in east Africa: results in 491 pupils attending 17 schools for the blind in Malawi, Kenya and Uganda. Ophthalmic Epidemiol 2: 77–84.
8.Gilbert C, Foster A (2001) Childhood blindness in the context of VISION 2020–the right to sight. Bull World Health Organ 79: 227–232.
9.Gilbert CE, Anderton L, Dandona L, Foster A (1999) Prevalence of visual impairment in children: a review of available data. Ophthalmic Epidemiol 6: 73–82.
10. Dorairaj SK, Bandrakalli P, Shetty CRV, Misquity D, Ritch R (2008) Childhood blindness in a rural population of southern India: prevalence and etiology. Ophthalmic Epidemiol 15: 176–182.
11. Dandona R, Dandona L (2003) Childhood blindness in India: a population based perspective. Br J Ophthalmol 87: 263–265.
12. Chirambo MC, Tielsch JM, West KP, Katz J, Tizazu T, et al. (1986) Blindness and visual impairment in southern Malawi. Bull World Health Organ 64: 567–572.
13. Cohen N, Measham C, Khanum S, Khatun N, Ahmed N (1983) Xerophthalmia in urban Bangladesh. Implications for vitamin A deficiency preventive strategies. Acta Paediatr Scand 72: 531–536.
14. West S, Sommer A (2001) Prevention of blindness and priorities for the future. Bull World Health Organ 79: 244–248.
15. Kalua K, Patel D, Muhit M, Courtright P (2008) Causes of blindness among children identified through village key informants in Malawi. Can J Ophthalmol 43: 425–427.
16. Aguayo VM, Baker SK (2005) Vitamin A deficiency and child survival in sub-Saharan Africa: a reappraisal of challenges and opportunities. Food Nutr Bull 26: 348–355.
17. Gilbert C (2007) Changing challenges in the control of blindness in children. Eye 21: 1338–1343.
18. Zedian Z, Hashim K, Muhit MA, Gilbert C (2007) Prevalence and causes of childhood blindness in camps for displaced persons in Khartoum: results of a household survey. East Med Health J 13: 580–585.
19. Courtright P, Chirambo M, Lewallen S, Chana H, Kanjaloti S (2000) Collaboration with African traditional healers for the prevention of blindness. Singapore: World Scientific Publishing.
20. Murthy VB, Gupta SK, Ellwein LB, Munoz SR, Pokharel GP, et al. (2002) Refractive error in children in an urban population of New Delhi. Invest Ophthalmol Vis Sci 43: 623–631.

21. Guggenheim JA, Pong-Wong R, Haley CS, Gazzard G, Saw SM (2007) Correlations in refractive errors between siblings in the Singapore Cohort Study of Risk factors for Myopia. Br J Ophthalmol 91: 781–784.
22. Gogate P, Deshpande M, Sudrik S, Taras S, Kishor H, et al. (2007) Changing pattern of childhood blindness in Maharashtra, India. Br J Ophthalmol 91: 8–12.
23. Njuguna M, Msukwa G, Shilio B, Tumwesigye C, Courtright P, et al. (2009) Causes of severe visual impairment and blindness in children in schools for the blind in eastern Africa: changes in the last 14 years. Ophthal Epidemiol 16: 151–155.
24. Sitorus RS, Abidin MS, Prihartono J (2007) Causes and temporal trends of childhood blindness in Indonesia: study at schools for the blind in Java. Br J Ophthalmol 91: 1109–1113.
25. Tumwesigye C, Msukwa G, Njaguna M, Shilio B, Courtright P, et al. (2009) Inappropriate enrolment of children in schools for the visually impaired in east Africa. Ann Trop Paediatr 29: 135–139.
26. Muhit MA, Shah SP, Gilbert CE, Hartley SD, Foster A (2007) The key informant method: a novel means of ascertaining blind children in Bangladesh. Br J Ophthalmol 91: 995–999.
27. Muhit MA, Shah SP, Gilbert CE, Foster A (2007) Causes of severe visual impairment and blindness in Bangladesh: a study of 1935 children. Br J Ophthalmol 91: 1000–1004.
28. Boye J (2005) Validating key informant method in detecting blind children in Ghana. J Comm Eye Health 18: 131.
29. Kalua K, Patel D, Muhit M, Courtright P (2009) Productivity of key informants for identifying blind children: evidence from a pilot study in Malawi. Eye 23: 7–9.
30. Razavi H (2008) Childhood blindness: piloting the key informant method in Lorestan Province, Iran. J Comm Eye Health 21: 65.
31. Shirima S, Lewallen S, Kabona G, Habiyakare C, Massae P, et al. (2009) Estimating numbers of blind children for planning services: findings in Kilimanjaro, Tanzania. Br J Ophthalmol.. In press.
32. World Health Organization (1999) Preventing Blindness in Children: report of a WHO/IAPB Scientific Meeting. WHO/PBL/00.77. Geneva: World Health Organization.
33. Waddell KM (1998) Childhood blindness and low vision in Uganda. Eye 12: 184–192.
34. Courtright P, Williams T, Gilbert C, Kishiki E, Shirima S, et al. (2008) Measuring cataract surgical services in children: an example from Tanzania. Br J Ophthalmol 92: 1031–1034.
35. Khandekar R, Sudhan A, Jain BK, Shrivastav K, Sachan R (2007) Pediatric cataract and surgery outcomes in central India: a hospital based study. Indian J Med Sci 61: 15–22.
36. Courtright P, Bowman R, Gilbert C, Lewallen S, van dijk K, et al. (2008) Childhood cataract in Africa. Veenendaal, Netherlands: Dark & Light Blind Care.
37. Mwende J, Bronsard A, Mosha M, Bowman R, Geneau R, et al. (2005) Delay in presentation to hospital for surgery for congenital and developmental cataract in Tanzania. Br J Ophthalmol 89: 1478–1482.
38. Eriksen JR, Bronsard A, Mosha M, Carmichael D, Hall AB, et al. (2006) Predictors of poor follow up in children that had cataract surgery. Ophthal Epidemiol 13: 237–243.
39. Kishiki E, Kishiki E, Shirima S, Lewallen S, Courtright P (2009) Improving post-operative follow up of children receiving surgery for congenital or developmental cataract in Africa. JAAPOS 13: 280–282.

40. Eckstein M, Vijayalakshmi P, Gilbert C, Foster A (1999) Randomised clinical trial of lensectomy versus lens aspiration and primary capsulotomy for children with bilateral cataract in south India. Br J Ophthalmol 83: 524–529.
41. Yorston D, Wood M, Foster A (2001) Results of cataract surgery in young children in east Africa. Br J Ophthalmol 85: 267–271.
42. Gogate P, Kishore H, Dole K, Shetty J, Gilbert C, et al. (2009) The pattern of childhood blindness in Karnataka, South India. Ophthal Epidemiol 16: 212–217.
43. Hornby SJ, Ward SJ, Gilbert CE, Dandona L, Foster A, et al. (2002) Environmental risk factors in congenital malformations of the eye. Ann Trop Paedtr 22: 66–77.
44. Hornby S, Ward SJ, Gilbert CE (2003) Eye birth defects in humans may be caused by a recessively inherited genetic predisposition to the effects of maternal vitamin A deficiency during pregnancy. Med Sci Monitor 9: HY 23–26.
45. Zin A (2001) The increasing problem of retinopathy of prematurity. J Comm Eye Health 14: 58–59.
46. Varughese S, Gilbert C, Pieper C, Cook C (2008) Retinopathy of prematurity in South Africa: an assessment of needs, resources and requirements for screening programmes. Br J Ophthalmol 92: 879–892.
47. Chen Y, Li XX, Yin H, Gilbert C, Liang JH, et al. (2008) Beijing ROP Survey Group. Risk factors for retinopathy of prematurity in six neonatal intensive care units in Beijing, China. Br J Ophthalmol 92: 326–330.
48. Chawla D, Agarwal R, Deorari AK, Paul VK (2008) Retinopathy of prematurity. Indian J Pediatr 75: 73–76.